

Positioning the Family and Patient at the Center

A Guide to Family and Patient Partnership in the Medical Home

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FORWARD

For decades, the American Academy of Pediatrics (AAP) has acknowledged the need for family-centered care for children and youth with special health care needs within the primary care medical home. The AAP, the Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA), and Family Voices collaborated on the first policy statement about the medical home in 2002. However, the first known documentation of the term “medical home” appeared in *Standards of Child Health Care*, a book published by the AAP in 1967. Since that time, there has been ongoing and increasing support and understanding of the need for families’ and patients’ intimate involvement in the health and well-being of all—especially children and youth. Indeed, it is now widely acknowledged by physicians, families, medical societies, payers, and even businesses that without true family and patient centeredness, the goal of transforming health care by improving the quality of care, reducing per-capita costs, and achieving better population health cannot be reached.

In 2012, the AAP published its policy statement “Patient and Family-Centered Care and the Pediatrician’s Role,” further defining this care and documenting core principles as well as benefits, outcomes, and recommendations. As stated in the policy, “the perspectives and information provided by families, children, and young adults are essential components of high-quality clinical decision-making” and “patients and families are integral partners with the health care team.” This principle has been at the core of AAP strategic priorities for nearly a decade and is the foundation of the work undertaken by the National Center for Medical Home Implementation, a cooperative agreement between the AAP and MCHB/HRSA.

Many national organizations have recently acknowledged the need for patient- and family-centered partnerships at all levels of care. The Patient Centered Primary Care Collaborative now includes Patients, Families and Consumers as a new center. This center works on behalf of and with patients, families, and advocates, ensuring that the medical home model incorporates patients’ perspectives, needs, and experiences and achieves true patient centeredness. The Patient-Centered Outcomes Research Institute (PCORI) also has been established to help people make informed health care decisions and to improve health care delivery and outcomes by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader health care community. The PCORI will also work to ensure that patients and the public have the information they need to make decisions that reflect their desired health outcomes.

Examples of additional involvement, as well as publications supporting this paradigm shift, include *Powerful Partnerships: A Handbook for Families and Providers Working Together to Improve Care* from the National Initiative for Children’s Healthcare Quality and the February 2013 edition of *Health Affairs*, “New Era of Patient Engagement.” Further, the Institute of Medicine (IOM) has identified family-centered care as 1 of the 6 key elements to improve the US health care system in *Crossing the Quality Chasm*. The IOM specifically describes the involvement of family and friends as a component of patient centeredness, focusing specifically on “accommodating family and friends on whom patients may rely, involving them as appropriate in decision-making, supporting them as caregivers, making them welcome and comfortable in the care delivery setting, and recognizing their needs and contributions.”

Recent literature confirms that when there is a family-centered partnership within a practice, there are improved patient and family outcomes, increased staff satisfaction, increased cost-effectiveness, and significant benefits for pediatricians. Appropriate and critical areas of family involvement are needed in the medical home as well as among hospital systems, agencies, community resources, payers, and others. Obviously, the family is the primary source of knowledge, support, and strength for their child. However, as is revealed in this monograph, there are additional opportunities and needs for family involvement in the areas of coordination of care, linkages to community resources, practice and system redesign and governance, policy and advocacy efforts, and all quality-improvement initiatives.

It is important to acknowledge that implementing true family-centered care is difficult, but the practices highlighted in the monograph have identified ways to do it. The partnership between the National Center for Medical Home Implementation, the American Academy of Pediatrics, the National Center on Parent/Professional Partnerships and Family Voices, the Institute for Patient and Family-Centered Care, and the National Partnership for Women and Families on the development of this monograph as well as other initiatives has been so important to moving this agenda forward. The contributions of the staff of the aforementioned organizations to the development of the monograph at all levels, including their efforts to help identify promising practices of family-centered care, are worthy of acknowledgement.

One of the greatest privileges of my career has been what I have learned from—and with—families. This monograph demonstrates the remarkable work and partnership of pediatricians and families in true medical homes. Now is the time to actualize these and other examples of family-centered care to make a difference in the lives of children and families.

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PARTICIPATING ORGANIZATIONS

American Academy of Pediatrics (AAP)

<http://www.aap.org>

The AAP is a professional membership organization of 60,000 pediatricians committed to the optimal physical, mental, and social health and well-being for all infants, children, adolescents and young adults.

National Center for Medical Home Implementation (NCMHI)

<http://www.medicalhomeinfo.org>

The NCMHI is a cooperative agreement between the Maternal and Child Health Bureau and the AAP with a mission to ensure that every child and youth, with and without special health care needs, has access to a medical home.

Family Voices (FV)

<http://www.familyvoices.org>

Family Voices is a national grassroots organization that aims to achieve family-centered care for all children and youth with special health care needs. Through their national network, they provide families with the tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

National Center for Family/Professional Partnerships (NCFPP)

<http://www.fv-ncfpp.org>

The NCFPP promotes families as partners in the decision-making of health care for children and youth with special health care needs at all levels of care. The NCFPP works to increase leadership capacity and promote knowledge and measurement of family-centered care through the Family-to-Family Health Information Centers and communities of learners.

Institute for Patient- and Family-Centered Care (IPFCC)

<http://www.ipfcc.org>

The IPFCC is a nonprofit organization that takes pride in providing essential leadership to advance the understanding and practice of patient- and family-centered care. By promoting collaborative, empowering relationships among patients, families, and health care professionals, the institute facilitates patient- and family-centered change in all settings where individuals and families receive care and support.

National Partnership for Women and Families

<http://www.nationalpartnership.org>

The National Partnership for Women and Families is a nonprofit, nonpartisan organization with the goal of creating a society that is free, fair, and just where nobody has to experience discrimination, all workplaces are family friendly, and no family is without quality, affordable health care and economic security.

LIST OF ABBREVIATIONS

AAP	American Academy of Pediatrics
ADHD	attention-deficit/hyperactivity disorder
ASQ	Ages & Stages Questionnaire
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CCNC	Community Care of North Carolina
CHA	Children's Health Alliance
CHAM	Children's Hospital at Montefiore
CMHI	Center for Medical Home Improvement
CYSHCN	Children and Youth with Special Health Care Needs
EHR	electronic health record
EMR	electronic medical record
F2F HICs	Family-to-Family Health Information Centers
GCH	Guilford Child Health
HCH	health care home
LINCS	Linking Individual Needs of Children with Services
MCHB	Maternal and Child Health Bureau
MHFI	Medical Home Family Index
MHLC	medical home learning collaborative
MSU	Michigan State University
NCQA	National Committee for Quality Assurance
OPS	Oregon Pediatric Society
PCMH	patient-centered medical home
PHQ-2	Patient Health Questionnaire-2
WMPA	Westwood-Mansfield Pediatric Associates
YCHC	Young Children's Health Center

Introduction

The highest-rated show in prime time for the 1970-1971 television season was “Marcus Welby, MD,” a program about 2 physicians trying to treat people as individuals in an age of increasingly specialized medicine and impersonal providers. At a time when doctors still made house calls, “Marcus Welby, MD” was entertaining and informative—addressing the health issues of the era while also helping to educate the viewing public about compassionate, patient- and family-centered care. Many of us have fond memories of that era and of pediatricians who, like the fictitious Dr Welby, gave generously of their time and skills to help us and our families.

In 2012, medical treatment and technology is vastly more complex than it was in 1970, and more than a few people speak disdainfully about how “the days of Marcus Welby are long gone” (Google has 17,600 search results for that exact phrase). However, today throughout the country, families and health professionals are working together in ways evocative of the Welby style by adopting the principles of the patient- and family-centered medical home. The concepts of a medical home, first articulated by pediatric health care providers as they worked with families to create more effective partnerships to improve care for children with special health care needs, have greatly evolved and expanded. Fueled by the support of their own professional societies as well as other private and public resources and the health research community, both adult and child primary care physicians have opened up unprecedented areas of collaboration among families, physicians, and their staff. Overwhelmingly, families and health professionals express excitement about these new collegial relationships and describe the positive changes that can—and have—occurred when parents and professionals work together.

The American Academy of Pediatrics—via the National Center for Medical Home Implementation, a cooperative agreement between the academy and the Maternal and Child Health Bureau of the Health Resources and Services Administration—decided to document some of these exciting changes in the form of a monograph of case studies focusing on 17 pediatric practices nominated by their peers or patients as exemplary patient- and family-centered

medical homes. The Academy asked the six of us to serve as an advisory group for the project. Each of us, as well as the organizations we represent, is a strong supporter of this model. We know the enormous benefits patient- and family-centered care offers to health care providers, patients, and their families. As primary care practices struggle with issues related to quality, safety, HIPAA (Health Insurance Portability and Accountability Act) compliance, workforce capacity, the use of technology, and the pressure to control costs, they are recognizing that patient- and family-centered approaches and the perspectives of patients and families are essential to their efforts.

We know, also, that making change is hard, especially in the light of the other changes occurring within our national health care system, and hoped this monograph would be a source of information and support to other patient- and family-centered medical homes as they, too, bridge the gap between past experiences and new expectations.

We were prepared to see the case studies featured in this monograph document practice improvements such as greater use of health information technology, enhanced access to medical professional staff outside regular office hours, and some form of feedback capturing patient/family experience with care. What we did not expect to see, however, is the amazing breadth and depth of the collaborative efforts these practices have in place. In the area of improving communication with patients and families, for example, most of the practices reported using at least 3 separate strategies, often 4 or 5. In the area of gathering feedback from patients and families, all but 3 practices not only use mechanisms like patient/family experience questionnaires, but also have made patients and families a formal part of practice governance via membership on an advisory board or the practice quality improvement committee or by actually joining the staff as a parent advisor. An overview of the different strategies and tools used by the 17 practices is provided in Appendix IV.

As noted above, the primary purpose in commissioning this study was to enhance the resources available to pediatricians and other pediatric health care providers who are

involved in—or contemplating becoming involved in—implementing the patient- and family-centered medical home model in their practices. This monograph is an important contribution to the medical home literature and will be of interest to health professionals, patients, families, planners, and policymakers. The examples of patient- and family-centered design and delivery approaches are accompanied by information on how the pediatric practices began to make these changes and comments from patients and providers on the value of these approaches.

These 17 practices vary in size, organizational structure, and location, but all of them tell a similar story: the active involvement of patients and families as advisors and members of improvement and redesign teams is essential to the design and delivery of optimal care and services. Without sustained patient and family participation in all aspects of policy and program development and evaluation, the health care system will fail to respond to the real needs and concerns of the people it is intended to serve. Effective patient/family and health care provider partnerships will help to redesign health care and ensure safety and quality. It will lead to better outcomes and enhance efficiency and cost-effectiveness. Health professionals will also discover a more gratifying, creative, and inspiring way to practice.

We hope this monograph will inspire readers to consider how they too can implement changes that will advance the implementation of patient- and family-centered medical homes.

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Positioning the Family and Patient at the Center: A Guide to Family and Patient Partnership in the Medical Home

Rebecca A. Malouin, PhD, MPH

The objectives of this monograph are to provide context of the history and importance of family-centered care in the care of pediatric patients, particularly in the medical home, to describe case studies of best practices in family-centered care, to identify specific processes and structures within a medical home associated with provision of family-centered care, and to discuss research, practice, and policy implications of this research.

Section I: Patient- and Family-Centered Care

THE PEDIATRIC MEDICAL HOME

Over the past 40 years, the concept of the medical home has evolved from a place to store medical records of children cared for by health care providers to a comprehensive approach to the provision of primary care.^[1] Primary care has been associated with decreased health care expenditures, improved population health, reduced disparities in health outcomes, and increased patient and family satisfaction with health care.^[2-4] In an environment of rising health care costs, increasingly poor population health outcomes, and increasing dissatisfaction among health care providers, patients, and families, the medical home model is an attractive solution for increasing the availability and quality of health care and the payment for primary care services.^[5,6]

The term *medical home* originated in pediatrics and initially focused on children and youth with special health care needs (CYSHCN). The Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB) defines CYSHCN as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."^[7]

In 1992, the American Academy of Pediatrics (AAP) Ad Hoc Task Force on the Definition of Medical Home defined a medical home as:

...medical care of infants, children, and adolescents [that] ideally should be accessible, continuous, comprehensive, family-centered, coordinated, and compassionate. It should be delivered or directed by well-trained physicians who are able to manage or facilitate essentially all aspects of pediatric care. The physicians should be known to the child and family and should be able to develop a relationship of mutual responsibility and trust with them.^[8]

This definition was reiterated in the 2002 AAP policy statement on the medical home, which further described the desirable characteristics of a medical home (Appendix I).^[9] The AAP also described comprehensive health care for infants, children, and adolescents to include: family-centered care; information sharing about relevant services; provision of primary care; continuously available ambulatory and inpatient care for acute illnesses; continuity of care and organized transitions; coordination with medical subspecialists and surgical specialists; interaction with community resources, such as education programs; care coordination, including a care plan implemented by a team; maintenance of a confidential, accessible, and comprehensive child health record; and provision of developmentally appropriate and culturally sensitive health assessment.^[9] The 2002 policy was reaffirmed by the AAP in May 2008.^[10]

In March 2007, the American Academy of Family Physicians, the AAP, the American College of Physicians, and the American Osteopathic Association developed a statement titled "Joint Principles of the Patient-Centered Medical Home."^[11] The statement described the patient-centered medical home (PCMH) as "an approach to providing comprehensive primary care for children, youth, and adults. The PCMH is a health care setting that facilitates partnerships between individual patients, their personal physicians, and when appropriate, the patient's family." (Appendix II)^[11] Although family is mentioned within the definition of the PCMH, family-centered care is not articulated as a unique principle or dimension of the PCMH. Family-centered care is described as a principle element of the pediatric medical home within the AAP definition, but it is not a core principle of the PCMH as defined in the 2007 statement. The AAP encourages the use of the term *patient- and family-centered care* and recognizes the specific contribution of family-centered care in pediatric practice.

DEFINING FAMILY-CENTERED CARE

Family has been defined as a “collection of individuals who are connected to each other by blood ties or strong emotional ties, and who in most circumstances reside together.”^[12] The important role of family, including the interrelatedness of the health of a child and family function, is increasingly being acknowledged in pediatric practice. As the AAP Committee on Children with Disabilities states:

The focus of health and developmental services has evolved from a child-centered, traditional, ‘medical’ model to a family-centered ‘developmental’ model. That is, it also takes into consideration the important contributions of the family unit, the stressors that affect families (be they social, financial, and/or psychological), and the ability of families to adapt to new challenges.^[13]

Over the past 30 years, the importance of family-centered care in social services and health has gained prominence, beginning with children with special health care or educational needs. In the 1980s, visionary leaders in the MCHB began to evolve the concept of family-centered care to include family-professional partnerships and the medical home as essential components of a comprehensive system of services for CYSHCN. The MCHB recognized the critical role that families played in caring for their children’s health, particularly families of children with special needs. Throughout the process of developing and defining the concepts of family-centered care, the MCHB partnered closely with families.^[14] At a 1987 conference sponsored by the AAP and the MCHB, Surgeon General of the US Public Health Service, C Everett Koop, called for the establishment of a national agenda for families and professionals involved in the care of children with special needs to work together “to improve the lives of these children and their families through a system of family-centered, community-based, coordinated care.”^[15] Care managers (care coordinators) and financing for care coordination were recognized as essential elements in the provision of family-centered care for children with special needs. In 1992, families of children with special needs formed a grassroots national network, Family Voices, to promote the voice of families in health care for children and families as partners in improving health care for children with special health care needs. Together, MCHB leaders, Family Voices, and families created key publications to describe family-centered care and family professional collaborations in action, and created a MCHB definition of family-centered care.^[16,17]

The MCHB characterizes family-centered care as that which:

Assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions, and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high-quality service.^[18]

Foundational to family-centered care is the partnership between families and professionals, which builds on the following principles:

- Families and professionals work together in the best interest of the child and family. As children grow, they assume partnership roles.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.^[19]

Based on this partnership, family-centered care:

1. Acknowledges the family as the constant in a child’s life.
2. Builds on family strengths.
3. Supports children in learning about and participating in their care and decision-making.
4. Honors cultural diversity and family traditions.
5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
10. Celebrates successes.

Other national organizations have developed definitions and characterized the principles of family-centered care. The Institute for Patient- and Family-Centered Care describes family-centered care as “an approach to the planning, delivery, and evaluation of healthcare that is governed by mutually beneficial partnerships between healthcare providers, patients, and families. Family-centered care applies to patients of all ages, and it may be practiced in any healthcare setting.”^[20] The Institute for Patient- and Family-Centered Care also developed essential practice elements of patient- and family-centered care as described in Table I.^[20]

TABLE I. ELEMENTS OF FAMILY-CENTERED CARE

Recognizing that the family is the constant in a child's life, and that the service systems and personnel within those systems fluctuates

Facilitating family-professional collaboration at all levels of health care

Honoring the racial, ethnic, cultural, and socioeconomic diversity of families

Recognizing family strengths and individuality, and respecting different methods of coping

Sharing with parents, on a continuing basis in a supportive manner, complete and unbiased information

Encouraging and facilitating family-to-family support and networking

Understanding and incorporating the developmental needs of infants, children, adolescents, and families into health systems

Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families

Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs

In 2003, the AAP published a report from the AAP Task Force on Family which promoted a “family-oriented pediatrician,” and recommended specific actions for all pediatricians, such as learning more about a child’s family, providing information, access, and opportunities for discussion for families, establishing roles for families and family-centered policies for the practice, referring families to appropriate services, and displaying community resources and welcoming visual cues of diverse types of families.^[21]

In 2012, the AAP Committee on Hospital Care and the Institute for Patient- and Family-Centered Care developed core principles for patient- and family-centered care that are specific to the pediatrician’s role (Table II).^[22]

TABLE II. PATIENT- AND FAMILY-CENTERED CARE AND THE PEDIATRICIAN’S ROLE—CORE PRINCIPLES:

Listening to and respecting each child and his or her family. Honoring racial, ethnic, cultural, socioeconomic backgrounds, and patient and family experiences, and incorporating them in accordance with patient and family preference into the planning and delivery of health care.

Ensuring flexibility in organizational policies, procedures, and provider practices so services can be tailored to the needs, beliefs, and cultural values of each child and family, and facilitating choice for the child and family about approaches to care.

Sharing complete, honest, and unbiased information with patients and their families on an ongoing basis and in ways they find useful and affirming, so that they may effectively participate in care and decision-making to the level they choose. Health information for children and families should be available in the range of cultural and linguistic diversity present in the community and take into account health literacy.

Providing and/or ensuring formal and informal support (eg, peer-to-peer support) for the child and family during each phase of the child’s life.

Collaborating with patients and families at all levels of health care: in the delivery of care to the individual child; in professional education, policy-making, program development, implementation, and evaluation; and in health care facility design.

Recognizing and building on the strengths of individual children and families, and empowering them to discover their own strengths, build confidence, and participate in making choices and decisions about their health care.

This AAP statement encourages use of the term *patient- and family-centered care* to explicitly capture the importance of engaging both families and patients in care. Some people argue that the terms *patient-centered* and *family-centered* differ slightly but have the same meaning as they both call for consumer involvement in health care. Family-centered care is also often considered a principle of patient-centered care. The Institute of Medicine defines family-centered care as 1 of the 6 key elements to improving the US health care system in *Crossing the Quality Chasm*.^[23,24] The Institute of Medicine specifically describes the involvement of family and friends as a component of patient-centeredness, focusing specifically on “accommodating family and friends on whom patients may rely, involving them as appropriate in decision-making, supporting them as caregivers, making them welcome and comfortable in the care delivery setting, and recognizing their needs and contributions.”^[24] Family-centered care has been an important element in nursing,

obstetrics and gynecology, emergency medicine, family medicine, and end-of-life care. It likely will continue to increase in importance, not only in the management of chronic illness in geriatric practice, but throughout health care. Consequently, the importance of family in family-centered primary care continues to grow. The need to recognize, operationalize, evaluate, and disseminate best practices in family-centered primary care from the perspective of families, particularly in the practice-specific context of the medical home, is imperative for improved health care, better population health, and lowered health care costs.

THE EVIDENCE FOR FAMILY-CENTERED CARE

Much of the work on family-centered care in pediatric practice has been focused on the hospital setting.^[25-27] Most pediatric health care is delivered in the outpatient setting, yet very little has been published about implementation of family-centered care in outpatient settings, within the context of the medical home. Research has revealed a greater receipt of anticipatory guidance and reduced unmet needs for CYSHCN when family-centered care is present.^[28,29]

For families of CYSHCN, the receipt of family-centered care has been associated with less delays in health care, fewer unmet service needs, reduced odds of requiring more than 1 hour of care coordination per week, and reductions in health care costs.^[29] The receipt of family-centered care by CYSHCN is also associated with more stable health care needs, reduced odds of emergency department visits, and increased odds of medical home visits.^[29]

In a 2011 literature review, Kuhlthau et al defined family-centered care as: family-provider partnership, physician-patient communication, family-to-family peer support within the medical home, family as staff, treatment alliance, self-management and educational support, peer support, home care intervention, and learning collaboratives.^[30] Kuhlthau et al found positive associations of family-centered care with improvements in efficient use of services, health status, satisfaction, access to care, communication, systems of care, family functioning, and family impact/cost.^[30] However, little evidence for reductions in cost and improvements in care transitions has been documented.

UNDERSTANDING BEST PRACTICES IN FAMILY-CENTERED CARE

The Healthy People 2010 goals state: (a) “Families of all children with special health care needs will participate in decision-making, and will be satisfied with services, and (b) All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.”^[31] Since passage of the Omnibus Budget Reconciliation Act in 1989, states have been charged with developing policies and systems of care that meet these goals. In 2005, Congress passed the Family Opportunity Act creating Family-to-Family Health Information Centers (F2F HICs) in every state, a goal that Family Voices has been working toward for more than 10 years. These consumer-run centers, connected through Family Voices in a national network, provide information, support, and training for families and health professionals, promoting effective family-professional partnerships and family-centered care at state and local levels around the country. The Patient Protection and Affordable Care Act of 2010 extended funding for F2F HICs through 2013. The Family Voices National Center for Family Professional Partnerships, funded by MCHB, supports F2F HICs and partners in working toward this goal, and the AAP National Center for Medical Home Implementation, also funded by MCHB, focuses on increasing the implementation of pediatric medical homes throughout the country.

Despite progress, there is still much work to do to accomplish a patient- and family-centered medical home for each child with special health care needs. National estimates indicate that one-third of families of a child with special needs report dissatisfaction with at least one aspect of their child’s care. The 2001 National Survey of Children with Special Health Care Needs found that within families of children with special needs, 22% had difficulty obtaining a referral for their child.^[32] Families of the children who were most severely affected were significantly more likely (odds ratio, 12.66) than families with children who were mildly affected to report having unmet needs for family support services.^[32]

Rates reported for the receipt of family-centered care for CYSHCN are concerning, and the disparities among the rating by families of different ethnic, racial, and socio-economic groups and among families of children with different special needs is very troubling. Using the 2005-2006 National Survey of Children with Special

Healthcare Needs, Kuo et al found that only 65.5% of respondents reported receipt of family-centered care.^[29] Analysis of a linked dataset of the Medical Expenditure Panel Survey and the National Health Interview Survey from 2003 to 2006, revealed that Latinos reported less receipt of family-centered services than both whites and blacks.^[33] Results of the 2005-2006 National Survey of Children with Special Health Care Needs revealed that families of children affected by autism were less likely to report receiving family-centered care, and within these families, black families were less likely than white families to report receiving family-centered care.^[34]

Recently, using the 2007 National Survey of Children's Health, Zickafoose et al found that only 58% of publicly insured children reported receiving family-centered care compared with 76% of privately insured children after adjusting for socio-demographic characteristics.^[35] Furthermore, in every state, family-centered care was the component of the medical home with the lowest prevalence for children with both public (45%-76%) and private insurance (68%-82%).^[36] In states with low medical home prevalence, publically insured children were less likely to report receiving nearly all aspects of family-centered care.^[36]

The next section of this document describes a project, conducted in 2011 with support from the MCHB and the National Center for Medical Home Implementation, to better understand the processes and structures that characterize best practices of family-centered care within pediatric medical homes. The final section describes an analysis and results of the case studies as well as potential implications from these findings.

Section II: Case Studies of Best Practices in Patient- and Family-Centered Care

INTRODUCTION

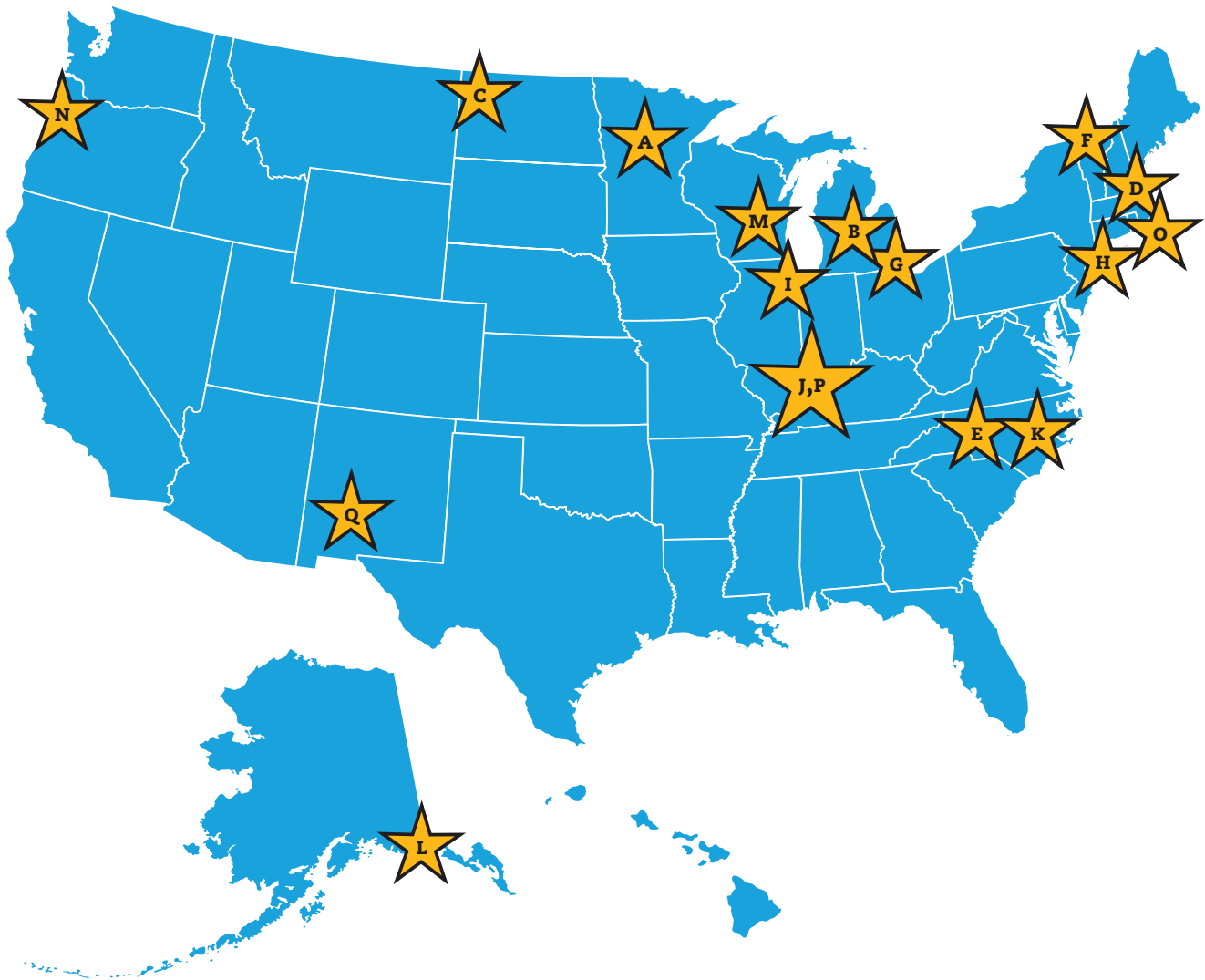
To better understand characteristics of family-centered medical homes serving pediatric patients, the National Center for Medical Implementation, with financial support from the MCHB, engaged Rebecca Malouin, PhD, MPH, from Michigan State University to conduct case studies on exem-

plary practices. Dr Malouin, with assistance from Michelle Esquivel, MPH, from the National Center for Medical Home Implementation, invited leaders in family-centered care to serve as advisors to the project. In addition to Michelle Esquivel, the patient advisory committee consisted of Barbara Kahl, JD, and Joanna Kaufman, RN, MS, of the Institute for Patient- and Family-Centered Care; Marie Mann, MD, MPH, of the MCHB of the Health Resources and Services Administration; Lee Partridge of the National Partnership for Women and Families; and Nora Wells, MS, of Family Voices and the National Center for Family/ Professional Partnerships. The project was reviewed and approved by the Biomedical and Health Institutional Review Board of Michigan State University.

The patient advisory committee solicited nominations from listserves of the MCHB and the AAP and elsewhere to identify exemplary practices. Nominators were asked to complete detailed nomination forms. The patient advisory committee selected 17 practices from 28 nominations by using a standardized scoring scheme that was based on descriptions of family-centered processes and tools within the practice as well as diversity in practice type, organizational structure, and geographic location. During July and August 2011, physicians, staff, and families identified by the selected practices were contacted and invited to participate in 30- to 60-minute key informant interviews via telephone. The interviews were transcribed, and researchers analyzed the qualitative data to identify common themes.

The case studies in this section are derived from the key informant interviews with physicians, staff, and family partners. These case studies provide detailed descriptions of the most noteworthy practices and the approaches that key informants have found successful in implementing family-centered care. The case studies are organized around the domains of family-centered care that were identified through the key informant interviews and include the larger themes of access, care management, collaborative learning, communication, cultural diversity and sensitivity, family feedback, and quality improvement. All case studies were reviewed by key informants for accuracy. As not all domains were mentioned by all informants, key informants were also asked to complete tables including practice characteristics and specific structures and processes within each practice within each of the key themes (Appendices III and IV). Geographic locations of the practices are indicated on the map at the right.

FIGURE 1: MAP OF SELECTED NOMINEES WITH BEST PRACTICES IN PATIENT- AND FAMILY-CENTERED CARE



- A) CentraCare Clinic–Women and Children Pediatrics – St. Cloud, Minnesota
- B) Child Health Care Clinic – East Lansing, Michigan
- C) Comprehensive Pediatric Care – Williston, North Dakota
- D) Core Pediatrics – Exeter, New Hampshire
- E) Guilford Child Health of Triad Adult and Pediatric Medicine – Greensboro, North Carolina
- F) Hagan, Rinehart, & Connolly – Burlington, Vermont
- G) Henry Ford Pediatrics New Center One – Detroit, Michigan
- H) The LINGS Program at Children’s Hospital at Montefiore – Bronx, New York
- I) North Arlington Pediatrics – Arlington Heights, Illinois
- J) Pecar Health Center – Indianapolis, Indiana
- K) Pediatric Partners – Raleigh, North Carolina
- L) Rainforest Pediatrics – Juneau, Alaska
- M) Children’s Medical Group–Southwest Pediatrics – New Berlin, Wisconsin
- N) The Children’s Clinic, PC – Portland, Oregon
- O) Westwood–Mansfield Pediatric Associates, PC – Westwood, Massachusetts
- P) Wishard Primary Care Pediatrics – Indianapolis, Indiana
- Q) Young Children’s Health Center – Albuquerque, New Mexico

CENTRA CARE CLINIC—WOMEN AND CHILDREN

Practice address:	1900 CentraCare Cir St. Cloud, MN 56303 http://www.centracare.com
Geographic location:	Small city/rural
Type of practice:	Large multispecialty pediatrics
Organizational structure:	Affiliated with the CentraCare Health System, which includes hospitals, clinics, and specialty care services
Size of practice:	17 pediatricians 6 nurse practitioners
Number of patients:	26,000 patients; approximately 133 patients per day in walk-in clinic
Patient insurance:	65% commercial/private insurance 24% Medicaid 11% self-pay
Medical home recognition:	Certified HCH by Minnesota's HCH Program
Patient/family questionnaire	–Medical Home Index and MHFI experience administered annually for 7 years as part of the MHLC –Press Ganey clinic satisfaction survey
EMR system:	Yes
Other information:	–EMRs include a text field for “social documentation.” –MyChart—A patient portal system that allows patients and families access to portions of the child’s medical record, reliable information on health topics, notification of laboratory results, and direct, secure communication with the child’s health care provider. –Clinic Facebook page—to facilitate communication with and among patient families.
Funding source(s):	Primarily funded through the practice’s operating funds. Small amount of funding from Medical Home Learning Collaborative (MHLC) to fund stipends for parent partners and costs associated with implementation of medical home initiatives. Funding from Minnesota HCH certification to fund salaries of care coordinators.

Abbreviations: EMR, electronic medical record; HCH, health care home; MHFI, Medical Home Family Index; MHLC, medical home learning collaborative.

PRACTICE OVERVIEW:

CentraCare Clinic—Women and Children became familiar with the principles of patient- and family-centered care as a participant in state and national learning collaboratives. CentraCare received a 3-year grant from the CentraCare Health System Foundation to enhance its efforts related to the medical home; grant funding supported patient- and family-centered processes and structures within the practice. The enhanced payments the clinic receives as a certified state health care home (HCH) have not fully covered the initial and ongoing costs associated with achieving certification. The clinic considers the cost an investment in patient and family care.

LESSONS LEARNED:

- Practices affiliated with a health system should communicate with administrators and seek their support when planning to implement change. When the proposed initiatives begin to broaden in scope and involve infrastructure-level changes, administrative support will be integral to success.
- Administrators can be helpful in integrating patient- and family-centered language and principles into hiring practices and performance reviews.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

Access has been improved by the creation of a pediatric walk-in clinic. An **after-hours triage nurse** is available to families via telephone to answer questions or transfer relevant calls to an on-call physician. The implementation of efficient **pre-visit planning** workflows has reduced the appointment time necessary to assess and treat complex patients. The need for interpreter services is assessed during pre-visit planning.

“I have a direct phone number to my care coordinator...so I don’t have to sit in a queue and wait for 20 minutes on a Monday morning.”
—family member

CARE MANAGEMENT

Most improvements in care at CentraCare have been attributed to the implementation of **care plans** for CYSHCN. The care plan facilitates a systematic, disciplined approach to care in clinic and home settings, ultimately reducing the need for emergency care.

In conjunction with parent partners, the clinic staff developed and implemented a triage workflow that allows families of CYSHCN to quickly and easily reach a **care coordinator** through the standard telephone triage nurses’ line or a direct line during clinic hours. The clinic has utilized

the services of **outside organizations** to improve coordination of care and linkage to community services. Examples of these services include: transportation services; county social workers available for referrals to home-care agencies;

“We just keep a copy [of the care plan] in the glove box, so if we were traveling and stopping at some emergency room in another state we’d have all of our information with us.”
—family member

the clinic’s autism collaborative, which fosters partnerships among school administrators and educators, community-based autism resources, and clinic providers and staff to enhance care management.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

CentraCare began efforts to make its pediatric clinic more patient- and family-centered almost a decade ago as part of the Institute for Clinical Systems Improvement, a collaborative of clinical organizations, health plans, and business representatives formed to improve patient care in Minnesota. While participating in the Institute’s practice improvement workshops, the CentraCare pediatrics team focused on patient- and family-centered care, resulting in their participation in medical home learning collaboratives (MHLGs) at the state and national levels.

Activities sponsored by the Title V Maternal and Child Health Program in Minnesota and the Minnesota chapter of the AAP have been foundational to jumpstarting improvement efforts at CentraCare. Grant funding and activities provided by these groups have led the way for medical home initiatives at CentraCare.

Through active participation in these groups, CentraCare has shared both paper and electronic versions of its care plan template with other practices, the Minnesota MHLG, as well as the clinic’s electronic medical record (EMR) software company, Epic Software.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

Patient and **parent partners** serve on all practice improvement projects, including the HCH Learning Collaborative, the Asthma Improvement Project, the Autism Learning Collaborative, and the Developmental and Fetal Alcohol Syndrome Screening Project.

COMMUNICATION WITH PATIENTS & FAMILIES

Large **banners** in the clinic lobby invite families to “Ask us about Health Care Home,” and **brochures** in the examination rooms contain details about the services offered to

those who participate in the HCH program. All patients are welcome to register for the HCH and receive a customized care plan.

The practice maintains regular communication with its patients and their families through a quarterly HCH **newsletter** containing program updates, health information resources, pertinent event dates, as well as a column highlighting a “Star Child” with special health care needs. The clinic is also creating a community resource board in the lobby.

MyChart, a **patient portal** system, allows patients and families access to portions of the child’s medical record, giving them the opportunity to: review records from previous appointments; schedule a new appointment; view lists of the child’s medications, allergies, and immunizations; access reliable information on a range of health topics; and receive laboratory results. MyChart also provides the opportunity for direct, secure communication with the child’s health care provider. Patients older than 12 years have the option to be active in the MyChart system and can choose to grant parents limited access to their medical record.

The HCH team, comprised of clinic administrators, parent partners, and a representative from Family Voices of Minnesota and the Healthy and Ready To Work National Resource Center, has developed a **transition information** packet for patients and families to assist in the transition from childhood to adulthood.

The practice is developing a video documenting the experiences of some of the clinic’s parents of CYSHCN and how the implementation of the HCH program has affected their children’s care.

CULTURAL DIVERSITY & SENSITIVITY

CentraCare offers services which enhance the clinic’s ability to serve its culturally diverse families, including: access to free interpreter services, a list of vetted websites containing health information in several languages, and a cultural diversity coordinator who serves on the clinic’s HCH steering committee.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

Since 2009, the clinic has regularly asked patients to participate in a Press Ganey satisfaction survey. This **patient satisfaction survey** is used throughout the CentraCare Health System. An **advisory committee**, which includes parent representatives, meets once a month at the clinic to discuss survey results and other feedback or concerns and brainstorm potential changes to improve patient care. The clinic also employs a systematic approach to recognizing and remedying process and operations issues. For example, the clinic’s autism collaborative is currently running a

Plan-Do-Study-Act cycle to improve parent completion of the Ages & Stages Questionnaire (ASQ): Social and Emotional, a developmental screening tool. Also, the clinic periodically conducts **walk-throughs** with parents, asking for their comments and suggestions for improvements.

The clinic uses multidisciplinary **care teams** to tackle specific improvement initiatives. These teams include parents or family members to ensure any changes implemented in the clinic are truly patient- and family-centered. Parent partners are nominated by physicians and care coordinators to participate as advocates on the care teams. The

clinic compensates participating partners with gas cards or other gift cards.

PRACTICE QUALITY IMPROVEMENT

The clinic conducts monthly reviews of patient registries as part of the Minnesota Community Measurement, a public reporting program reporting on clinic performance. The reports enable the practice to monitor and detect improvements as they occur. Practice successes are celebrated with small treats; individual patient success stories are documented; and coworkers are recognized for outstanding work.

CHILD HEALTH CARE CLINIC

Practice address:	788 Service Rd East Lansing, MI 48824
Geographic location:	Urban/small city
Type of practice:	General pediatrics
Organizational structure:	Academic, affiliated with the MSU HealthTeam
Size of practice:	7 pediatricians (sharing 4 full-time equivalent positions) 1 care coordination nurse 1 part-time social worker
Number of patients:	4,000
Patient insurance:	50% commercial/private insurance 50% Medicaid
Medical home recognition:	- MHLIC demonstration project through the Health Resources and Services Administration - Blue Cross Blue Shield Provider Group Incentive Plan PCMH recognition annually since 2010 - Michigan Department of Community Health-sponsored Family-Centered Medical Home focusing on CYSHCN
Patient/family experience questionnaire:	- Yearly patient satisfaction surveys administered by the MSU HealthTeam to a sample of 300 patients - Primary Care Assessment Tool- Child Version administered to both families and providers - MHFI administered to families - Medical Home Index administered to providers
EMR system:	Yes
Other information technology:	Yes, written care plan template integrated into the EMR
Funding source(s):	- As a Michigan Department of Community Health-sponsored Family Centered Medical Home demonstration practice with a focus on meeting the needs of CYSHCN, the practice receives funding to support the salaries of its care coordinators, a part-time social worker, and a registered nurse care coordinator who oversees the CYSHCN. - By participating in the Blue Cross Blue Shield Provider Group Incentive Plan program and meeting the criteria to achieve PCMH recognition, the practice receives funding for infrastructure development, such as the maintenance and improvement of information technology systems. This funding was used to convert the clinic's care plan template to an electronic version that is integrated into the EMR system. - The practice has received assistance internally within the MSU HealthTeam for administration and information technology services. Other more specialized grants have been obtained to fund specific initiatives.

Abbreviations: CYSHCN, children and youth with special health care needs; EMR, electronic medical record; MHFI, Medical Home Family Index; MHLIC, medical home learning collaborative; MSU, Michigan State University; PCMH, patient-centered medical home.

PRACTICE OVERVIEW:

The practice believes that by tailoring interventions to each individual family, it is not just family-oriented, but patient- and family-centered, a style of practice that is “all about the families.”

LESSONS LEARNED:

- Participation in a MHLIC is helpful to learn from the experiences of other providers implementing patient- and family-centered initiatives, as well as to educate one another on the resources and services available to assist practices, patients, and families.
- Learning collaborative meetings are not only helpful for physicians, but for care coordinators and nurse managers as well.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

The practice has seen an increase in the number of complex patient referrals since establishing itself as a medical home for CYSHCN. The practice has had difficulty transitioning CYSHCN to adult care providers. The practice works with each family to develop an individualized **transition plan** and ease them through the transition process. Each family is given a copy of *Transition Planning: A Guidebook for Young Adults and Family* created by Michigan’s Children’s Special Health Care Services and asked to set a timeline for the transition to adult care. The clinic ensures completion of an updated care plan in the patient’s EMR and gives the family a hard copy prior to the first appointment with the adult care provider.

The Child Health Clinic provides access to **behavioral health services** through a social worker who emotionally supports families and links them to community services and a child psychiatrist who works in the practice one afternoon each week to provide comprehensive mental and behavioral health evaluations or consults at the request of the clinic’s primary care pediatricians.

CARE MANAGEMENT

Since 2006, the practice has created **care plans** for CYSHCN, easing the burden on families to continually provide their child’s medical history to providers unfamiliar with the child’s background. The care plan is integrated into the EMR, enabling easy updates and modifications. Most importantly, the care plan lists current patient and family goals and delineates the tasks that need to be done (and by whom) to achieve these goals.

To work around the difficulties with registry functions in an adult care-based EMR system, the clinic has built its own **registry** of CYSHCN in Microsoft Excel. Information pertaining to each complex patient is kept in a central location, allowing for easier tracking and reporting of care coordination.

Developmental screening with the ASQ, the Modified Checklist for Autism in Toddlers, an oral health questionnaire to screen infants and toddlers for risk of dental caries, and the Edinburgh Postnatal Depression Scale to screen mothers for postpartum depression have been integrated into the practice’s well-child visit protocols.

The clinic improved its ability to link families to **community resources** by establishing a relationship with the local health department nurse who offers recommendations for health care resources and other resources and services to meet each family’s specific needs and assists in the referral process to augment clinic efforts. Additionally, the clinic invites staff from community services and other organizations to conduct presentations at biweekly practice-level staff meetings.

A part-time licensed **social worker** was hired by the clinic to help families navigate through the system of services available to them. She provides emotional support and guidance to families in times of stress and links them with appropriate services. She maintains a list of community resources that is updated based on family feedback. The practice utilizes funding from the Michigan Department of Community Health to support the salaries of its care coordinators, a part-time social worker, and a registered nurse care coordinator who oversees the CYSHCN.

Early in its medical home initiatives, the practice modified its process for making and **tracking referrals** to “close the loop.” The practice referral specialist has since established a system to track referrals, patients’ visits to subspecialists, and the reports and recommendations from the subspecialists.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

The practice is a Michigan Department of Community Health–sponsored Family-Centered Medical Home demonstration practice with a focus on the needs of CYSHCN. The practice also participates in a statewide MHLIC sponsored by Michigan’s Children’s Special Health Care Services.

The Child Health Care Clinic based its Health Skills Checklist for youth on a similar tool created by Michigan’s Children’s Special Health Care Services. Copies of the notebook for tracking health records of CYSHCN have been made available to other practices in Michigan through a Health Resources and Services Administration grant to create an integrated system of care for CYSHCN.

COMMUNICATION WITH PATIENTS & FAMILIES

Specific **communication tools** for patients and families include a bulletin board that is updated by the care coordination nurse at least once a month with information and notices for families. The Health Care Checklist for youth helps young people to engage in their health care and fami-

lies to prepare for the transition to adulthood. Focus groups and the Primary Care Assessment Tool surveys have proven to be the best means for obtaining meaningful input from

“Integral to all our interactions with children/youth and family members is respect for the primacy of family in the life and health of the child... Family-centeredness is operationalized in encounters with every family where the family is really part of the decision-making about the child, a lot of shared decision-making from the time they call the front desk. It’s not perfectly operationalized, but families are respected; they’re treated well, we try to accommodate their needs, understand their values, and work with them to achieve their goals for their child. So I think the really important part of the patient- and family-centeredness is just in every interaction, and just how we set things up to make it not just family-oriented, really patient- and family-centered; that it’s all about the families.”

—practice

“They accepted the fact that I know more than them about [my child’s] condition, so they tend to listen to me more.”

—family member

from Family2Family, the practice has purchased books from the AAP on infant care, adolescent health, obesity, healthy weight, and attention-deficit/hyperactivity disorder (ADHD) to give families when appropriate for the age or health condition of the patient.

CULTURAL DIVERSITY & SENSITIVITY

As a product of the clinic’s affiliation with Michigan State University, and given the large refugee population in the surrounding area, the clinic sees families from many different countries who have limited English proficiency. A telephone interpreter service through AT&T is utilized during these encounters. Through recent EMR upgrades, family language preference is now a recorded field used regularly during the nurse intake process, and the electronic care plan template contains fields for noting cultural or religious preferences.

families and gathering specific ideas for practice improvement. The clinic designed a notebook (a 3-ring binder with labeled sections including resource lists and the child’s care plan) to help families organize and keep track of information about their child’s health. One of these notebooks is given to each family with a child with special health care needs and all families caring for a foster child. The notebook is intended to go with the foster child if he/she changes homes.

Families are provided with **educational materials** during clinical encounters. Handouts regarding child development and age-appropriate anticipatory guidance are routinely given out, as well as condition-specific printed information when appropriate.

Through grant support

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

Beginning in April 2011, the practice began holding **focus groups** led by parents of patients. The parent leaders were trained through a state-level leadership program, Parent to Parent. The practice has been challenged by how to weigh the opinions and advice received from advisory focus groups. Some of the recommended interventions have been cost-prohibitive.

On a practice level, input from families is sought through **patient satisfaction surveys**, the Primary Care Assessment Tool–Child Version, and the Medical Home Family Index (MHFI). The patient satisfaction survey is offered by front-desk staff members at every visit. The practice used the MHFI for patients and families and its companion tool, the Medical Home Index for providers, in the early stages of building its medical home for CYSHCN. However, as the medical home initiatives have expanded to include all patient care delivered in the clinic, the Primary Care Assessment Tool–Child Version for patients and families along with its companion tools, the provider and facility versions, are now administered annually.

PRACTICE QUALITY IMPROVEMENT

By participating in the Blue Cross Blue Shield Provider Group Incentive Plan and meeting its criteria to achieve PCMH recognition, the practice receives funding from Blue

“When the doctors leave [the focus group] the parents can feel more comfortable opening up and saying it’s a great practice, but we’ve noticed this recently, or noticed that... I’ll take all that and communicate with the social workers and the nurse to see what can be done to improve the clinic.”

—family member

Cross Blue Shield for infrastructure, such as information technology systems maintenance and improvement. The practice has received assistance internally, within the Michigan State University Health-Team, for administration and information technology services on some initiatives.

Achieving the intended heightened level of **care coordination** services for the patients who most need it, namely CYSHCN, is dependent on finding a balance between identifying a key point person to oversee care coordination efforts for the more complex cases and having everyone in the practice take responsibility for the care of all patients.

“They’ve started not wearing lab coats into the rooms, which really helped the kids because... [the kids] know what was associated with the white coat and don’t want anything to do with it.”

—family member

As one provider from the practice stated, “You have to work with people, and help bring people along, and help them understand that this is the way they really want to do it, not because you told them they have to.”

COMPREHENSIVE PEDIATRIC CARE, PC

Practice address:	1411 W Dakota Pkwy, Ste 2A Williston, ND 58801
Geographic location:	Rural
Type of practice:	General pediatrics
Organizational structure:	Private practice
Size of practice:	1 pediatrician/developmental pediatrician 2 care coordinators 4 registered nurses 1 infant massage therapist 1 parent consultant/patient and family advocate
Number of patients:	5,500
Patient insurance:	70% commercial/private insurance 25% Medicaid 5% self-pay
Medical home recognition:	NCQA Physician Practice Connections Patient-Centered Medical Home application in progress
Patient/family experience questionnaire:	Practice-created patient satisfaction surveys written by the full-time parent advocate
EMR system:	Yes
Other information technology:	Yes, patient portal
Funding source(s):	Funded through the practice's operating funds

Abbreviations: EMR, electronic medical record; NCQA, National Committee for Quality Assurance.

PRACTICE OVERVIEW:

Comprehensive Pediatric Care is committed to the philosophy that every child deserves a medical home. Because the clinic understands that all families are unique and embraces the family as the constant in a child's life, providers and staff partner with families, regarding them as the experts on their own children. The clinic's practice of engaging the whole family in the identification of concerns and the resolution of needs for each child, while respecting and valuing the family's input, engenders trust within the family-provider relationship, thereby facilitating effective, meaningful communication.

The practice realizes the diversity of the families it serves and the importance of staying accountable to each family's individual needs, "...we understand it is difficult to always adhere to rigid rules, what works best for one family doesn't always work for others. Because of that, we must change as needed."

LESSONS LEARNED:

- Building a medical home must start with committed and passionate leaders and a carefully selected, nurturing staff.
- Modeling detail-oriented behavior and a passionate work ethic will help others learn and embrace the core values of the team. Sharing a vision and establishing a path to accomplish it is necessary and must be recognized by the entire staff. To build a successful medical home,

"you have to truly want to make your office be a home away from home for your families."

- Rather than looking outside your practice for people to help with the endeavor, "get to know your families. Most of your families will have the skills you need." The practice has found it beneficial to have a parent consultant on staff to administer post-visit patient satisfaction surveys and to identify cases when service was not well received.
- Perhaps most importantly, "have fun in your practice... It's never too late to have a happy childhood... Cherish your staff and provide opportunities for them to grow professionally through travel to other clinics, conferences, or time off for education."

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

Families are given **barrier-free access** (24 hours a day, 7 days a week, 365 days a year) to the physician via her cell phone. Though the clinic does have set business hours, if there is a problem after hours, arrangements are made for the child to be seen by the doctor rather than have the child taken to the emergency department.

The practice maintains a philosophy of barrier-free access, providing what others have termed as "concierge care" for patients and families. Parents and children are encouraged to feel at home during their clinic visit. The office environment is designed for **family comfort**. Front desk staff are

ready to recognize and respond to the details of caring for “guests,” offering coffee while parents wait, making oatmeal or pancakes for the child who skipped breakfast, or providing supplies a parent may need while in the office, such as diapers, changing materials, and extra clothes for the child who has an accident. Parents know that if they need to step out for a moment there are trusted members

“We go into a room where there’s a child and a family who have questions, and everything else disappears while we’re in there...And that’s a good feeling, and that leaves us all feeling energized at the end of the day, because we feel like we’ve connected, listened, and accomplished something. But we do it in concert with what the family wants...”
–practice

of the staff ready to watch their child. “Families know that we respect their time, and when they experience delays they will receive a sincere apology for making them wait as well as an explanation for the delay.”

Children quickly learn where the Popsicle freezer is located and

how to find the drawers full of stickers. Patients are all aware of the clinic’s rule that if they are made to cry over a procedure we have to “make it up to them” with a toy or a trip to the local book and toy store where they can choose their own prize and charge it to the clinic.

Children are encouraged to appreciate the importance of prevention and taught to have a sense of ownership of the **shared responsibility** to stay healthy. This philosophy is fostered by clinic practices like the one concerning influenza vaccines. The clinic strives to vaccinate not just the patient identified as needing an influenza vaccine, but all family members, including grandparents who children are encouraged to bring along on their clinic visits.

To support families with limited financial resources, the practice never uses a collection agency to recover unpaid bills. Instead, the clinic offers **flexible payment** options and will work out payment plans. If families truly cannot afford to pay, the clinic will treat the children without billing for the visit.

CARE MANAGEMENT

Comprehensive Pediatric Care employs 4 full-time nurses, a scheduling/logistics coordinator, and a family coordinator who together provide the **care coordination** for all of the clinic’s patients. The clinic’s parent consultant handles much of the patient advocacy work. When advocating for older patients with special needs, the parent consultant includes both the parent and the child in any discussions about an Individualized Education Program 504 application or other support services the child may require.

The practice has a nearly 100% success rate in preventing children with asthma from requiring emergency department care. This success is attributed to care plans, parent education, and a policy of ensuring that children are seen promptly at the first sign of illness. The clinic maintains a policy that a sick child must be seen the same day no matter how long it takes. The clinic staff believe that minor problems will not escalate into serious problems when attended to early.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

The practice’s parent consultant has attended Family Voices seminars, AAP events, and other functions to network with other practices, learn from their experiences, and share Comprehensive Pediatric Care’s successes and challenges. These forums have been instrumental in facilitating access to a multitude of community resources for families.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

Under the supervision of the parent consultant, the practice has created **support groups** for parents going

“Parents appreciate the time and effort we expend to minimize discomfort and make them and their children comfortable. We want our patients and their families to feel at home with us, to encounter no barriers to our attention and care. We encourage siblings to attend a child’s appointment freeing the parent from the expense and hassle of child care. Parents know that their children will want to come back, not just for popsicles and toys, but for the attention and respect they receive. Every child is listened to actively and with genuine interest in what he or she has to say. Every question is answered on the spot. No child is allowed to leave unhappy. Everyone is tasked to quickly redirect tears into a pleasant experience so as to minimize the strength and longevity of traumatic memories. Everyone knows that a child crying during an exam needs extra attention like bubbles, distractions, play, or one of our famous organic fruit juice suckers.”
–practice

through similar situations, such as a group for new mothers. The group for new mothers was created with the hope that families will use each other’s strengths to get through the day-to-day struggles in caring for a child with this illness.

Comprehensive Pediatric Care partners with a local **community group** called Oilfield Wives and Girlfriends, a group of women whose significant others work in the nearby oilfields. The practice maintains open lines of communication with the group, making the clinic’s services known and available to members, inquiring as to how the clinic could further meet their needs, and supporting the group’s activities in the community.

COMMUNICATION WITH PATIENTS & FAMILIES

Clinicians routinely elicit and respond to the needs of family members other than just the child being seen during a visit. To further facilitate smooth, uninterrupted communication and focus on the patient and their family during the visit, the physician has a **scribe** who is present in the examination room and is responsible for documenting examination findings and discussions.

Over time, the entire staff becomes familiar with each family and is quick to greet and engage in conversation with anyone in the waiting room. Families know that they can ask for assistance at any time and that they will receive an immediate response. All of the administrative staff have **open door policies** and warmly welcome questions about logistics, billing, or services.

The clinic supports parents in times of crises by identifying available resources, assuring access to needed services, facilitating parent-to-parent support, and hosting support groups within the clinic. Reputable Internet-based information and models are made available to patients.

A **patient portal** system allows patients and families direct access to medical information including laboratory results, immunization records, and appointment notes, as well as secure e-mail access to correspond directly with the physician. Patients older than 13 years have increased privacy functions within the portal system, allowing for sensitive laboratory results and notes to be uploaded into a confidential section that does not print out as part of the patient's medical record and has restricted access.

Children and families are involved in all clinical decisions. To foster **shared decision-making**, providers cite the advantages and disadvantages of each potential course of action, and families are encouraged to engage in the decision-making process.

CULTURAL DIVERSITY & SENSITIVITY

As several of the patients and families in the practice are from Russia or Turkey and do not speak English, a telephone-based interpreter service is utilized. Nurses print information in the native language of the families.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The practice hired a patient's mother to fill the role of parent consultant. The parent consultant is a full-time, salaried member of the team who advises the practice on areas for improvement. She solicits feedback from families through satisfaction surveys as well as in-person or telephone conversations and then shares de-identified feedback with providers and staff. She has earned the respect of all of the clinic staff and is given the authority to override any clinic decision that she deems to not be in the best interests of families. Her responsibilities include guiding the practice through medical home recognition requirements and securing the practice's participation in the Quality Improvement Innovation Network through the AAP.

The clinic is establishing a **parent advisory committee** and therefore actively seeking parents who want to be involved in shaping clinic policy and offering suggestions to providers and staff as to how to serve the community better.

PRACTICE QUALITY IMPROVEMENT

Under the guidance of the parent consultant, the practice is currently pursuing National Committee for Quality Assurance (NCQA) Physician Practice Connections Patient-Centered Medical Home recognition and recently completed a **Bright Futures Preventive Services Improvement Project** through the AAP Quality Improvement Innovation Network. While participating in the improvement network, the practice had the opportunity to talk with and learn from other practices nationwide. During the year-long project, practice staff participated in monthly conference calls to discuss ways to improve the practice as it relates to Bright Futures. Monthly medical record reviews of patients between the ages of 9 and 24 months were conducted to monitor practice performance and offer real-time feedback to staff and providers.

CORE PEDIATRICS–EXETER

Practice address:	9 Buzell Ave Exeter, NH
Geographic location:	Rural
Type of practice:	General pediatrics
Organizational structure:	3 office locations; affiliated with the Core Physicians Health System
Size of practice:	- 4 full-time and 4 part-time pediatricians at Exeter site; 2 full-time pediatricians at each of the other sites in Plaistow and Kingston - 3 part-time nurse practitioners (2 at Exeter; 1 at Kingston) - 1 licensed social worker/care coordinator
Number of patients:	12,000
Patient insurance:	75%-80% commercial/private insurance 17%-18% Medicaid 2% self-pay
Medical home recognition:	One of the original New Hampshire medical home pilot practices with the CMHI
Patient/family experience questionnaire:	- Anonymous post-visit patient satisfaction surveys—no longer administered - Press Ganey patient satisfaction survey administered throughout the Core Physicians Health System; administered monthly at Exeter, yielding 300 survey responses per month - Medical Home Index administered annually to providers and staff
EMR system:	Yes
Other information technology:	Yes, patients who are at least 12 years old use Palm Pilots to complete screening tools, including the CRAFFT Behavioral Health Screening Tool for high-risk behaviors, the PHQ-2 to screen for depression (and if positive, a PHQ-9), and an anxiety screening tool; parents of patients 5-11 years old use Palm Pilots to complete screening questionnaires, including a PHQ-2 to screen for parental depression.
Funding source(s):	As a pilot practice in the CMHI Rural Medical Home Improvement Project, the services of a meeting facilitator were provided to oversee 90-minute meetings with parent partners and practice staff twice a month for the first 3 years of the project. The grant also provided funding for parent-partners stipends. The practice employed a care coordinator before being purchased by the Core Physicians Health System and negotiated the continued funding of the care coordinator position as a condition of the sale.

Abbreviations: CMHI, Center for Medical Home Improvement; EMR, electronic medical record; PHQ, Patient Health Questionnaire.

PRACTICE OVERVIEW:

As one of the first Center for Medical Home Improvement (CMHI) medical home pilot sites in New Hampshire beginning in 1997, Core Pediatrics–Exeter has a long history of partnering with families. The practice initially focused on improving care coordination for CYSHCN, but has since broadened its focus to include all patients and families in the practice. Exeter trusts in its family partners' advice and weighs their opinions as “equally as valid as doctors or care coordinators.”

Core Pediatrics found that slow buy-in to the implementation of new ideas and projects has been a challenge. By securing support at multiple points along the process chain, practice-wide support becomes easier to achieve. Furthermore, staff support for a new project is significantly improved by keeping the patient- and family-centered goal of any initiative at the forefront of every discussion.

LESSONS LEARNED:

- Exeter has always found it beneficial to foster an environment where families are respected. Particularly

during focus groups, the practice conveys to parents that their opinions are valued.

- As the practice underwent its transformation into a medical home, monthly lunchtime staff meetings were helpful for communicating changes around the office.
- The inclusion of a broad group of participants (not only clinicians and office staff, but parents, too) in the implementation of practice changes made it easier to transform policy, because changes were not seen as something only 1 or 2 people were privately working on, but an effort the whole practice had bought into.
- Lastly, the practice advises others to identify strong internal leaders, who are comfortable championing new projects and engaging with families.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

Continuity of care is ensured by **care teams** of 2 or 3 physicians who are responsible for covering one another's patients when a child's primary doctor is unavailable. Parents are comforted by the knowledge that their child will be seen by a physician with whom they have developed

a working relationship, rather than just any of the 8 physicians in the practice.

CARE MANAGEMENT

The practice has had a **care coordinator** on staff for more than 16 years who has helped facilitate its patient- and family-centered initiatives. The salary for the care coordinator position was initially funded by one of the health insurance plans accepted by the clinic and was later negotiated as a continuously funded line item in the sale of the practice to Exeter Health Resources, the parent company of Core Physicians Health System.

When Core Pediatrics first started working toward becoming a medical home as part of the Rural Medical Home Improvement Project through the CMHI, the practice developed a number of “products” that providers and staff use to facilitate the delivery of coordinated, patient- and family-centered care to CYSHCN. Ninety percent of these products or tools were developed in collaboration with parent partners. The products have included:

- A computerized **registry** of patients with complex or chronic conditions with the adoption of EMRs
- **Complexity scoring system**—a standardized set of criteria used to score, on a scale of 1 to 10, patients with complex or chronic conditions. This system allows the practice to better understand the mix of case complexity among its more than 12,000 patients.
- **Care plans** for CYSHCN—a computer-generated document formulated by the care coordinator, a nurse, or a physician in cooperation with the family of CYSHCN. The care plan compiles the patient information, medical history, list of medications, list of specialists, community resources or services accessed by the family, and personal preferences of the patient and family regarding the child’s health care all together in one place.
- **Pre-visit screening questionnaire**—Developed by the practice in the late 1990s, the pre-visit screening tool allows parents to direct the physician’s focus to issues the parent feels are most pressing at the time of the appointment.
- **Post-visit questionnaire**—Though the practice no longer uses this tool, it was helpful in providing immediate feedback to providers and staff regarding patient satisfaction with practice visits. The questionnaire was administered to every patient or family following their office visit.
- **Transition roadmap**—Beginning at the 12-year physical, a transition sheet is given to parents and children annually. This handout contains a list of topics for families to discuss with teenagers during the next 8 years to help them become responsible adults and health care consumers. Beginning with this same visit, teenagers are encouraged to take an active role in their own health care by completing computerized screening questionnaires on a Palm Pilot before each physical. The questionnaires include the CRAFFT Screening Tool,

a **behavioral health questionnaire** recommended by the AAP Committee on Substance Abuse for use with adolescents, and a Patient Health Questionnaire-2 for depression and anxiety. At every re-check appointment for chronic conditions, such as asthma or ADHD, the teenager is seen first to assess the patient’s knowledge of his/her own condition, as well as the name, dosage, and reason for taking all medications.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

As one of the original New Hampshire medical home pilot practices in the Rural Medical Home Improvement Project run by the CMHI, Core Pediatrics was continuously engaged in activities related to the collaborative learning group at the CMHI during the first 3 years of implementing the clinic’s medical home initiatives. As part of the project, the practice held parent partner meetings twice a month to discuss quality improvement initiatives.

Providers and staff who helped champion the medical home at Core Pediatrics have been called upon to speak to other practices about their experiences nationally. All of the “products” and tools that were generated by Core Pediatrics to assist in patient- and family-centered initiatives are available to other practices through the CMHI website.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

The practice’s involvement with families and local community leaders extends beyond the walls of the offices. On a monthly basis, providers and the care coordinator meet with educators and administrators from the local elementary, junior high, and high schools, as well as local pediatric mental health providers and the director of the local Early Intervention Center. These **community partner meetings** allow all parties to become familiar with each other and build rapport, ultimately improving communication and collaboration between educators and health care providers and facilitating better continuity of care for children with learning and behavioral issues.

COMMUNICATION WITH PATIENTS & FAMILIES

The patient- and family-centered philosophy permeates all aspects of the practice, but begins with the pre-visit screening questionnaire, which sets the agenda for each patient appointment. Beginning at the 12-year physical, a transition sheet is given to parents and children annually to encourage the child to take a more active role in setting the agenda of visits in partnership with the parents and the practitioner.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The practice holds monthly **parent partner meetings** to brainstorm and discuss progress of incremental quality improvements. The practice has always emphasized that these parent volunteers are actually parent partners and not parent advisors. Meetings include 2 parent partners,

who each have a child with special health care needs, the care coordinator, a nurse, a member of the front office staff, a hospital/health system administrator, and a physician. Though improvements geared toward CYSHCN were originally the focus of quality improvement initiatives, most of the changes made in recent years target the care of all patients.

Over the years since beginning its medical home initiatives, Core Pediatrics has held a number of **focus groups** with families to get feedback on specific questions or initiatives.

“Everybody we talk to seems to be aware...of [my daughter’s] history. So, we don’t need to tell her story many times.”
–family member

In the first focus group that the practice held, families were asked 3 key questions, namely: (1) What is going well for you in this practice?; (2) What would you like to see changed?; and (3) What would you like this practice to look like in 5 years? The practice received funding from the Rural Medical Home Improvement Project to pay a facilitator to run the meeting and provide small stipends to parent partners. Practice physicians gave suggestions of parents to invite, but were not present at the sessions.

In addition to administering a Press Ganey patient satisfaction survey and the Medical Home Index provider survey annually, the clinic gives all patients and families a short pre-visit screening questionnaire in the waiting room before well-child appointments and re-check appointments for complex conditions (eg, ADHD, asthma, or diabetes). This questionnaire gives patients and their parents the opportunity to formulate and document any questions or concerns to be covered during the visit.

PRACTICE QUALITY IMPROVEMENT

Every week for the last 20 years, Core Pediatrics has held **weekly practice meetings**, which is something that no other practice in its health system does. “We meet specifically to discuss just patient care issues for 45 minutes every Monday morning. The culture of meeting together once a week to discuss patient care issues has made this kind of work a lot easier to do.” A child psychiatrist attends meetings once a month to consult on cases, and a former colleague often attends to keep providers up-to-date on medical literature.

GUILFORD CHILD HEALTH OF TRIAD ADULT AND PEDIATRIC MEDICINE

Practice address:	1046 E Wendover Ave Greensboro, NC
Geographic location:	Urban
Type of practice:	General pediatrics and pediatric subspecialties
Organizational structure:	Operates as a private, nonprofit practice, but has maintained an academic partnership with the local hospital for over 20 years and receives grant funding from the county and state; recently entered a residency partnership with the University of North Carolina; recently merged with an adult private, nonprofit clinic and consequently achieved Federally Qualified Health Center look-alike status.
Size of practice:	16 full-time pediatricians 1.4 full-time developmental pediatricians 7 nurse practitioners
Number of patients:	39,000 pediatric patients 15,000 adult patients
Patient insurance:	86% Medicaid 7%-8% Children's Health Insurance Program 6%-7% uninsured/underserved
Medical home recognition:	- NCQA Physician Practice Connections Patient-Centered Medical Home recognition program application in progress - Community Care of North Carolina Medical Home
Patient/family experience questionnaire:	- Patient satisfaction surveys performed regularly; clinic currently switching to a patient and family experience survey based on the CAHPS Patient-Centered Medical Home Item Set - Patient wait-time studies conducted every 6 months
EMR system:	Yes, implementation in progress
Other information technology:	Yes, utilizes the Community Care of North Carolina Informatics Center as a provider portal to quality data
Funding source(s):	Primarily funded through the practice's operating funds. A Medical Home Project grant funded the development of risk stratification tools and a rudimentary patient registry. Several smaller specialized grants have funded initiatives over the last 8 years, such as the Moses Cone-Wesley Long Foundation Take Charge Healthy Weight Initiative. Licensed clinical social worker and registered dietician services are covered by North Carolina Medicaid. The practice's community liaison position salaries are offset by increased provider time devoted to patient care.

Abbreviations: CAHPS, Consumer Assessment of Healthcare Providers and Systems; EMR, electronic medical record; NCQA, National Committee for Quality Assurance.

PRACTICE OVERVIEW:

Guilford Child Health (GCH) strives to provide comprehensive, high-quality care that addresses the emotional and personal needs of their patients and their families. The clinic uses a team-based approach to providing patient- and family-centered care, while emphasizing their commitment to making each child developmentally prepared at home, in school, and in the community.

For over 20 years, GCH has served the community as a private, nonprofit practice treating pediatric patients from families whose incomes are less than 200% of the federal poverty level while maintaining a strong relationship with the residency program of the local community hospital. In 2011, the pediatric clinic merged with a similarly structured, local adult clinic. The practice is applying for Federally Qualified Health Center status. The merger has allowed GCH to achieve Federally Qualified Health Center look-alike status.

LESSONS LEARNED:

- Communication and the development of a longitudinal relationship with families are important in the development of a medical home.
- Routine screenings for family concerns has improved the physicians' ability to hear family concerns and communicate with families.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

The practice touts emergency department utilization below the North Carolina state average, which it credits to open appointment access. The practice also noticed decreased absenteeism at local schools, which is believed to be a result of its asthma initiatives.

Mental health integration is a priority for GCH. Onsite licensed clinical social workers are embedded within the provider teams, thus facilitating the seamless integration

of counseling services following positive results from a maternal or postpartum depression screening or any other concern observed by a clinician. Furthermore, the introduction of a mental health provider as “just another member of the team” helps minimize any stigma families may associate with a referral to mental health services.

Access to the services of **specialized providers**, such as a dietician and an asthma/allergy specialist, as part of the team care approach is facilitated by grants and initiatives targeting specific patient populations. One day per week an asthma/allergy specialist sees children with the most complex conditions and co-manages the asthma patients seen by the primary care pediatricians. Her presence has immensely benefited asthma management and has decreased emergency department visits among the clinic’s asthma patients. A pediatric neurologist sees patients onsite one day per week and coordinates with the primary care pediatricians. Three full-time dieticians are available to patients and families as part of a Moses Cone-Wesley Long Foundation grant supporting the Take Charge Healthy Weight Initiative. Through this program, the 40%-45% of the pediatric clinic patients considered obese, overweight, or at-risk are offered services targeting comprehensive weight management and healthy living. In the program’s early stages, 42% of participants decreased their body mass index, and 28% of participants maintained their body mass index. An oral health prevention program, Into the Mouth of Babes, has yielded a reduction in dental caries among young clinic patients by providing oral screening, parent and caregiver education, and fluoride varnish application to children from the time of tooth eruption until 3 years of age.

CARE MANAGEMENT

The practice primarily engages its families by educating them about community resources and linking them to these resources. This task is performed primarily by the community liaison position that employs individuals with diverse health education backgrounds, experience with the Special Supplemental Nutrition Program for Women, Infants, and Children, or early childhood development degrees. These liaisons are dedicated to care coordination and are available to families immediately following each appointment to schedule referrals, coordinate transportation, and provide ancillary resources or services that may benefit the family. When GCH was privatized, the community liaison positions were created to free clinicians from the time spent on care-coordination telephone calls and paperwork; the physicians could then spend more time actually seeing patients. One clinic physician states: “Our community liaisons are worth their weight in gold, and they’re probably the most important staff members.”

If patients and families prefer, links on the clinic’s website allow them to search independently for community services.

Since 1997, GCH has collaborated with **community partners** to link families to “wrap-around” services, such as public health services, school services, child care, and community nursing programs. One such program is the Nurse Family Partnership Project, which research has shown to be the most effective model to prevent child abuse. In this program, nurses are teamed with high-risk pregnant mothers to help them understand and navigate the health care system during pre-natal care and throughout the first year of their child’s life.

Monthly wraparound meetings include a GCH provider, GCH social workers and community liaisons, Department of Social Services staff, county mental health staff, as well as public health, school, and child care nurses. These meetings provide open lines of communication between the practice, school system, and home care of patients that require coordinated care. For patients with asthma, school nurses will take a child’s asthma action plan established in the clinic and review it in-person with the child’s teacher.

In an effort to track the ongoing care of patients with chronic conditions, the clinic has established patient **registries** by diagnosis. Patients with medically complex chronic conditions, such as asthma, developmental disabilities, sickle cell disease, obesity, or visual impairment, and patients with chronic psychosocial issues receive reminders every 6 months if records indicate that the patient has not been in for a check-up. As part of the practice’s **care team** model, clinicians have a half-day per week built into their schedules that is dedicated to seeing patients who have complex conditions. By making use of the patient management system to flag patients with chronic conditions, schedulers are alerted to book a longer appointment time for these patients.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

The practice has piloted and participated in **state and national projects** that have informed and shaped policy and practice changes in other pediatric practices. In 2004, through the Assuring Better Child Health and Development grant program supported by the Commonwealth Fund, Dr Marian Earls, the clinic’s medical director, led a multidisciplinary team to develop a training seminar for pediatric practices throughout North Carolina on the integration of periodic developmental screening into routine practice. As a result, GCH became 1 of 5 model pediatric practices nationally that could document the long-term effectiveness and benefits of developmental screening. In addition, GCH has participated in pilot programs for mental health

integration and medical home implementation and shared information on its successes and challenges with other pediatric practices statewide.

As co-chairperson of the North Carolina AAP chapter's Mental Health Committee, GCH's medical director worked with fellow AAP members and the North Carolina Medicaid program to obtain reimbursement for the services of licensed clinical social workers employed by practices statewide.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

Through its partnership with the Center for New North Carolinians at the University of North Carolina Greensboro, the practice has offered assistance tailored to the specific needs of its families who have recently emigrated from other countries. Through treating such a culturally diverse population, clinic providers and staff are inherently engaged in a process of perpetual learning and growing as they broaden the scope of their knowledge about attitudes and health behaviors in the cultures of their patients.

COMMUNICATION WITH PATIENTS & FAMILIES

In 1999, GCH began tracking the use of child **development screening tools** in the clinic. Through this effort, it was determined that the tool the clinic was using was not being administered to those children who could potentially benefit most, because of the time demands it placed on providers and the requirement for the child's cooperation throughout the screening. At the same time, Community Care of North Carolina (CCNC), the state's Medicaid program, recruited GCH to be the pilot practice in North Carolina for an Assuring Better Child Health and Development project grant to integrate routine developmental screening into the standard care for children ages 0 to 5 years. In 2000, GCH began administering the ASQ, which was completed by parents. In the initial stages of the project, training for CCNC practices around the state included parents as co-faculty. As a result of the project piloted by GCH and the subsequent adoption of routine screening practices by CCNC, North Carolina is the state with the highest rate of developmental screening, according to the most recent National Survey of Children's Health.

CULTURAL DIVERSITY & SENSITIVITY

In 2004, the clinic experienced a surge in the number of Latino families seeking health care, which presented a language barrier impeding communication between providers and families. The clinic responded by offering onsite beginning, intermediate, and advanced **Spanish classes** to providers and staff, as well as by making 12-week Spanish courses at local nonprofit agencies available to staff. As a result of these efforts, more than 20 staff members in the practice are now conversant in medical Spanish.

Sensitivity to **cultural differences** in attitudes toward health and medical treatment is a priority for the clinic. The University of North Carolina's Center for New North Carolinians is often called upon, not just to provide native-speaking translators for the more obscure dialects, but to provide culturally sensitive support in discussing health issues with families. In addition, many of the programs integrated into clinical care cater to a multicultural patient population. For instance, as part of the Reach Out and Read program, which sets aside time at every well-child visit for children aged 0 to 5 years for the doctor to stress to parents the importance of reading to their child every day, the clinic offers books in English, Spanish, Cambodian, Vietnamese, Arabic, and French. The clinic celebrates its patient diversity by encouraging kids to mark the country that they are from by pinpointing it on the large map posted at the nurses' station.

FEEDBACK FROM PATIENTS & FAMILIES

The practice administers periodic **patient satisfaction surveys** to parents who complete the surveys with a touchscreen. The number of survey questions is limited so that parents will actually take the time to complete the survey after an appointment. The Medical Home Index was also completed by providers and staff in the past.

In converting to a Federally Qualified Health Center, the clinic now maintains a **community board**. The majority of board members are health center patients and parents of patients who represent the population served. Families seen frequently or by multiple providers, particularly families of CYSHCN, are nominated to serve as volunteers on the board by office managers, community liaisons, and providers.

PRACTICE QUALITY IMPROVEMENT

The practice has more than a 20-year history of regular medical record audits for well-child care and acute/chronic condition care. The practice has standardized, evidence-based, best-practice protocols and guidelines for preventive care and disease management, which are regularly reviewed and updated by clinicians. For the past 6 years, GCH has maintained a quality improvement group that includes representatives from all departments.

The clinic employs a full-time **quality improvement specialist** who tracks clinic performance based on

"One of the things we do is routine screening at all well visits from infancy to adolescence. So [the physician] walks into the room having an idea of what the concerns of the family are, knowing what's top on their list before entering the room. And I think that has made a huge difference for care to use the approach of listening to what the parents are most concerned about today."

—practice

statewide measures, as required by CCNC, and coordinates internal quality improvement activities.

Every 4 to 6 months, the practice manager conducts a wait-time study. She enlists families to participate and gives them a clipboard and a watch. The participating families

record the amount of time they wait before being called in to an examination room, the amount of time they wait in the examination room before the nurse enters to measure vital signs, and then the amount of time they wait for a physician to see their child. The wait-time information provides immediate feedback to the staff regarding clinic flow.

HAGAN, RINEHART, & CONNOLLY PEDIATRICIANS

Practice address:	128 Lakeside Ave, Ste 115 Burlington, VT
Geographic location:	Urban-based practice serving more rural surrounding areas
Type of practice:	General pediatrics
Organizational structure:	Private practice with academic affiliation to the University of Vermont College of Medicine where practice physicians are clinical faculty members
Size of practice:	3 full-time pediatricians 2 part-time nurse practitioners 1 child psychologist
Number of patients:	4,000
Patient insurance:	65% commercial/private insurance 35% Medicaid
Medical home recognition:	- NCQA Physician Practice Connections PCMH Level III recognition (March 2011) - 1st pediatric practice to receive Vermont Blueprint for Health Integrated Health Service Advanced Primary Care Practice recognition (May 2011)
Patient/family experience questionnaire:	MHFI administered at the outset of medical home initiatives in 2005
EMR system:	Yes, since February 2010
Other information technology:	Yes, Vermont Blueprint for Health-sponsored DocSite to track patient medical conditions and treatments, guide chronic care treatment decisions, and measure health outcomes at the group and individual levels. The practice also has access to the local health department database to aid in tracking patient care.
Funding source(s):	- Primarily funded through the practice's operating funds. The added time and effort invested by families, providers, and staff is provided as in-kind service to the practice. Efforts to optimize billing practices to reflect the complexity of cases and multidisciplinary care visits ensure provider time is appropriately compensated. By achieving NCQA Physician Practice Connections PCMH Level III recognition, the practice is eligible for increased reimbursement. - As the pediatric pilot practice for Vermont Blueprint for Health, a collaboration between public and private payers statewide, recognition as an Integrated Health Service Advanced Primary Care Practice allows the practice to access funding to facilitate the adoption of information technology and streamline statewide information exchange. - Vermont Interdisciplinary Leadership Education for Health Professionals grant funding through Vermont's Leadership Education in Neurodevelopmental and Related Disabilities program, which is federally funded through the MCHB, supports family participation in medical education.

Abbreviations: EMR, electronic medical record; MCHB, Maternal and Child Health Bureau; MHFI, Medical Home Family Index; NCQA, National Committee for Quality Assurance; PCMH, patient-centered medical home.

PRACTICE OVERVIEW:

Drs Hagan, Rinehart, and Connolly believe in a strength-based approach to care that draws upon the talents and knowledge of families, emphasizing families' positive assets in planning each patient's care and in building provider-family relationships. Integral to each patient's care plan is the acknowledgment of the family as the constant in the child's life and the promotion of an individual and developmental approach, recognizing the importance of community-based services. Practice providers utilize a care coordinator, who is also a registered nurse, to link families

with medical home services and to organize face-to-face collaborative meetings known as care conferences, which bring together families, medical providers, educators, and other community service providers to discuss care issues for CYSHCN.

LESSONS LEARNED:

- As a result of the implementation of patient- and family-centered initiatives, clinicians seem more satisfied and confident in their delivery of care to CYSHCN. Instead of feeling overwhelmed by complex cases with an often

daunting list of multidisciplinary problems that need to be addressed, practice clinicians are more at-ease and feel prepared to break potentially complex case management down into smaller, more manageable parts.

- The practice found the AAP *Building Your Medical Home* toolkit particularly useful in building its medical home and adopting an increasingly patient- and family-centered model. The Building Your Medical Home toolkit is available at <http://www.pediatricmedhome.org>.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

The practice has a process for flagging CYSHCN in the EMR to alert schedulers to allot ample time for the more complex patients' appointments, thus facilitating smooth clinic flow on the appointment day, and enabling providers and staff to tailor the visit to the specific needs and preferences of the child.

One of the biggest, most recent changes to the practice is the move to a newly renovated location. Careful consideration was given to **practice accessibility** issues in the plans for the new space, especially with regard to wheelchair accessibility of examination rooms and the provision of ample handicapped parking. During the decision-making process in planning the new space, providers and staff solicited the comments and suggestions of patient families.

CARE MANAGEMENT

In March 2011, the practice received NCQA Physician Practice Connections PGMH Level III recognition, making it eligible for an increased payment per patient per month across all Vermont payers, as well as securing its place as the first pediatric practice recognized as a Vermont Blueprint for Health Integrated Health Service Advanced Primary Care Practice. The primary barrier the practice

"Families need not repeat their stories, they can say 'I'm McKayla's mom' and we will know who that is!"
—practice

encountered along the road to earning recognition was the time requirement associated with practice transformation activities. Though the staff

managed the transition well, practice personnel did feel a strain on staff resources as they worked hard to remain accessible and responsive to families while troubleshooting logistical and operations issues resulting from workflow and process changes, as well as the practice relocation into its new building.

Through the Vermont Blueprint for Health, a public-private initiative to improve chronic care, Vermont is creating a patient **registry**, DocSite, to track patient medical conditions and treatments, guide chronic care treatment decisions, and measure health outcomes at the group and

individual levels. In addition to using the Vermont Blueprint for Health registry, the practice has access to the Vermont Department of Health central statewide registry to upload and obtain immunization records and lead screening results.

As a recognized Advanced Primary Care Practice through the Vermont Blueprint for Health, the practice is characterized by seamless **care coordination**. It stresses the importance of preventive health by engaging people when they are well, as well as by giving patients the tools to keep existing conditions from worsening. Patients are encouraged to become active partners in their own care, and practices become effective and efficient teams.

Care conferences are usually billed as highly complex office visits, based on the time spent in a face-to-face meeting where families and interdisciplinary providers are present, as well as the time spent on documentation related to the visit. While the reimbursement does not fully cover the provider's time, the visits are more efficient and reduce the need for follow-up visits.

The practice develops **care plans** for CYSHCN. Having an electronic-based care plan template is helpful for keeping information up-to-date. Care plans are updated at care conferences and office visits, usually by the provider, or in some cases, the care coordinator.

The practice uses **pre-visit questionnaires** for well-child visits, and with the implementation of its pediatric-based EMR, added the automatic printing of age-appropriate questionnaires based on the most recent AAP **Bright Futures guidelines** for well-child visits. The EMR has streamlined well-child visits to match the Bright Futures guidelines, with prompts for universal screening and selective screening based on patient age. At the conclusion of each well-child visit, the EMR prints an updated immunization record for the family, a sports participation form, and an age-appropriate educational tool with developmental expectations and health tips for the child and family.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

Drs Rinehart and Hagan share their experiences as medical home physician champions and the experiences of their practice through forums including the AAP national conference and exhibition, annual meetings of other national organizations, AAP chapter meetings, national AAP medical home webinars, and grand rounds presentations. Dr Hagan is the lead author of the 2008 Bright Futures guidelines, which hold patient- and family-centered care principles at their core. Dr Jill Rinehart's current efforts are focused on designing a community health team to serve the pediatric population in her service area and ensure a community-wide benefit, as part of the Vermont Blueprint for Health

Initiative. Partnering with the Vermont Children’s Hospital, University Pediatrics, and Timber Lane Pediatrics, Hagan, Rinehart, & Connolly Pediatricians is launching a pilot project to create a coalition of practice-based care coordinators that will collaborate and interface throughout the community. These efforts will be supported by medical home curriculum and training provided by Vermont Interdisciplinary Leadership Education for Health Professionals.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

As a result of the practice’s affiliation with the University of Vermont College of Medicine, families have the opportunity to be involved in **medical student and resident education**. The Families FIRST (Families Involved in Resident/Student Training) curriculum, developed in collaboration with the local Parent to Parent organization and the pediatric residency program at Vermont Children’s Hospital, is part of the pediatric resident and medical student experience, allowing families to speak to future health care providers about home care issues and care coordination efforts from a non-provider perspective. Families with CYSHCN serve as “family faculty members,” taking part in lectures and hosting home visit opportunities for medical students and residents.

COMMUNICATION WITH PATIENTS & FAMILIES

The practice believes that a big role of the medical home when partnering with families is to serve as a sounding board for patient and family concerns when a child returns from **subspecialty visits** with an assessment and recommendation. The parents “often feel like they need to run that idea by somebody else, and so we would bring them back and talk in terms of helping them understand the recommendation—see if it feels right to them and it feels right to us before putting forth the recommendation.

“[The medical home] is not just for those kids with special needs, but for our entire practice and that starts right from the beginning—from birth.”
—practice

CULTURAL DIVERSITY & SENSITIVITY

When interpretation services are needed for an urgent matter or a scheduled appointment, the Vermont Interpreter Referral Service provides access to interpreters via telephone. Families are asked their preferred language, and many of the practice’s handouts are available in other languages. There is a “reminders” box in the EMR that enables practice staff to note specific instructions and religious or cultural considerations to ensure practice-wide **cultural sensitivity**.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The practice did have a formal **parent advisory board** for a few years, but has opted not to maintain a group that meets regularly. Instead, the practice prefers to solicit

family feedback either one-on-one or in ad-hoc group settings when new initiatives or practice changes are being considered.

The practice has administered the MHFI survey in the past and found it particularly helpful in identifying and planning areas to target for improvement during the early stages of building a medical home. Although the survey has not been used in recent years, there are plans to administer the MHFI or similar **family surveys** when the practice undergoes the NCQA Physician Practice Connections PCMH renewal process.

PRACTICE QUALITY IMPROVEMENT

With a long history of engaging in **quality improvement projects**, the practice has taken on both broad, operations and process improvement initiatives utilizing Plan-Do-Study-Act cycles to implement changes, as well as more focused, issue-specific improvement projects. In 2005, the practice participated in the national Bright Futures Training Intervention Program as 1 of 15 practices that helped determine how to incorporate the Bright Futures guidelines into the routine of a busy pediatric practice in a measurable manner.

In 2007, the practice took part in an Adolescent Preventive Services Improvement Project, during which it achieved high screening rates of risks and strengths among teenagers seen for health supervision visits. In 2010, the practice took part in a Vermont Children’s Health Improvement Project—supported adolescent health improvement Maintenance of Certification unit focused on *Chlamydia* screening, immunizations, body mass index, and yearly preventive services visits. Through the project, data on health outcomes for youth in Vermont is gathered and used to inform quality improvement efforts by engaging practices in tangible practice change through Plan-Do-Study-Act cycles.

Over the years, the practice has demonstrated improvements in **ADHD and depression screening**. In 2010, the practice piloted the use of the Achenbach System of Empirically Based Assessment, a mental health screening tool, and the use of wellness coaches to work with parents of children at high risk for mental health problems. Since the pilot study, the practice has purchased the rights to the assessment tool, and parents, teachers, and adolescents can access the screening questionnaires online. Completed questionnaires are scored by the practice, and physicians review results with patients and their families to make mental health treatment plans based on the outcomes.

When preparing to apply for NCQA recognition, the practice underwent an in-depth self evaluation and streamlined processes for handling laboratory results, patient scheduling, prescriptions, and EMR documentation.

HENRY FORD PEDIATRICS NEW CENTER ONE

Practice address:	New Center One, 3031 W Grand Blvd Detroit, MI
Geographic location:	Urban
Type of practice:	General pediatrics
Organizational structure:	Affiliated with the Henry Ford Health System; a teaching practice for Wayne State University medical students and residents from Children's Hospital of Michigan on a rotating basis.
Size of practice:	2 full-time pediatricians 3 part-time pediatricians 1 care coordinator
Number of patients:	5,500
Patient insurance:	25% commercial/private insurance 75% Medicaid
Medical home recognition:	Blue Cross Blue Shield Provider Group Incentive Plan PCMH recognition
Patient/family experience questionnaire:	- Informal patient satisfaction surveys used occasionally - Medical Home Index for providers/staff and MHFI for families administered periodically between 2002 and 2007
EMR system:	Yes
Other information technology:	Yes, a care plan template integrated into the EMR
Funding source(s):	The salary of the practice's care coordinator is funded by the practice's health system, Henry Ford Health System. The initial medical home implementation efforts were funded by a grant from the Community Access To Child Health Program, a national program of the AAP to improve access to health care by supporting pediatricians and communities involved in community-based efforts for children. Over the last 10 years, the clinic has funded specific initiatives with smaller grants (\$2,000-\$5,000) to cover the costs of things like books and focus groups. Examples include a Health Literacy Grant and a Parent to Parent grant, which funded the training of parent advocates.

Abbreviations: AAP, American Academy of Pediatrics; EMR, electronic medical record; MHFI, Medical Home Family Index; PCMH, patient-centered medical home.

PRACTICE OVERVIEW:

The practice feels that the incorporation of the principles of patient- and family-centered care into care delivery is essential, as providers' perspectives do not always parallel those of the family, and it is imperative that the family's interests be given priority. Henry Ford Pediatrics empowers families to openly communicate and challenges physicians and staff, as advocates for their patients, to respect and incorporate patient- and family-centered policies into daily practice.

LESSONS LEARNED:

- Creating an environment that fosters communication and partnership is achieved by listening to families through focus groups.
- Important questions to ask include: (1) What do you like about our practice?; (2) What do you dislike about our practice?; and (3) What would you like to change about our practice?

STRATEGIES OR TOOLS UTILIZED TARGETING: ACCESS

The practice has developed policies that facilitate healthy transitions from pediatric to adult care for patients and their families. During a 2007 pilot program, the practice

identified 44 youth with special health care needs who were in the process of transitioning to adult care providers. The practice arranged a focus group that included 4 internists within the Henry Ford Health System who were willing to add these patients to their caseloads. In a series of meetings conducted over a 4-month period, a **transition process** was created. Now, as a standard practice, patients with special health care needs who are 16 years old and their families are given a brochure explaining the upcoming transition. The receipt of the brochure is followed by the scheduling of an initial visit with an internal medicine physician, which is handled by a care coordination nurse. The practice provides the new physician with a current, personalized, comprehensive care plan integrated into the EMR for each transitioning patient. The pediatrician also serves as a direct source of information when new providers are faced with an unfamiliar diagnosis.

CARE MANAGEMENT

The practice has a dedicated **care coordinator** paid for by the Henry Ford Health System. She is responsible for maintaining the family resource room and is available to meet with families on the day of their visit. Most recently, the care coordinator has updated the information in the family resource room on mental health services. The practice now

uses free resources and downloadable brochures provided by the National Alliance for Mental Illness.

The practice developed a paper-based **care plan** that was converted to an electronic version integrated into the Henry Ford Health System EMR. Once the care plan was in the EMR, the practice went through a series of steps to review

“[The care plan] is a whole kind of mini reference letter into all her health issues. So when we go to the emergency department I make sure I carry the care plan with me...it kind of helps put the physician and nurses at ease”

—family member

it for accuracy, including a telephone interview and meeting with the parents or caregivers of each patient with special health care needs.

The practice currently conducts developmental screenings, but plans to

add screenings for anxiety, mental illness, and depression. The practice has repeatedly experienced difficulty in maintaining communication with families referred to community mental health programs. The referral process often becomes overwhelming for families, and the practice rarely receives information back from the mental health providers such as prescribed medications or services received. Parents often have difficulty understanding information provided by the mental health provider and thus have trouble relaying information back to the primary care provider. Therefore, Henry Ford Pediatrics is interested in aiding families with **referral tracking** with the goal of building stronger lines of communication between mental health providers and the practice. Plans are in place to integrate a social worker or psychologist into the practice 1 or 2 days a week to meet directly with families and refer the children to the appropriate services.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

When the practice began building its medical home in 2002, it joined the Medical Home National **Learning Collaborative** and also worked closely with the Title V Maternal and Child Health Program. The practice’s medical home physician champion has regularly attended meetings with other practices to learn what strategies have been effective and share accomplishments and new ideas.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

Henry Ford Pediatrics collaborated with the Michigan Parent Participation Program in its efforts to operate a statewide Family2Family Health Care Information and Education Center. Additionally, the Michigan Parent Participation Program provided grant support to Henry Ford Pediatrics to assist its efforts in medical home training for primary care providers.

COMMUNICATION WITH PATIENTS & FAMILIES

With family members taking more active roles and visits becoming less rigid, clinicians have been challenged to

“I can recommend things all day long, but if parents don’t buy in, if they don’t contribute, if they don’t participate in the discussion, I just feel like I’m talking to a brick wall really. So I think for me, I’ve learned a lot because I’ve learned to look at other perspectives on the issue, and it has affected how I communicate to families, and not just going in and dictating, saying ‘oh this is what we need to do,’ but really stopping to say, ‘you know, what do you think we need to do?’ It’s made me a better communicator; it’s made me a better listener. And I don’t know it’s, I And...I think it’s made me a better provider.”

—practice

“[The support staff] have the good habit of calling your child by their name and not ‘sweetie’ and ‘honey.’”

—family member

families. The practice conducted focus groups when it began its medical home efforts in 2002. In exchange for time and participation, families were provided a meal, an onsite babysitter, and a gas card. Based on the focus group discussions, the practice generated a list of suggestions to meet the expressed needs of families.

For the practice’s most recent medical home initiative on health literacy, the practice identified 2 parents willing to take leadership roles in planning the initiative. The parents attended a 2-day **Parent Leadership in State Government**

Initiative in September 2010. After the training, the parents partnered with practice pediatricians and together began hosting focus groups. During the focus groups, families and patients were asked to rate and comment on resources

available in hardcopy for their review. The parent leaders and practice staff used these ratings to make decisions on which resources to purchase and make available to all families through the family resource room with the aim of improving health literacy.

become better communicators and more responsive to each family’s explicit needs.

CULTURAL DIVERSITY & SENSITIVITY

Henry Ford Pediatrics utilizes telephone translation services for patient and families. The need for this service is identified prior to the office visit during the intake process.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The most important aspect of increasing patient- and family-centeredness is to embrace advisory groups and actively partner with families. The practice recommends engaging in **focus groups** with

The practice has periodically utilized **family surveys**, including the Medical Home Index and the MHFI, since 2002 to identify practice strengths and weaknesses, and to direct patient- and family-centered change. Over the years,

the practice has seen steady increases in its scores on the MHFI, specifically on themes pertaining to family feedback, involvement, support, and child and family education.

THE LINKING INDIVIDUAL NEEDS OF CHILDREN WITH SERVICES (LINGS) PROGRAM AT CHILDREN’S HOSPITAL AT MONTEFIORE (CHAM)

Practice address:	3415 Bainbridge Ave, CHAM 5 Bronx, NY
Geographic location:	Urban
Type of practice:	General pediatrics with integration of subspecialty care
Organizational structure:	Housed within the CHAM and affiliated with the Albert Einstein College of Medicine
Size of practice:	1 full-time pediatrician 1 case manager
Number of patients:	303 (85% CYSHCN, 15% healthy siblings)
Patient insurance:	85% Medicaid 15% commercial/private insurance
Medical home recognition:	None
Patient/family experience questionnaire:	CHAM administers a Press Ganey patient satisfaction survey throughout the hospital
EMR system:	Yes
Other information technology:	No
Funding source(s):	The LINGS program is fully funded and provides subsidized care through its affiliation with CHAM.

Abbreviations: CHAM, Children’s Hospital at Montefiore; EMR, electronic medical record; LINGS, Linking Individual Needs of Children with Services.

PRACTICE OVERVIEW:

The Linking Individual Needs of Children with Services (LINGS) program provides primary care to children with complex chronic conditions. More than a third of the program’s caseload is comprised of children dependent on technology, and hospitalizations are frequent. The LINGS program provides collaborative, multidisciplinary care. Physicians partner with families to address unmet needs for support and care coordination and to aid in the pursuit of parents’ goals for their children’s well-being and comfort. Providers and staff work to create an environment that can be flexible to the needs of whole families, which includes providing assessments of siblings in addition to the scheduled patient.

A broader, overarching challenge has been reconciling the practice’s intent to stay unconditionally responsive to patients and their families although this high level of responsiveness does not necessarily bring money into the practice or its institution. The practice points out that while the care it offers oftentimes might not be lucrative, its ability to reduce the caseload of subspecialty clinics and care for complex pediatric patients independently fosters efficiency throughout the hospital system that is intrinsically cost-effective. The LINGS program is fully funded and provides subsidized care through its affiliation with the Children’s Hospital at Montefiore.

LESSONS LEARNED:

- The AAP policy statements are helpful in guiding policy changes and transformative goals.
- Flexibility to the needs of the whole family results in assessment of siblings during patient visits.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

To serve the needs of the family as a whole, in addition to providing primary care to children with complex conditions, the practice provides **primary care for healthy siblings** of patients. This provision of sibling care helps prevent feelings of isolation or neglect that may be affecting healthy siblings due to the attention that the child with complex conditions receives. It also helps to alleviate the stress on family members who would otherwise need to take their other children to separate primary care physicians. Given that some LINGS patients require palliative care and eventually die, the program policy is to continue to maintain its relationship as the primary care provider for healthy siblings after a patient’s death.

The practice routinely provides prolonged outpatient appointments (30-60 minutes). During appointments providers orient families to **agenda setting**, prioritizing the needs of families and building on families’ strengths

through the provision of multidisciplinary care and support. **Home visits** and expert provision of support and symptom management, including oversight of inpatient management for every child on every hospitalization, are provided when necessary.

CARE MANAGEMENT

The **principles of palliative care** are integrated into patient care, which include emotional, decisional, and spiritual support for patients and families. A hallmark of the practice is their emphasis on evidence-directed care.

The practice employs a **case manager**, a mother of a child with special needs, who utilizes the skills she has developed as a parent advocate to handle care coordination for the LINCS program's patients. She has also started an initiative to facilitate patient transition to adult care. For many of the program's patients, the transition process is further complicated by guardianship issues and the need to find adult specialists, both of which the care coordinator helps to aid the family with. She assists families in addressing guardianship issues and helping to find adult specialists.

Bereavement support is provided for families through referrals to community programs and prearranged family-to-family support groups.

COMMUNICATION WITH PATIENTS & FAMILIES

Families of children with chronic conditions, syndromes, genetic disorders, technology-dependence, and other specialized care needs are actively linked to one another for **family-to-family and peer support**. Through specific regional and national organizations, the LINCS program helps families obtain additional informational and social support. A family representative employed by the Children's Hospital at Montefiore meets families and organizes a well-attended support group that meets in English or Spanish on alternate weeks.

CULTURAL DIVERSITY & SENSITIVITY

The practice provides access to services for Spanish-speaking populations. As a product of the practice's **Spanish fluency**, it has noticed an increased number of non-native

“A commitment to building an excellent family-centered medical home for children with complex chronic conditions demands flexibility, adjustments, and shifts in orientation towards meeting the multifaceted needs of these children and their families. It demands a willingness on the part of practice members to forgo some remuneration, as most of the work is unreimbursed or poorly financed. A commitment of extra time is necessary in order to understand how best to partner with families in the care of their children. Providers of care have to learn to envision each child's need for care from the perspectives of many others, both inside and outside the health professions.”
—practice

English-speaking families coming to the practice. The practice offers opportunities for partnerships and empowerment that are difficult for Latino families to locate in New York City.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

Parent advocates from the Children's Hospital at Montefiore are involved with the LINCS program and invited to provide feedback and input in staff meetings. Additionally, the hospital utilizes a Press Ganey patient satisfaction survey and shares the results with the LINCS program.

PRACTICE QUALITY IMPROVEMENT

The practice maintains that its **care coordination** efforts have prevented long hospitalizations and emergency department visits. To reduce emergency department visits, the practice will arrange to meet families in subspecialty clinics if the primary care clinic is not open. Additionally, clinicians are authorized to directly admit patients from the clinic into the hospital to circumvent emergency department visits.

NORTH ARLINGTON PEDIATRICS

Practice address:	1430 N Arlington Heights Rd Arlington Heights, IL
Geographic location:	Suburban
Type of practice:	General pediatrics
Organizational structure:	Private practice
Size of practice:	3 full-time pediatricians 5 part-time pediatricians 1 care coordination nurse
Number of patients:	12,000
Patient insurance:	95% commercial/private insurance 5% Medicaid
Medical home recognition:	Illinois Division of Specialized Care for Children–designated medical home
Patient/family experience questionnaire:	MHFI administered bi-annually
EMR system:	Yes, implemented in November 2011
Other information technology:	Yes, a patient registry created in Excel and searchable by diagnosis (through the newly implemented EMR system more searchable registries are available); an electronic care plan template created in Microsoft Word by the care coordinator and stored on a designated laptop computer bought with medical home grant funding; and a protocol for flagging medical home patients by problem severity in the patient roster used by front desk staff for scheduling appointments.
Funding source(s):	- Primarily funded through the practice’s operating funds. The practice recoups about 70% of the cost of the care coordination nurse’s position by billing insurance payers for care coordination oversight, meaning “interaction with the physician on behalf of the family.” - Medical home grant funding obtained during the initial stages of medical home implementation efforts from the Illinois chapter of the AAP was used to purchase a laptop computer to store written care plans and patient registries and to provide parent partner stipends. Throughout its medical home transformation, an external facilitator funded by the Title V Maternal and Child Health Program and an Illinois Division of Specialized Care for Children representative guided the practice toward a more patient- and family-centered way of providing care.

Abbreviations: AAP, American Academy of Pediatrics; EMR, electronic medical record; MHFI, Medical Home Family Index.

PRACTICE OVERVIEW:

At North Arlington Pediatrics, from hosting family member panels to partnering with school administrators, partnering with families means tailoring the practice to fit families’ needs. In allowing parents to collaborate in shaping practice policy, North Arlington Pediatrics has realized that, “It’s not just enough to offer things; you’ve got to be offering what it is they need.”

The main challenge the practice has faced has been maintaining the momentum established during the initial phases of the medical home pilot. Parents on the quality improvement panels did not feel as useful once the medical home was firmly established. The practice has sought to overcome this challenge by finding new topics and projects that keep the panels interesting and useful to families.

LESSONS LEARNED:

- When making changes to office policies, it is important to go slowly and not do too much at once.
- One of the most beneficial changes made during the medical home pilot was the extension of the time allotted for the visits of patients with special health care needs.
- For quality improvement patient panels, it is important

incorporate families with children of different ages who require differing levels of health care complexity.

- Most importantly, “Involve your front desk staff. Go slow, baby steps. Implement change in the tiniest increment you can come up with, because you want to keep the momentum up, and you’re not going to have a winner every time, and so you don’t want it to have burned anybody. You don’t want to try to do too much too soon because you’ll get bogged down; you’ll get frustrated, and you’ll quit.”

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

Front desk staff who are responsible for scheduling patient appointments in the computer- based patient roster discern the potential complexity of a patient’s medical needs and allot the appropriate time in the schedule for that patient’s appointment. Additionally, the care coordinator is alerted to contact the family before the scheduled appointment to address any pre-visit needs or track down records or test results from other providers.

To make scheduling an appointment as convenient as possible for its families, the practice offers **open access**, including evening and Saturday hours. Additionally, a

"I know what's going on. So if there's something that the family needs, I can get a hold of a subspecialist I can talk to before they come, or I can talk to the doctor about what's going on, what does he think the best strategy is? So that by the time the family gets here we are well prepared for them. We've allowed them enough time."

—practice

practice provider is on-call 24 hours a day/7 days a week.

CARE MANAGEMENT

The practice implemented an EMR system in November 2011. The **care coordination nurse** stated that by engaging and partnering with families, she has a better understanding of the nonclinical aspects that

accompany caring for a child with special health needs.

To effectively track and coordinate care for CYSHCN without the advantages of an EMR, the practice used some of its medical home grant funding to purchase a laptop computer for the care coordination nurse. On the laptop computer, the care coordination nurse developed a simple yet effective medical home patient registry in an Excel spreadsheet. The practice recoups about 70% of the cost of the care coordination nurse's position by billing insurance payers for care coordination oversight. The care coordinator handles a large portion of work that would otherwise land on the physicians' desks. Thus, care coordination tasks are prevented from cutting into the physicians' time devoted to seeing patients.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

Throughout its medical home transformation, an **external facilitator** funded by the Title V Maternal and Child Health Program guided the practice toward a more patient- and family-centered way of providing care. North Arlington Pediatrics now serves as a mentor practice through the Illinois chapter of the AAP to other practices looking to build a medical home.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

Though efforts to start a support group for siblings of CYSHCN were unsuccessful due to scheduling issues, the siblings identified as potentially benefitting from additional support have been connected with a local psychologist interested in addressing the needs of siblings of CYSHCN. Additionally, families dealing with similar issues are linked up with one another by request.

COMMUNICATION WITH PATIENTS & FAMILIES

The practice developed **educational materials** for patients and families, including a brochure outlining the services offered through its medical home, and a patient portal system is currently being developed. There is a bulletin board outside the medical home office where helpful information for families is posted and the achievements of patients and families are acknowledged and celebrated by the practice.

North Arlington Pediatrics is currently involved in the Transition Project of the Illinois chapter of the AAP and is serving as a pilot site for a web-based teaching curriculum regarding transition issues.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

North Arlington Pediatrics implemented **quality improvement panels** that incorporate families. These panels allow families to share their perspectives on their children's care. The monthly panel meetings have been instrumental in guiding office policy. For example, the care plan template

was informed by families based on the questions that are most frequently asked during specialty or emergency department visits. The quality improvement panels, including stipends for the families involved, were supported by grant funding as the practice initially transitioned into a medical home.

Currently, the quality improvement panel is working on storybooks about well-visits and sick-visits for kids who have limited language skills, whether due to a cognitive deficit or limited

English. Parent volunteers came into the practice and took pictures, which are being assembled into storybooks. The idea for this project came from parents during one of the quality improvement panel meetings.

The practice has administered the MHFI to parents and family members twice during the first 4 years of its efforts to build a medical home. The results showed an increase in families' satisfaction with the practice.

PRACTICE QUALITY IMPROVEMENT

At North Arlington Pediatrics, the assimilation of patient- and family-centeredness into the culture of the practice was described as slow and steady. One of the most important factors in successful implementation of patient- and family-centered initiatives was asking for provider and staff input. "When people have input they're more likely to buy in, and they actually have great ideas." Once patient- and family-centeredness is part of the culture, and everybody buys-in, providers and staff are all "on the lookout" for ways to improve. "Because when you make it easier for the families, you make it easier for everybody."

"[W]hat is probably the most enlightening thing about when you become a medical home practice is you think you know what people want, and then when you find out what they want, it's so not what you thought. So it's amazing what makes a difference in families lives compared to what we think is going to make a difference. And so I think the open dialog and the respect for everybody's opinion is really important to be able to call yourself family-centered...that really collaborative relationship between the practice and families, I think that's what exemplifies it—collaboration of care in terms of what they need, what their goals are."

—practice

PECAR HEALTH CENTER

Practice address:	6940 N Michigan Rd Indianapolis, IN http://www.wishard.edu/find-a-location/pecar
Geographic location:	Urban
Type of practice:	Health center with general pediatrics, obstetrics and gynecology, family, and internal medicine providers on staff
Organizational structure:	Affiliated with the Wishard Health Services and the Indiana University Medical School offering medical student and resident rotations. Similar to a Federally Qualified Health Center with strong affiliation to the Marion County Hospital.
Size of practice:	4 part-time pediatricians 1 part-time pediatric nurse practitioner 2 family medicine physicians 2 internal medicine physicians 1 obstetrician-gynecologist 2 nurse practitioners in obstetrics and gynecology 1 full-time social worker 1 part-time psychiatrist 1 part-time psychologist
Number of patients:	3,500 pediatric patients; 4,500 adult patients
Patient insurance:	20% modified self-pay (through the health system's insurance program)/self-pay 80% Medicaid
Medical home recognition:	- Member of the MHLC through the Indiana Community Integrated Systems of Services Project - NCQA Physician Practice Connections PCMH recognition program application in progress
Patient/family experience questionnaire:	- Visit-Specific Satisfaction Questionnaire administered by the health system to a random sample of patients each quarter with results tied to physician compensation - MHLC Family Survey administered in June 2011 in both English and Spanish versions at 8 MHLC member practices. Survey contains 18 questions with a Likert-scale response set to measure medical home attributes.
EMR system:	Yes
Other information technology:	Yes, patient portal
Funding source(s):	Primarily funded by the clinic's operating funds. Participation in the MHLC sponsored by Indiana Community Integrated Systems of Services Project has given the practice access to funding for parent partner stipends. The health center's parent health system, Wishard Health Services, recently announced the hiring of a patient navigator to assist new patients in acclimating to their medical home.

Abbreviations: EMR, electronic medical record; MHLC, medical home learning collaborative; NCQA, National Committee for Quality Assurance; PCMH, patient-centered medical home.

PRACTICE OVERVIEW:

The Pecar Health Center, a “one-stop shop,” offers comprehensive care for families. When visiting the clinic, patients and families can easily coordinate additional services including internal medicine; family medicine; obstetrics and gynecology; Women, Infants, and Children Program services; mental health services; dental care; social work services; and legal services, as these services are all located in the same facility. Pecar Health Center clinicians find it of great benefit to patients that “with a simple phone call or a short walk [we] can activate all of these resources.”

LESSONS LEARNED:

- Communication and transparency are the most important aspects to implementing change effectively.

- Internally, daily morning “team huddles” prepare the staff for that day’s patients, which increases efficiency.
- Communication with other practices was also a significant facilitator of transformation.
- Transparency of the pilot’s aims was also found to be essential, “...the other thing that’s been pivotal for us is having all of the staff from the doctors all the way to maintenance staff, every single person needs to understand what it means to be a medical home; they need to be completely empowered and activated to do anything and everything they can for a patient within their license.”
- Patient- and family-centered, high-quality care can be achieved in a predominantly poor, underserved population. Although the clinic does not have a significant amount of money, providers and staff believe that they have been successful in the provision of comprehensive, accessible care.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

Pecar Health Center offers **same-day appointments** for well and sick children. Significant effort is made to schedule appointments for siblings in consecutive timeslots or provide last-minute accommodation for a sibling during a patient's appointment.

CARE MANAGEMENT

The clinic implemented **pre-visit telephone calls** and uses an adapted version of the pre-visit questionnaire from the AAP Building Your Medical Home toolkit to ensure that any pre-visit records requests or other pre-visit tasks are completed before the scheduled appointment and to better tailor well-child visits to each family's needs. The introduction of the pre-visit questionnaire launched the staff into holding **"team huddles"** every morning. The staff meets 15 minutes before the first scheduled appointment to review the questionnaires of the patients to be seen that day and discuss any vaccines, medication refills, referrals, or other paperwork that may need to be completed.

"The pediatricians do check in with me personally and make sure everything is going okay with me; they check in with my husband [too]."
—family member

As a product of more standardized policies, the practice has increased the percentage of immunized patients and is now more compliant with the use of **developmental and autism screening tools**, including the ASQ and the Modified Checklist for Autism in Toddlers. In addition, all mothers of newborn patients are screened for postpartum depression.

The clinic's parent health system, Wishard Health Services, recently announced the hiring of a patient who will facilitate the delivery of comprehensive care to new patients by gathering all of the necessary pre-visit information.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

As part of the MHLIC sponsored by Indiana Community Integrated Systems of Services Project, Pecar Health Center's team has shared its successes and ways to overcome implementation challenges with other practices in the collaborative. The clinic's medical director provides **medical home training** to residents to enhance their

understanding of the importance of patient- and family-centered care. In her teaching, she emphasizes the importance of the family/professional partnership, cultural diversity, and community resources.

COMMUNICATION WITH PATIENTS & FAMILIES

A collection of **health education resources** and information on community services and specific diseases is available to families. These resources include developmental calendars that include milestones for young children, Wellness Passports to organize immunization records, brochures on state programs available to families (eg, health care financing), as well as the telephone numbers and websites of other important resources. Many of the resources are available in Spanish.

"I never feel talked down upon. I never feel like just because... they've had to explain something to me a couple of different ways...that I'm uneducated."
—family member

CULTURAL DIVERSITY & SENSITIVITY

Pecar Health Center's patient population is 80% to 90% Spanish-speaking. All of the providers and staff are **bilingual**, speaking both English and Spanish, which makes it easy to provide information to the families about diagnosis, treatment, health management, and education. Information on community resources for CYSHCN is made available in Spanish.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The clinic has 2 **parent partners** who were identified based on 2 criteria: (1) they had children with special health care needs; and (2) they were predicted to be opinionated and offer honest appraisals of the clinic despite cultural pressures that could potentially temper any form of criticism. Once selected, the clinic began by scheduling one-on-one conversations with the parents, the medical director, and one of the medical assistants involved in the MHLIC. Themes discussed were shared at clinic staff meetings. The clinic plans to continue informal telephone or face-to-face meetings to solicit parent feedback, and in the coming months, the clinic plans to integrate the family partners into clinic staff meetings. A grant from Indiana Community Integrated Systems of Service made funds available to offer stipends, daycare, and transportation reimbursement to the parent partners.

Patient satisfaction surveys, following the Visit-Specific Satisfaction Questionnaire, are mailed quarterly by the clinic's health system to a random selection of 15 to 20 patients seen during the quarter. Results are calculated on scale of a 1 (low) to 5 (high) and are tied to the physician compensation packages. As part of the MHLC funded by the Indiana State Department of Health, the clinic recently conducted a more specific survey focusing on questions of patient- and family-centeredness. A homegrown, 18-question survey tool was used to gather feedback from parents across the 8 practices that participate in the MHLC. Both Spanish and English copies of the survey were available for families to complete based on their experience at the clinic.

PRACTICE QUALITY IMPROVEMENT

The practice noticed an increase in confidence amongst providers after implementing the medical home initiatives. The practice runs more efficiently, which has increased customer satisfaction as well. Despite having a staff of people who are engaged and open to new ideas, there was some "change fatigue" experienced by providers and staff.

For the last 8 years, the providers and staff have held weekly meetings to discuss quality issues. A dry-erase board in the clinic is used to collect ideas from providers and staff throughout the week. These ideas are called "**opportunities for improvement**," and they drive the agenda of the meeting each week. The person who creates an opportunity for improvement leads the discussion of his or her idea at the meeting.

Periodically throughout the year, the clinic sends individual staff members to observe in another primary care office. The staff member is charged to observe the patient and

"We don't have very much money to spend on things, but that doesn't mean that you can't be a medical home, and it doesn't mean that you can't be family-centered and do comprehensive care and do the right thing."

-practice

clinic flow, the workflow and daily functioning of the medical records area, or how the other clinic's staff handles customer service. After this "**field study**," the staff member reports back to the Pecar Health Center clinic staff.

PEDIATRIC PARTNERS

Practice address:	Magnolia Place 5816 Creedmoor Rd, Ste 104 Raleigh, NC http://www.pediatricpartnersraleigh.com
Geographic location:	Suburban
Type of practice:	General pediatrics
Organizational structure:	Private practice that receives graduate nursing and medical students affiliated with Duke University and University of North Carolina at Chapel Hill during their clinical rotations
Size of practice:	1 full-time pediatrician 1 part-time pediatrician 1 pediatric nurse practitioner 1 registered nurse/lactation consultant 1 registered nurse 1 licensed practical nurse
Number of patients:	2,675
Patient insurance:	76.5% commercial/private insurance 17.3% Medicaid 6.2% uninsured/self-pay
Medical home recognition:	NCQA Physician Practice Connections PCMH recognition
Patient/family experience questionnaire:	- Customized patient satisfaction surveys are administered every year. - Periodic project-specific questionnaires gauge patient/family interest and solicit feedback regarding new services or practice changes.
EMR system:	Yes
Other information technology:	Yes, patient portal and practice Facebook page containing current pediatric topics/news such as formula recalls, seasonal advice, and disease/influenza outbreaks
Funding source(s):	Funded through the practice's operating funds. Practice improvement expertise and assistance provided by the North Carolina Area Health Education Center's Improving Performance in Practice Asthma Collaborative, a program funded by the Robert Wood Johnson Foundation that "provides small practices with tools, support, coaching and a collaborative learning environment in which they can assess their performance and engage systematically in improvement activities using their own practice data and comparisons to others in their cohort groups as benchmarks."

Abbreviations: EMR, electronic medical record; NCQA, National Committee for Quality Assurance; PCMH, patient-centered medical home.

PRACTICE OVERVIEW:

Pediatric Partners believes that a smaller patient base allows for a personalized approach that focuses on the unique health care needs of each patient. As the practice name implies, providers and staff partner with patients and families to provide uninterrupted developmental, behavioral, preventive, and acute and chronic sick care from birth through the transition to adulthood.

LESSONS LEARNED:

- There is a distinct difference in models of care motivated by profit and those motivated by quality.
- Having a clearly defined patient- and family-centered business model offers an underlying organizational structure informing all aspects of a pediatric practice.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

Access to care is one of the practice's major strengths. In addition to routine extended hours, **open access** appointments are available in the morning and afternoon through-

out the week. One of the practice's providers is on-call and available to patients and families 24 hours a day/7 days a week via cell phone. The practice routinely schedules longer appointments for complex cases, which are color-coded in the scheduling system to alert staff to the special needs of each patient. Scheduling appointments is made easier for families by a telephone system that is answered by a live person during business hours, including over the lunch hour. Families are also able to schedule planned or same-day appointments through the practice's patient portal.

The **patient portal** offers information and services to patients and their families via a secure electronic system. Patients are able to view their medical record, request referrals or medication refills, and communicate with the health care team electronically.

As a standard practice, the practice offers pertussis vaccine boosters and seasonal influenza vaccinations to parents, grandparents, babysitters, and other adults who come into regular contact with pediatric patients, especially infants.

CARE MANAGEMENT

The practice follows the **Bright Futures** guidelines and recommended screenings, including postpartum depression, developmental milestones, and autism spectrum disorder screenings. Pediatric Partners uses the EMR to customize data entry fields to meet their tracking and reporting needs. Process reminders are used to ensure routine tests and screenings are administered during the appropriate office visit.

The practice maintains comprehensive patient information in its EMR system, such as medications, visits to specialists, medical history, recent test results, self-care information, and data from recent hospitalizations, specialty care referrals, or emergency department visits. Process reminders in the EMR system further serve to make queries regarding any non-referred specialty visits or medication use, including over-the-counter and herbal medications, routine.

To enhance care transitions, Pediatric Partners has implemented Axial MD Alerts with the community hospital. Axial MD Alerts is software used by the hospital to e-mail **real-time electronic alerts** to Pediatric Partners when one of the practice's patients seeks emergency treatment or is admitted to or discharged from the hospital. In addition, Pediatric Partners has electronic access to the hospital providers' notes and summaries and can alert the hospital to pertinent patient medical issues.

The practice utilizes the **CYSHCN screener** for new patients to identify children across the wide spectrum of diverse childhood chronic conditions and special needs, thus alerting the practice to the need for a more comprehensive assessment of health needs. As advocates for CYSHCN, the practice partners with parents and helps them build upon their own family strengths and further leads and empowers them to become effective advocates for their children locally within the public school system and even nationally in the arena of federal policy.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

Pediatric Partners offers patients opportunities to participate in **health education programs**, such as classes and peer-support groups. One such example, born out of parent request, is the Beyond Abstinence presentation offered to teenage patients on weekday evenings in a group setting.

COMMUNICATION WITH PATIENTS & FAMILIES

The **patient and family experience** begins when they walk in the door and are greeted by name by the receptionist. By maintaining a smaller patient panel, the providers and staff can more easily develop

*"The name [Pediatric Partners] really was referring to the partnership between the providers and the parents and the patients."
-practice*

relationships with patients and families. Additional services such as a lactation consultant and in-office ear piercing help the practice meet the needs of a small but diverse patient population.

Pediatric Partners providers and staff like to "celebrate and brag about our newsworthy patients." The staff and providers celebrate and reward patient **successes**

*"What we really like...is that it's real personal. It's a small town kind of situation where they work with you to help you make decisions"
-family member*

such as cooperative examinations, potty-training success, and lost teeth. Vaccinations are rewarded with a trip to the treasure chest, and achievements such as college acceptances, violin recitals, and scouting awards are acknowledged and celebrated through a "superstar" bulletin board.

CULTURAL DIVERSITY & SENSITIVITY

The practice uses data from its EMR system to assess and address the cultural and linguistic needs of its population. Information on race, ethnicity, and preferred language is collected directly from all patients and maintained in the EMR.

Language services include multilingual staff and third-party interpretation services as well as screening tools and hand-outs in other languages. Practice physicians have completed **cultural competency training** through Blue Cross Blue Shield, and the skills gleaned through this training were passed on to all practice staff through in-service training.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The practice conducts annual **patient/family experience surveys** to evaluate its care, access, communication, coordination, and whole-person care/self-management support, especially in regard to vulnerable patient groups. The practice also solicits feedback from patients and families through qualitative means such as a suggestion/comment box and patient interviews. Pediatric Partners recently began implementation of a medical home team to guide continuous quality improvement efforts.

PRACTICE QUALITY IMPROVEMENT

The practice utilizes its EMR system to create custom reports to inform quality improvement efforts. The regular **review of performance data** both on the practice and provider levels assists in the evaluation of performance against goals and benchmarks. A formal quarterly review and evaluation offers opportunities to identify and prioritize areas for improvement, analyze potential barriers to meeting goals, and formulate a plan for implementation to address and overcome any anticipated barriers. This process is accomplished with assistance from the North

Carolina Area Health Education Center's Improving Performance in Practice Asthma Collaborative, a program funded by the Robert Wood Johnson Foundation.

The practice partners with local community organizations as well as public service agencies such as the Children's Developmental Service Agencies of North Carolina, which refer children aged 0 to 3 years who have special health needs for early intervention services. Pediatric Partners is also a contracted provider with Community Care of Wake

and Johnston Counties, a partnership that focuses on population management of medically high-risk and high-cost Medicaid patients.

As a benefit of providing patient- and family-centered care, the practice noted an increase in the staff's personal satisfaction, which has been attributed to the sense of achievement felt by providing patients with high-quality, comprehensive care.

RAINFOREST PEDIATRIC CARE

Practice address:	3268 Hospital Dr, Ste D Juneau, AK
Geographic location:	Suburban
Type of practice:	General pediatrics
Organizational structure:	Private practice
Size of practice:	2 pediatricians (sharing 1 full-time equivalent position)
Number of patients:	1,250-1,500
Patient insurance:	60%-70% commercial/private insurance or self-pay 30%-40% Medicaid or other publically funded coverage
Medical home recognition:	None
Patient/family experience questionnaire:	None
EMR system:	No
Other information technology:	No
Funding source(s):	Funded through the practice's operating funds

Abbreviation: EMR, electronic medical record.

PRACTICE OVERVIEW:

Rainforest Pediatric Care's staff has an unspoken, philosophy based on respect for both patients and their families. The practice believes in partnering with families stating, "We strive to acknowledge that parents know their children best...there is never a question that the parents' concerns are valid. We feel it is our job to learn what is worrying the parent regarding their child's health, and respond with a clear plan for evaluation of the concern, or reassurance if no evaluation is necessary." It was also noted that a generally positive attitude, as well as staff-wide appreciation and respect for families helps the practice present itself as a friendly, safe place to receive care.

LESSONS LEARNED:

- Rainforest Pediatric Care attempts to learn the names of all family members of patients as a form of respect and family-centeredness.

- The practice hires staff who appreciate and respect families as an important component of the hiring process.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

One of the physicians in the practice offers **improved accessibility** by means of after-hours, on-call availability on weeknights and weekends. If necessary, she is willing to open the practice after-hours to see a sick patient. On occasion, clinicians will make **home visits**, using these opportunities to offer follow-up care and give family members moments of respite from the management of chronically ill children.

When clinicians see one child, during that same visit, the staff allows time to assess and care for any additional siblings. Clinicians also incorporate older siblings in the care of their infant siblings.

CARE MANAGEMENT

Rainforest Pediatric Care recognizes that for many families one visit does not offer enough time to process and accept that there might be a concern regarding their child's development. With that in mind, the practice schedules a series of future visits for parents of children with suspected developmental delays, which eases and supports these families as they work with the physician and practice staff to formulate a care plan and discuss the appropriate referrals.

The practice utilizes many **community resources**. These include support from the Infant Learning Program, a

*"[The doctor] got us started with speech therapy and with physical therapy—the Infant Learning Program. She suggested all of that before I had even known there was such a thing."
—family member*

community resource for children ages 0 to 3 years with developmental delays. Also, Women, Infants, and Children Program coordinators are utilized for nutritional guidance and breastfeeding coaching.

Other community resources include the public health center, lactation specialists at the local hospital, care coordinators for CYSHCN, and school nurses.

The staff has realized that children have much better outcomes when their families are incorporated into the process of formulating **care plans**. As a result of a closer relationship between the practice and its patients' families, providers and staff feel better equipped to anticipate

*"When the flu shots are available they'll call and remind me that my children should come in and get them. They're on top of it."
—family member*

broader needs that warrant attention during well-child visits, such as the care of other siblings as opposed to just the primary patient.

COMMUNICATION WITH PATIENTS & FAMILIES

The practice encounters occasional cases where a child repeatedly misses a routine well-child visit or the practice has faced difficulty maintaining communication with a patient's family. In these cases, the clinician has worked with the staff to establish an informal but standard practice of tracking down and following-up on patients who have neglected to make regular appointments.

The practice uses a variety of tools to facilitate increased **communication with families**. The practice routinely connects families with similar concerns or diagnoses with one another and refers family members to community support groups, such as new parents groups or a group geared specifically to fathers. The practice has also established communication lines with local daycare providers. With parental consent, the daycare provider and physician can communicate directly with one another during daytime hours should a family member be unavailable. For families with non-emergent needs, physicians offer health coaching over the telephone. In addition, the practice regularly communicates with school nurses and encourages them to contact the practice with concerns regarding patients, especially in the cases of children with chronic health conditions.

CULTURAL DIVERSITY & SENSITIVITY

Day-to-day practice **operations policies** that facilitate an environment of patient- and family-centeredness include:

- recognition of the importance of extended family in the local Tlingit culture, and thus making a concerted effort not to discourage their inclusion in the child's care, whether it be by provision of extra written instructions or a post-visit call to the parents of a child brought in by a grandparent;
- arranging transportation through an outside resource for families who require such assistance;
- supporting breastfeeding by allowing mothers extra time in the privacy of the examination room if they prefer not to breastfeed in the waiting room; and
- maintaining a policy not to limit the number of Medicaid patients the practice will serve.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

Word-of-mouth referrals from the patients' families are the primary source of new families who join the practice. Local organizations such as the US Coast Guard and the University of Alaska, as well as seasonal employment opportunities, often only keep families in Juneau a few years at a time, causing a fair amount of turn-over. Therefore, between a steady stream of word-of-mouth referrals and the somewhat transient nature of the local population, the practice size remains fairly constant.

CHILDREN'S MEDICAL GROUP–SOUTHWEST PEDIATRICS

Practice address:	3610 Michelle Witmer Memorial Dr, Ste 100 New Berlin, WI http://www.Southwest-Pediatrics.com
Geographic location:	Suburban
Type of practice:	General pediatrics
Organizational structure:	Operates independently, but affiliated with the Children's Medical Group of the Children's Hospital of Wisconsin Health System; receives medical students and residents from the Medical College of Wisconsin, physician assistant students from Marquette University, and nurse practitioner students from the University of Wisconsin-Madison
Size of practice:	5 full-time pediatricians 2 part-time nurse practitioners 1 medical assistant 1 part-time child psychologist 20 registered nurses
Number of patients:	13,000
Patient insurance:	81% commercial/private insurance 17% commercial Medicaid 1% other publically funded coverage 1% self-pay
Medical home recognition:	Star Community recognition by the Champions for Inclusive Communities Project, a national leadership and resource center through Utah State University
Patient/family experience questionnaire:	- Patient satisfaction surveys in conjunction with implementation of specific medical home initiatives - Medical Home Index completed by providers, staff, and parent advisors
EMR system:	No, currently in development
Other information technology:	Yes, QSI billing software is used to identify CYSHCN by diagnosis.
Funding source(s):	- Primarily funded through the practice's operating funds. - Practice newsletter was initially funded by a grant from the Wisconsin Medical Home Initiative and the Children's Hospital of Wisconsin Health System. The grant has since expired, and the newsletter is now self-sustained through the utilization of articles authored mainly by practice staff and parents and the editing and publishing expertise of the practice's parent health system's public relations department. - Staff of the Special Needs Program at Children's Hospital of Wisconsin shared their expertise in care coordination for CYSHCN. - Title V The Title V Maternal and Child Health Program and the Wisconsin chapter of the AAP have been sources of grant funding and medical home expertise.

Abbreviations: AAP, American Academy of Pediatrics; CYSHCN, children and youth with special health care needs; EMR, electronic medical record.

PRACTICE OVERVIEW:

Children's Medical Group–Southwest Pediatrics (Southwest Pediatrics) facilitates family networking and, through a variety of tools, empowers families to play an active role in the health of their children. The practice believes that beyond systemic changes like increasing accessibility and improving continuity of care, a philosophy that engages families, discovers their needs, and respects those needs is most responsible for their patient- and family-centeredness.

There were 3 main challenges faced by the practice during implementation of medical home initiatives, namely time dedication, limited finances, and fragmented buy-in. The practice learned a valuable lesson through the failure of its first initiative, which was implemented via a top-down directive that offered no opportunity for staff input. However, the practice quickly acknowledged and corrected

this mistake. Once the subsequent initiative proved successful, it became apparent to providers and staff that the cost of time and financial resources invested was outweighed by the resulting benefits. Physician champions from the practice reiterate how valuable the parent advisory board was in guiding practice improvement initiatives, as well as identifying patient- and family-centered initiatives that involved process changes or time commitments, but not necessarily additional funding.

LESSONS LEARNED:

- “Do not worry about funding.” While a newsletter might be cost prohibitive, interventions like advisory boards only cost time.
- Avoid top-down directives. Buy-in is improved tremendously if staff members are educated and engaged in designing and implementing initiatives within the practice. Take small steps, one at a time, and do not try to make big changes all at once.

- Interventions tended to happen in stages, where the implementation of one project revealed a need and served to guide new undertakings.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

When a parent calls to schedule an appointment, whether for a well-child visit or a sick visit, practice staff make a deliberate effort to understand the specific issues that the parent would like to discuss with the doctor during that scheduled appointment. By collecting this information in

“When I call [for an appointment]...they know not to put us in their tiniest exam room because it’s harder when you’ve got three kids, one that’s in a wheelchair.”
 –family member

advance, not only can the scheduler attempt to allot an **ample appointment length** to address all of the parent’s concerns, but the scheduler can make an informed effort to maintain balance in an

individual provider’s schedule by alternating the appointments of patients with fewer concerns with appointments for more complex, potentially time-consuming cases.

As a result of the practice’s efforts to build a medical home and its providers’ reputation for serving patients with special needs, specialists and families in the surrounding community frequently refer new families seeking care for CYSHCN, particularly children who have autism or ADHD.

CARE MANAGEMENT

The first initiative recommended by the parent advisory board was an increase in **care management** and coordination with families. The practice initially tried to implement heightened care management for a subset of patients, namely patients with ADHD. An attempt was made to implement improved care management for these patients by using a hierarchical approach involving a top-down directive issued to staff, but the entire project ended with little success. The practice found that clearly articulating new projects to the staff and asking for their input was the best way to implement change effectively and improve practice-wide buy-in.

Through the ADHD care management project, it was discovered that the nursing staff was uncomfortable conducting follow-up discussions with families regarding stimulants and behavior management. To resolve this issue, practice physicians held an **educational workshop**, which provided the nursing staff an opportunity to learn more about ADHD medications and management approaches. In addition to strengthening the ADHD knowledge-base of the nursing staff, and thereby bolstering their confidence when discussing ADHD-related care with families, these sessions led the nursing staff to identify other educational

topics for which additional training would facilitate better care management for the practice’s patients with special health care needs.

To provide support to families, Southwest Pediatrics partners with a community psychologist to host a support group that meets every 2 months for parents with children diagnosed with ADHD.

Given that Southwest Pediatrics is in the early stages of transitioning from paper-based medical records to an EMR system, the practice has found it necessary to address issues of **standardized documentation** to facilitate better communication between physicians both internally and with specialists and providers outside the practice. The practice has used its billing software to generate comprehensive lists of patients with specific conditions through the use of diagnostic codes. Two staff nurses use these **registries** along with **medical record reviews** to coordinate the care needed for more complex patients. In addition, part of these nurses’ clinical time is dedicated to generating care plans. Once work begins on a child’s individual care plan, the parents are notified that a care plan is being devised, and the nurses then gather all of the information necessary to complete the practice’s care plan template and finish the write-up. Upon completion, the care plan is sent to the child’s parents to be used with specialists, emergency department physicians, or any other providers that the child sees. The care plan provides a thorough patient history and will hopefully facilitate better care and management of the child’s health.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

In 2004, the practice was invited to participate in the state-wide **MHLC** sponsored by the Wisconsin Department of Health and Human Services. The Medical Home Learning Collaborative met quarterly for the first few years, then yearly for an additional 2 years.

Southwest Pediatrics consulted the knowledgeable staff of the Special Needs Program at Children’s Hospital of Wisconsin who shared their expertise in care coordination for CYSHCN and suggested helpful community and state-wide resources. One of the most valuable tips resulting from this collaboration was information about the 5 state-funded Regional Centers for CYSHCN in Wisconsin dedicated to supporting families of CYSHCN and the providers who serve them.

Southwest Pediatrics also contributed to the creation of a **Medical Home Toolkit** prepared by the Wisconsin Department of Health Services, which is freely accessible on the AAP website. It provides information, suggestions, and resources helpful for a practice looking to build a medical home.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

In an effort to engage with parents, share information about community resources, and educate families and community members on specific health topics, the practice hosts **parent resource meetings** quarterly at the public library located across the street from the practice. Typically, these meetings are physician led, and families have the opportunity to learn about care management for specific diseases, conditions, and behavioral issues. Simultaneously, while educating parents, physicians hear first-hand accounts of parents' experiences accessing community resources.

Though not necessarily intended to be the target audience when the practice began holding the parent resource meetings in 2008, through the diligent efforts of practice staff to advertise these meetings to the community, there is now a strong following of daycare providers, teachers, special needs educators, and community members who regularly attend these meetings to learn how to advise parents as well as to expand their own knowledge-base about the care for children with special health care needs or behavioral issues.

COMMUNICATION WITH PATIENTS & FAMILIES

The parent advisory board has served as a launch pad for all of the initiatives undertaken by the practice to improve its service as a medical home. One of the issues raised by parent advisors was a lack of knowledge about community resources. As a solution, Southwest Pediatrics developed a quarterly **newsletter** that, in addition to informing families about community resources and events, includes an educational component, serial disease-specific columns, and articles written from patient or sibling perspectives. Articles are authored mainly by practice staff and parents, most of whom are parent advisory board members.

*"I don't ever feel like I am being dictated to. They always give out a lot of information...they respect my choices."
-family member*

Families also now have access to a **community resource center** in the office lobby. While waiting for their child's appointment, parents can peruse the shelves in the lobby, which contain information on community resources divided into categories and lists of literature that can be used by families to better understand certain illnesses.

CULTURAL DIVERSITY & SENSITIVITY

The practice offers translation and interpreter services through the Children's Hospital of Wisconsin. Printed materials are available in English and Spanish. Most materials are written to accommodate all reading abilities. Staff members regularly volunteer to take **cultural e-learning courses** on cultural beliefs and the provision of health care to members of diverse cultural groups.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The first initiative the practice undertook was to form the parent advisory board that, over the past 7 years, has included 4 or 5 parents of CYSHCN who serve on the board for 2 or 3 years, as their availability permits. The board also includes 2 staff nurses, a practice administrator, 2 physicians, a representative from the regional center for CYSHCN, and a person with links to community resources—presently the local children's librarian. The group meets on a weekday evening every 6 weeks and offers guidance to the practice on areas to target for improvement. Initially, participating parents were given a small stipend for their time, but in recent years the parents give their time on a volunteer basis, and a meal is now provided at the meetings.

PRACTICE QUALITY IMPROVEMENT

Southwest Pediatrics is planning the implementation of an **asthma care coordination program**. After identifying all practice patients with an asthma diagnosis, the goal of the program is to improve follow-up care based on the National Heart, Lung, and Blood Institute Expert Panel Report 3—Guidelines for the Diagnosis and Management of Asthma by increasing efforts to educate patients and families at the time of diagnosis and during follow-up appointments to improve quality of life and decrease the number of asthma-related emergency department visits and hospital admissions.

THE CHILDREN’S CLINIC, PC

Practice address:	9555 SW Barnes Rd, Ste 301 Portland, OR
Geographic location:	Suburban
Type of practice:	General pediatrics
Organizational structure:	Private practice with 2 office locations
Size of practice:	24 pediatricians (sharing 16 full-time equivalent positions 1 is a part-time pediatric pulmonologist) 1 part-time nurse practitioner 1 part-time lactation consultant
Number of patients:	50,000-55,000 between the 2 office locations
Patient insurance:	80% commercial/private insurance 15% Medicaid 5% self-pay
Medical home recognition:	None
Patient/family experience questionnaire:	- Child and Adolescent Health Measurement Initiative—Promoting Healthy Development Survey - Blue Cross Blue Shield patient satisfaction survey (a proprietary survey tool)
EMR system:	Yes
Other information technology:	Yes, patient portal (in development), web-based Plan Your Child’s Well-Visit (for family use), and a web-based registry for patients with asthma (for provider use)
Funding source(s):	Primarily funded through the clinic’s operating funds. The added time and effort invested by families, providers, and staff is provided as in-kind service to the practice. Efforts are made to optimize billing practices and utilize billing codes to receive reimbursement for developmental and other screenings.

Abbreviation: EMR, electronic medical record.

PRACTICE OVERVIEW:

The Children’s Clinic, a large practice with 2 locations, was originally founded by Dr Joseph Bilderback, the first pediatrician in the Northwest, and has been serving the Portland area since 1911. Providers adhere to a philosophy of “nothing about me, without me”—meaning that discussions and decisions about a patient’s care are always in partnership with a patient and his/her family. Accordingly, providers invest significant effort in attempts to shift the agenda of well-child visits from simply following the anticipatory guidelines script to focusing on families’ specific questions and concerns. From piloting the use of web-based questionnaires that allow families to direct the planning of their child’s well visits to holding parent advisory sessions to inform practice initiatives and changes, the clinic is progressive in its efforts to move past the assumption that it is meeting families’ needs and actually discover the reality of its patients’ and families’ experiences and perceptions of care.

LESSONS LEARNED:

- Implement patient- and family-centered changes in small steps to avoid becoming overwhelmed by a lengthy list of requirements for medical home recognition.
- The adoption of one patient- and family-centered change at a time allows the successes or challenges encountered through that experience to inform the next step in the transformation process. Eliciting parents’ opinions through a parent advisory group can be invaluable in

assessing the viability and potential benefit of a project, as well as in elucidating potential problems or logistical barriers that could hinder a project’s success. These groups simply require time investment and are fairly easy to implement, as practices need only identify areas where feedback is necessary, recruit family members by fliers or physician/staff recommendation, and then host a meeting.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

As a benefit of its large practice size, The Children’s Clinic provides families extended clinic hours and 24-hour on-call access to physicians.

CARE MANAGEMENT

The implementation of **standardized developmental screening** in the clinic has significantly enhanced the process of developmental surveillance. The use of parent-completed developmental screening tools helps the provider focus conversations about development on individual strengths, family strategies for stimulating development, and individual concerns related to developmental trajectories.

Providers at The Children’s Clinic participated in a free, statewide training program on developmental screening that introduced a panel of community-based services including Early Intervention/Early Childhood Special

Education, the Childcare Resource and Referral Network, community mental health agencies, and **home visiting** nurse programs. Therefore, since the fall of 2008, the clinic has been diligently administering the ASQ and the Modified Checklist for Autism in Toddlers. The screening costs are covered by billing appropriately for developmental screening. Additionally, the clinic developed and implemented a **common referral/release form** for early intervention referrals that permits direct communication between clinic providers and early intervention providers.

In conjunction with the integration of the Edinburgh Postpartum Depression Screener into standard practice, a training program was held at the clinic in cooperation with 2 community agencies, Baby Blues Connections and Postpartum Support International, providing care for mothers with postpartum depression. Depending on the situation, once screened, at-risk moms are either referred to one of the community organizations specializing in supporting moms with postpartum depression or their permission is requested for the clinic to contact the mother's obstetrician-gynecologist to assist with treatment or referrals. Additionally, providers familiarize themselves with other community resources available to families for referrals, including respite programs, child care, and nurseries.

The practice routinely administers a set of 2 **adolescent questionnaires** developed by the Oregon Medical Association that identify risk and protective factors for adolescents. One of the questionnaires is completed by the parent, and the other questionnaire is completed by the teenager. This screening system allows for confidential communication between the teenager and the provider in identifying risky behaviors.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

The clinic is a member of the **Children's Health Alliance (CHA)**, an organization comprised of 20 practices and 125 pediatricians with a major focus on quality improvement. Through the CHA, the practice has worked on developmental screening, immunizations, and asthma initiatives and is beginning to work on care coordination. The CHA also serves as an avenue to provide feedback to health plans regarding the quality measures used in provider quality report cards.

The Children's Clinic participates in a **MHLC** led by the Oregon Pediatric Improvement Partnership and funded by the Oregon Health Authority. This learning collaborative is working specifically on achieving medical home attributes in 8 pediatric and family medicine practices with a specific focus on improving services for children.

The Oregon Pediatric Society (OPS) and the **Oregon Pediatric Improvement Partnership** keep the clinic engaged in prac-

tice-based quality improvement. The clinic's developmental screening initiative was co-sponsored by the OPS and CHA. Through the OPS, the clinic has received training for maternal depression screening and is currently collaborating on mental health screening and treatment. One of the clinic providers serves on the OPS Mental Health Taskforce, which is in the process of developing a consultation line through which primary care providers can access psychiatrists for immediate consultations.

COMMUNICATION WITH PATIENTS & FAMILIES

As part of the practice's 100th birthday celebration, The Children's Clinic has undergone a rebranding and website redesign for which the clinic sought parent input by holding an ad-hoc parent advisory session. A **patient portal** with secure e-mail to directly contact providers and the ability for families to request an appointment will soon be available through the website.

"I think that patient- and family-centered care is about kind of shifting that agenda to what the parents need. And it's about empowering parents to get the information that they need and get their information needs met... We've implemented developmental screening and maternal depression questionnaires, and we have done some adolescent questionnaires as well, and all of those I think really help parents and patients sort of line-up their thoughts, and figure out what they have questions about; and so it's sort of a first step, an entry-level way of starting to turn some of that agenda over to the parents, particularly with the developmental questionnaires."

—practice

One of the most recent tools used by the practice to increase communication with families is the Plan Your Child's Well-Visit electronic **pre-visit questionnaire**. Adapted from various well-visit checklists, the Plan Your Child's

Well-Visit questionnaire incorporates developmentally appropriate screening questions as well as anticipated subjects typically brought up during a well visit. These customized online questionnaires are automatically generated based on the patient's age, and age-specific versions are currently available for children up to 5 years old.

CULTURAL DIVERSITY & SENSITIVITY

Because 25% to 30% of the clinic's families are Spanish-speaking, there is a full-time Spanish **interpreter** on staff at both clinic locations. For other languages, when the appointment is made in advance, an interpreter from a local company is brought in to assist. However, if the appoint-

"My oldest is 12 and mortified at the thought of a male physician looking at her body. The doctor recommended transferring care to one of his partners in the office [who is female] so my daughter is a little bit more comfortable."

—family member

ment is made last-minute for a sick child, without enough time to get an in-person interpreter, then a telephone translation service is utilized. The developmental screening questionnaires are available to families in Spanish.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The clinic utilizes **parent advisory group** sessions on an ad-hoc basis in the early planning or implementation stage of new processes or initiatives. A meeting is then held during which parents are asked their opinions as to whether they consider the change or initiative to be beneficial to their children and whether they have any concerns or suggestions pertaining to implementation.

The Children's Clinic has worked closely with the Portland-based Child and Adolescent Health Measurement Initiative. In 2009, the clinic piloted the online version of the Promoting Healthy Development Survey, which is a **parent survey** that goes beyond typical patient satisfaction surveys

"We hadn't ever really talked to parents about whether we were serving their needs. We sort of assumed we knew what their needs were, and so it was important to again make that shift and sort of say well we think we're providing what the parents need, but let's actually ask them."

—practice

into assessing the quality of care given during well-child examinations. In the clinic's initial online survey results, almost half of the parent respondents expressed unmet needs after their child's well visit, and 36% of those unmet needs were related to development and behavior. This finding informed the clinic's quality improvement initiative to implement standardized developmental screening followed by the implementation of **routine maternal and postpartum depression screening**.

The clinic was enlisted as one of 3 practices in a MCHB-sponsored study to pilot the online version of the Child and Adolescent Health Measurement Initiative's **Plan Your Child's Well-Visit tool**, which incorporates the **AAP Bright Futures guidelines**, the **ASQ developmental screening tool**, a maternal depression screener, and a family risk questionnaire into a single web-based module for parents to complete before the well-child appointment. The parents' responses to the screening tools and questionnaires are uploaded to the EMR. A list of corresponding community resources is generated for any issues flagged by the depression screener or family risk questions, and a list of the family's top priority questions and concerns is generated to guide the provider in refocusing the well-child visit to target the family's needs. The online module takes 15 to 20 minutes for parents to complete, assuming that the family utilizes little or none of the self-education functions of the module. However, the family is granted continued access to the self-education portions of the module even after the appointment.

PRACTICE QUALITY IMPROVEMENT

The Children's Clinic has noted a variety of **outcomes data** in support of its medical home initiatives. For one, 89% of families have experienced increased value in well-child visits. Since the implementation of standardized developmental screening, providers have noticed families are relieved that the practice is more efficient and proactive about childhood screenings, particularly with regards to autism, which was discovered to be a frequent parental concern.

WESTWOOD-MANSFIELD PEDIATRIC ASSOCIATES, PC

Practice address:	541 High St Westwood, MA http://www.wmpeds.com
Geographic location:	Suburban
Type of practice:	General pediatrics
Organizational structure:	2 office locations; private practice affiliated with the Pediatric Physicians' Organization at Children's Hospital
Size of practice:	8 full-time pediatricians 8 full-time nurse practitioners 1 education coordinator 1 medical care coordinator 1 registered nurse/lactation consultant
Number of patients:	11,000
Patient insurance:	94% commercial/private insurance 6% Medicaid
Medical home recognition:	None
Patient/family experience questionnaire:	- Massachusetts Health Quality Partners Survey administered annually - Patient satisfaction surveys administered throughout the year
EMR system:	Yes
Other information technology:	Yes, patient portal, e-newsletters, e-alerts through Constant Contact listserv, and YouTube educational videos for parents
Funding source(s):	Primarily funded through the practice's operating funds

Abbreviation: EMR, electronic medical record.

PRACTICE OVERVIEW:

As stated by the practice slogan, "Proactive in your child's care...Empowering families for over fifty years," Westwood-Mansfield Pediatric Associates (WMPA) accomplishes patient- and family-centeredness by emphasizing its role in educating families. The practice uses a variety of techniques to educate and empower families to handle acute, non-urgent conditions without making extra visits to the office. The practice is particularly committed to caring for patients with chronic diseases, offering patients and families care plans and follow-up guidelines to manage chronic conditions and avoid costly emergency department visits.

LESSONS LEARNED:

- Do not fear failure when trying new initiatives. If the initiative does not work, do not give up right away. Listen to parents for new innovations.
- Focus on the strengths of the child and the family and always start with the positives.
- Listen to the patient and the family, and engage the parents on a peer-level by not just telling them the diagnosis, but going through the process by which you arrived at that diagnosis.
- Avoid a paternalistic assumption that parents are incapable of managing some of their child's health care themselves. Instead, educate and empower parents with the proper knowledge and tools to appropriately engage in the health care of their child.

- Use technology to improve care. Create YouTube videos, develop a homepage, or recruit someone to help develop these resources.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

The practice has **extended access**, and thus is open 7 days per week and provides extended evening hours Monday through Thursday, as a convenience to its patients and families. Both locations comply with the **Americans with Disabilities Act** architectural guidelines, providing ramps, elevators, handicap parking, and wheelchair-accessible restrooms.

CARE MANAGEMENT

The practice places unique importance on the education of patients and families to care for acute, non-emergent illnesses outside of the office. This approach allows families to avoid the expense of unnecessary office and emergency department visits. To educate and empower parents to play a greater role in their child's health care, the practice provides the following **innovative tools for families**:

- (1) rapid *Streptococcus* test home kits to help families avoid a copayment for an office visit that would result in a negative test result;
- (2) forty educational YouTube videos linked to the practice website to provide 24-hour-a-day/7 day-a-week access to advice on topics such as rashes, concussions, newborn

care, Lyme disease, toddler behavior, toilet training, poison ivy, warts, and the prevention of emergency department visits;

(3) a fever manual and quick-reference card provided to families at 6-month and 18-month well child visits to help determine when an elevated temperature warrants increased concern;

(4) a color-coded sticker system (green, yellow, or red) for asthma medications, which corresponds to the colored zones on the asthma management plan, to assist extended family members or friends in administering appropriate medication to children with asthma who require chronic and/or episodic care;

(5) oral steroids and instructions given to parents at the 9-month and 18-month well-child visits for use in case of a croup attack;

(6) asthma management plans, prednisone, holding chambers, and peak flow meters given to families of children with asthma to prepare for an exacerbation of the condition (nurses review the proper use of these items at every asthma visit); and

(7) standardized forms with severity classification (based on the chronic disease model and a zone system) and a written management/follow-up plan provided to families of children who have certain chronic diseases to help them better manage their child's medical condition.

The **YouTube educational videos** have helped reduce after-hours calls by 13% to 18%, while the introduction of the rapid *Streptococcus* test home kits resulted in a 20% reduction in office visits for sore throats and high satisfaction rates from parents. When compared to other practices within its network, WMPA has seen a significant reduction in emergency department visits for croup among children ages 9 months to 3 years.

The practice has emphasized its commitment to the provision of comprehensive care for both acute and chronic conditions by broadening its array of onsite

"If you have something done, they follow up with you and give you results. They'll call you back and let you know how things came [out]."

—family member

services to include: onsite processing of laboratory tests, such as cholesterol, lead, and allergy testing; Dermabond repair of small lacerations; and the implementation

of developmental and emotional assessment tools to screen for autism, ADHD, anxiety, and depression.

Approximately 300 children with special health care needs, referred to as **SKIP (Special Kids in our Practice)** children, are given additional time during check-up appointments. Children with chronic issues such as asthma, ADHD, and obesity are also given additional time during check-up appointments, and the active management of their

treatment and follow-up care is facilitated through the effective utilization of the EMR system reminder and tracking functions.

The practice uses **care coordinators** to facilitate access to care for patients outside of the office. All referrals are computerized, and the specific question the clinician wants answered by the specialist is placed in a "Reason for referral" field. A **referral coordinator** assists families in scheduling appointments and navigating the network of Boston Children's Hospital affiliated clinics and providers.

In addition to a referral coordinator, WMPA employs an **education care coordinator**, with a master's degree in special education, who assists families in the management of school activities and the creation of Individual Education Programs for children requiring special education. With the help of the local fire department chief, the education care coordinator recently approached city management in the surrounding towns to encourage the linkage of the practice's standardized medical histories for its patients with special health care needs to the child's address in each town's database to alert first responders of that child's medical/emotional status.

The practice employs nurse practitioners who are trained **lactation specialists** to support and encourage breastfeeding. Both telephone and office lactation appointments are available, and the practice offers a service that provides same-day rental of hospital-grade breast pumps for families who need them.

The practice recognizes the importance of **community-based services** and routinely links families to organizations such as: the Westwood Family Autism Center; Little Hearts, a group for moms of kids with complex cardiac disease; special needs schools, many of which have been visited by WMPA providers and staff; and the Lurie Center for Autism through Massachusetts General Hospital, a multidisciplinary program to evaluate and treat children, adolescents, and adults with conditions including autism and autism spectrum disorders, Asperger syndrome, and developmental delays.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

The practice has made the plethora of patient- and family-centered tools it has developed available to other pediatric practices with limited financial resources to devote to patient- and family-centered initiatives. Providers and staff have participated in **community engagement**, most recently working with parent partners, teachers, and school nurses to develop a kindergarten through 12th grade curriculum on Lyme disease prevention to be used in local schools annually. Practice providers have spoken on the practice's patient- and family-centered care initiatives

at Tufts Health Care Institute and a national meeting of Aligning Forces for Quality. The practice's efforts have even been profiled on the local public radio station, WBUR.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

The practice routinely encourages **family-to-family and peer support**. The practice hosts **educational forums** in collaboration with experts from Boston Children's Hospital, Boston University, and local agencies to allow parents not only the opportunity to learn more about issues such as congenital heart disease, neurodevelopment, concussions, or kids in the digital age of communication and social-networking, but also to allow families to network and connect with one another.

COMMUNICATION WITH PATIENTS & FAMILIES

The practice believes in actively educating families and empowering them in their ability to self-manage certain illnesses. Interventions found to be helpful include improving live telephone access to nurses and creating standardized **care plans** that incorporate severity classifications

*"They've created this little informational piece, so if you're not a frequent patient they can look to see a picture of you, who you are, what your likes and dislikes are."
-family member*

so that parents can better assess the progression of an illness and react accordingly.

The practice also recommends a technique it calls **peer-level listening** when interacting with patients and families to promote shared decision-making and augment the perception of families and patients as central to effective care coordination. To further facilitate parent participation in the child's care, parents are given **Patient Dashboard** worksheets, a comprehensive, single-page history of the child, to complete at the beginning of each office visit. The Patient Dashboards are presently being used to develop care plans.

Ongoing **family education** is also accomplished through:

- (1) the practice's 40 YouTube **videos** that explain the etiology and treatment for acute conditions such as fever, croup, or musculoskeletal sprains;
- (2) the **SKIP (Special Kids in our Practice)** newsletter, which gives parents the opportunity to write articles and engage with other parents of kids with similar medical conditions;
- (3) **Constant Contact** software, which allows the practice to disseminate e-newsletters and e-news alerts containing timely and pertinent information through an e-mail listserv of families who opt to receive these announcements; and
- (4) a secure **web portal** that allows youth and families to e-mail questions to the office, request appointments and prescription refills, and conveniently access the patient's medical record at any time.

To address the issue of transitioning to adult primary care, specifically for youth with special health care needs, the practice developed a **transition educational packet**, and one of the parent partners on the medical home team who has transitioned her own child with special needs to adult care is available to speak with other families and share her expertise.

CULTURAL DIVERSITY & SENSITIVITY

Though it is a suburban practice, WMPA is well-recognized among local ethnic communities, and its minority population continues to grow. The practice serves families from eastern and southern Asia, African-Americans, Haitians, Arabic-speaking families, and orthodox Jews. During morning **staff huddles**, providers and staff frequently discuss the cultural issues and traditions of the day's patients and the potential impact of these issues on the delivery of care. In an effort to further accommodate the needs of multicultural families who travel abroad, most frequently to India, Lebanon, and Central America, the practice is establishing a **mini travel clinic**.

The practice has 24-hour-a-day/7-day-a-week access to **interpreter services** via telephone through AT&T.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The practice incorporates **parent partners** into its organizational structure. **Medical home team meetings** are held monthly and attended by the 5 parent partners. The input of this group of parents with differing opinions and perspectives allows the practice to remain aware of and responsive to the needs of parents. The parent partners receive a \$25 stipend for their participation in each meeting to defray the cost of child care and transportation, as well as to compensate them for their time. These stipends are funded by the practice.

As a result of the parent partners' participation in the medical home team meetings, a **Parent To-Do List** was developed and instituted. The Parent To-Do List is a tool given to every parent at the beginning of their child's appointment to help them keep track of any instructions or decisions made throughout a visit.

Additionally, WMPA is continually engaged in gathering feedback through **patient and family surveys**, such as the Massachusetts Health Quality Partners Patient Experience Survey administered annually state-wide with results reported in Quality Insights: Patient Experiences in Primary Care, as well as homegrown Survey Monkeybased patient satisfaction surveys administered in conjunction with the implementation of specific practice initiatives to assess how the initiatives have impacted families' experiences and satisfaction with the practice. Results of these surveys are reviewed and discussed at medical home team meetings.

PRACTICE QUALITY IMPROVEMENT

With its stated goal to be proactive in the care of children, WMPA set out to improve its patient experience, particu-

“We believe in a culture of continuous improvement, and all the staff and providers are aware that change is imperative to improving quality.”
—practice

larly in the areas of health promotion and access. The practice sees the education and empowerment of parents as not only an approach for improving health care, but also as a

critical piece of the access issue. To this end, the practice was deliberate in examining its Massachusetts Health Quality Partners Survey results from the perspective of which improvements would bring the most value to its patient families. Monthly **provider meetings** are held to discuss improvements and practice procedures, thus insuring standardized care in both locations. Additionally, during this meeting, lectures are offered by local child specialists on topics such as dental hygiene, constipation, food allergies, psychiatry, and learning disabilities.

WISHARD PRIMARY CARE PEDIATRICS

Practice address:	1002 Wishard Blvd Indianapolis, IN http://www.wishard.edu
Geographic location:	Urban
Type of practice:	General pediatrics
Organizational structure:	Health center affiliated with the Marion County Health System; serves as a teaching practice that hosts residents and medical students
Size of practice:	10-12 full-time pediatricians 3 behavioral health specialists 1 social worker 1 dietician
Number of patients:	18,000
Patient insurance:	6% commercial/private insurance 9% Medicaid 72% commercial Medicaid 7% other publically funded coverage 6% self-pay
Medical home recognition:	- NCQA Physician Practice Connections PCMH recognition program application recently submitted - Member of the MHLC through the Indiana Community Integrated Systems of Services Project
Patient/family experience questionnaire:	Visit-Specific Satisfaction Questionnaire—rolling, random telephone interviews conducted by the health system with families immediately following a scheduled appointment
EMR system:	Yes
Other information technology:	- Child Health Improvement Through Computer Automation System—A computer-based decision support system that uses age-specific pediatric preventive care guidelines to generate custom-tailored questionnaires for families to complete in the waiting room before a well-child visit. Responses regarding safety, risk factors, health protective factors, and child development are scanned and integrated into the EMR. - MyWishard powered by Relay Health—A secure patient portal system that gives families e-mail capability to request appointments, laboratory results, and prescription refills and also ask questions of nurses and send messages to their child’s physician.
Funding source(s):	As 1 of 18 practices in the MHLC made possible by the Indiana Community Integrated Systems of Services Project and funded through a grant to the Indiana State Department of Health from the federal MCHB, the practice receives grant funding to provide infrastructure support during the transformation period and for ancillary uses, such as reimbursing families that serve on the quality improvement team.

Abbreviations: EMR, electronic medical record; MCHB, Maternal and Child Health Bureau; MHLC, medical home learning collaborative; NCQA, National Committee for Quality Assurance; PCMH, patient-centered medical home.

PRACTICE OVERVIEW:

Located on the Indiana University–Purdue University at Indianapolis campus, Wishard Primary Care Pediatrics draws strength from its academic focus. In addition to tools like family advisors, informative brochures, and

referral coordinators, it is the culture of learning that guides the practice to, “...celebrate the fact that families have expertise that [the practice] may not, and to look to them for that expertise.”

LESSONS LEARNED:

- The most important facilitator of patient- and family-centeredness has been an overarching attitude and desire throughout the practice to promote collaboration with families.
- Instead of approaching practice improvement with an adversarial outlook and viewing feedback as criticism, providers and staff depend on families for honest, formative feedback.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

The practice has established a **pre-visit planning tool** that flags complex patients, thus alerting staff that these patients may need to be seen by multidisciplinary team members and prompting them to investigate and complete, if necessary, any pre-visit tasks, such as obtaining records from recent hospital or specialist visits or preparing immunization records by using the statewide registry.

CARE MANAGEMENT

As part of the county health system, the practice has a number of **multidisciplinary services** available to families, including co-located mental health services, a dietician, an asthma coordinator, a social worker, a referral coordinator, and full-time, onsite interpreters.

The Child Health Improvement Through Computer Automation System, a computer-based **decision support system** that uses pediatric preventive care guidelines to generate custom-tailored, scannable questionnaires for families to complete in the waiting room before a well-child visit, was adopted about 7 years ago. It allows the practice to generate questionnaires regarding safety, risk factors, health protective factors, and child development that are custom-tailored and age-specific for each patient. The parents' responses are scanned and integrated into the EMR. There is also a registry function built into the system, which allows for queries on specific questionnaire items.

MyWishard powered by Relay Health, a secure **patient portal** system which gives families e-mail capability to request appointments, laboratory results, and prescription refills and also ask questions of nurses and send messages to their child's physician, was launched by the practice's health system about 6 months ago.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

Wishard Primary Care Pediatrics is 1 of 18 practices in the MHLC of the Indiana Community Integrated Systems of Services Project. The grant money provides infrastructural support to participating practices during transformation

and is tapped for ancillary uses like reimbursing families that serve on the quality improvement team. Regular meetings and conference calls among MHLC members serve as a forum for sharing examples of patient- and family-centered interventions and learning from the successes and challenges of other practices. Wishard Primary Care Pediatrics providers are engaged in the leadership of the Indiana chapter of the AAP, through which they maintain a close relationship with Indiana's Title V Maternal and Child Health Program.

Envisioning a more integrated practice-family partnership, the MHLC created the Jumpstart Project with the goal of increasing **family involvement** in the MHLC. Participation in a kick-off conference with several other states working on similar patient- and family-centered projects helped to increase family partner participation. The project prompted the development of instructional material, such as an advisory member identification checklist that helps practices select candidates to serve as family partners. The pediatric practice is part of the Wishard Medical Home Workgroup, charged with making systems changes in the clinic to enhance its application for NCQA's Physician Practice Connections PCMH recognition.

COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES

Efforts to engage families in the practice were not always successful. The practice attempted to organize ADHD family education sessions held at static times during the work week and found them to be poorly attended. These sessions have since been transformed into **group visits**, and the practice has achieved success by bundling the group education with additional services such as physician consultations, medication refills, or immunizations.

COMMUNICATION WITH PATIENTS & FAMILIES

The clinic provides **tools for families** like a developmental calendar with milestones for young children and a Wellness Passport containing immunization records, both of which are available in Spanish. In addition, the clinic provides brochures for state programs that can aid families with health care financing and contact information for community resources such as the directors of special education programs.

The **Guide for families to your Medical Home** brochure, developed as a result of a family partner's feedback, introduces families to the services available, including after-hours contact information, community resource contacts, and an explanation of how to retrieve laboratory results, and generally describes what the Wishard medical home can do for patients and their families.

CULTURAL DIVERSITY & SENSITIVITY

Wishard Primary Care Pediatrics serves a diverse community, including a large number of Spanish-speaking families and French-speaking African families. As part of the county health system, the clinic has funding to support full-time, onsite **interpreters** for Spanish-speaking families and telephone-based interpretive services for other languages, as well as a video and audio interpreter system called Marti. Many of the clinic nurses are proficient in Spanish and triage patients, which comforts families and facilitates smooth clinic flow. Additionally, Wishard Primary Care Pediatrics provides Spanish versions of tools, such as a developmental calendar with milestones for young children and a Wellness Passport containing immunization records.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

With the Indiana MHLC's Jumpstart Project providing a model for action, Wishard Primary Care Pediatrics created

a **quality improvement team**, which includes a college-aged sibling of a practice patient who has complex medical needs. At one of the first meetings, that family member shared the need for clarity with regard to exactly what services are available to patients and whom to contact. In response to this feedback, the practice created a brochure entitled Guide for families to your Medical Home to introduce families to the services available as part of Wishard Primary Care Pediatrics' medical home.

PRACTICE QUALITY IMPROVEMENT

In biweekly **communication meetings**, providers and staff are encouraged to voice ideas for quality improvement. Once a month, the clinic holds a "stop-light report," in which at least 2 family members are asked what they believe the clinic is doing well, what could be improved, if they have any suggestions, and if there is any clinician or staff member that they believe is doing something particularly well.

YOUNG CHILDREN'S HEALTH CENTER

Practice address:	306-A San Pablo SE Albuquerque, NM
Geographic location:	Large city/urban
Type of practice:	General pediatrics for 30 years, but added multiple specialties in August 2011
Organizational structure:	Affiliated with the University of New Mexico; self-supported through city and state contracts and grants
Size of practice:	6 part-time pediatricians 1 part-time child psychologist 2 part-time nurse practitioners 1 pediatric pulmonologist 1 pediatric cardiologist 1 pediatric dermatologist 1 pediatric gastroenterology physician assistant 2 licensed social workers 1 counselor 2 case managers 1 care coordinator
Number of patients:	5,000
Patient insurance:	5%-7% commercial/private insurance 80%-85% Medicaid 10% uninsured/underserved
Medical home recognition:	- Centers for Medicare and Medicaid Services Tier I Medical Home; currently working toward achieving Tier II certification - Healthy Tomorrows grant recipient to support medical home initiatives - Calvin CJ Sia Community Pediatrics Medical Home Leadership and Advocacy Award
Patient/family experience questionnaire:	- Press Ganey patient satisfaction survey administered monthly - Staff satisfaction survey administered annually
EMR system:	Yes
Other information technology:	No
Funding source(s):	The YCHC is affiliated with University of New Mexico School of Medicine; however, it is mostly self-sufficient. It receives funding from 4-6 different sources that allow it to provide more comprehensive services than would otherwise be available. The YCHC has received competitive grants for a home visitation program, as well as gang prevention and gang intervention programs. For over 20 years YCHC has received direct funding from the state legislature, and it also receives direct funding from the city of Albuquerque.

Abbreviations: EMR, electronic medical record; YCHC, Young Children's Health Center.

PRACTICE OVERVIEW:

Since opening its doors to the Albuquerque community 30 years ago, Young Children's Health Center (YCHC) has had a patient- and family-centered philosophy as its core principle, guiding how this community-based clinic operates. This commitment to patient- and family-centeredness is explicitly cited in its mission statement. If there is ever a question regarding policy or procedures, the solution is rooted in the principles outlined in the mission statement, and thus always based on what will most benefit families. For YCHC, providing patient- and family-centered care has not been an initiative born from a singular conversation, but rather a consistent effort.

The YCHC has found that, especially in the service of a patient base living in the 2 neighborhoods surrounding the clinic with high rates of exposure to violence and poverty, providing patient- and family-centered care has been

heavily reliant on care managers, social workers, and behavioral health providers whose aggregate number are equal to the number of physician providers at YCHC.

The YCHC has found it difficult at times to reconcile competing interests. For example, in its pursuits to educate and incorporate providers-in-training into patient care, there have been occasions when families have expressed a preference for their children to be seen by a faculty member or attending clinician. In these situations, the clinic has collectively made the decision to recognize a family's preference.

LESSONS LEARNED:

- Patient- and family-centeredness has to be a priority to have successful implementation of change.
- Patient- and family-centered care needs to be deliberate and consistent, maintained through written policy, and anchored by champions within the practice.

STRATEGIES OR TOOLS UTILIZED TARGETING:

ACCESS

The YCHC is located in Albuquerque's inner-city and serves a population who lives and works in the neighborhoods surrounding the clinic. A patient survey determined that 50% of families seen in the clinic walk from home. The clinic is located along a bus route. In addition, YCHC has increased access to care by offering home visitation for new parents.

To facilitate continuity and support the clinic-family relationship, appointments are still scheduled by in-office staff, although the university health system has a centralized scheduling department. This allows families to interact with staff familiar with a family's particular needs.

*"They will be offering one hour of visits in the morning for emergencies that are not urgent. . .so we don't have to go to the hospital. I think that's a good idea."
-family member*

Scheduling practices at the office have been influenced by parent feedback; the clinic has tried several appointment systems including same day appointments, and now patients are able to be seen within 1-

3 days. During the winter months the number of well-child visits scheduled is reduced to accommodate increases in acute visits.

Stemming from parent requests and provider concerns regarding the impact of the closing of a nearby hospital on the community, YCHC successfully lobbied city officials, the local health department, and other community providers and health systems to gather the resources to offer extended weeknight and Saturday hours. Through this expansion, YCHC experienced a 25% increase in case volume.

In August 2011, the YCHC completed an **expansion and remodel** that allows the clinic to use additional space in the building that had been occupied by a family practice group. In addition to providing the opportunity to make patient- and family-centered structural additions, like a designated room for breastfeeding mothers, the expansion allows YCHC to bring in pediatric specialty providers whose services, including pediatric cardiology, pulmonology, and dermatology, have been previously unavailable in the community.

A part-time child **psychiatrist** works onsite to aid in integrating behavioral health and primary care in the office. The YCHC has contracts with the city and state to address gang prevention and intervention with middle and high school youth.

CARE MANAGEMENT

Having an EMR linked with the entire University of New Mexico Health System, including hospitals and specialists, helps facilitate continuity of care across different providers. The YCHC offers an extensive list of **care coordination services** and resources to support families struggling with poverty. The clinic employs care managers, counselors, and **behavioral health service providers** in equal number to the clinical staff. In 2009, the practice received a state grant allowing for the implementation of an onsite care management initiative. Patients referred by a clinician for behavioral health services or care management can be seen onsite the same day. The YCHC conducts routine developmental screenings and has developed relationships with early intervention programs to provide services to families as needed. Clinicians promote a **strength-based approach** to care, rather than focusing on a child's disabilities. One of the clinic social workers directs a **home visitation program** that follows infants for up to 3 years, uses a strength-based curriculum, and provides case management services for the family. The clinic assists families by offering **support groups**, such as Mas Mamas to help educate mothers and connect them to community resources and adolescent programs that include education and support. The YCHC utilizes Parents Reaching Out, a community resource, free to patients, that provides advocacy for parents who have critically ill children admitted to the neonatal or pediatric intensive care units.

COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS

The YCHC clinicians actively participate in local- and state-level **pediatric medical home initiatives**. As a product of the clinic's affiliation with the University of New Mexico Health System, the clinic collaborated with the other clinics in the system while undergoing the Centers for Medicare and Medicaid Services Tier 1 Medical Home certification process, as all of the system's clinics were required to meet the Tier 1 standards in order for YCHC to receive this designation.

With a reputation as a patient- and family-centered clinic equipped to handle the management of complex cases, YCHC has become a magnet for CYSHCN. As these patients age, there is a need to transition them to adult services. However, for many patients, overcoming the philosophical shift from the interdependence fostered by family-centered pediatric care to the self-determination and independence encouraged by adult patient-centered care is challenging. Therefore, YCHC is collaborating with the University of New Mexico to start a **Transition Consultative Clinic** for youth with developmental disabilities. The departments of pediatrics, internal medicine, and family & community medicine have convened to collaborate and establish

transition services. The university hospital, a separate administrative entity, provided the support staff for the transition clinic, therefore constituting it a de-facto hospital-run clinic.

COMMUNICATION WITH PATIENTS & FAMILIES

To provide access to community resources and to digital-based information, YCHC requested and received funds from the McCune Charitable Foundation to establish a **family education center**. Three computers are set up in the lobby of the clinic to assist families in accessing internet-based information. University of New Mexico undergraduate students, funded by a grant through the federal work-study program, offer computer assistance to families as needed. The clinic also plans to utilize these computers for adolescents and parents to respond to surveys, screening questionnaires, and self-assessment tools.

The YCHC holds teenager **group sessions** to address common adolescent interests and concerns. The sessions are run by nurses and a pediatrician who serves as the group facilitator.

In a collaborative partnership with Peanut Butter & Jelly Family Services Therapeutic Preschool, YCHC offers medical home services to all children, birth to age 5 years, who regularly attend class with their parents. Sessions focus on hands-on parenting, child development, and behavioral issues. The YCHC has also offered educational opportunities for preschool staff on health care-related topics. This venture was funded for 3 years by a Kellogg Foundation grant to the South Valley Healthy Communities Collaborative.

CULTURAL DIVERSITY & SENSITIVITY

Given Albuquerque's large Hispanic/Latino population, YCHC decided more than a decade ago to hire **bilingual personnel** to better connect with patients. This policy extends to all 32 clinic employees, including reception staff, nurses, and physicians. Through the university hospital, YCHC has access to Spanish, Navaho, and Vietnamese interpretive services. Families requiring other languages can be accommodated through telephone interpreter services.

Clinicians routinely acknowledge a family's preference to use holistic care methods and attempt to safely integrate their use into the plan for a child's health care. To facilitate this goal, the clinic has sponsored local curanderos (traditional healers) with whom the clinic has built trusted, cooperative relationships.

GATHERING FEEDBACK FROM PATIENTS & FAMILIES

The YCHC has conducted monthly Press Ganey **patient satisfaction surveys** for the past 10 years and utilizes a

*"I belong to a parent counseling group. They have a meeting once a month and ask us how they can improve or what we need."
-family member*

*"If [family-centeredness] is not part of the mission statement at least—the practice needs to be aware of what are the values of the practice? And it does help to have a core of people, hopefully in the leadership, that believe that... because I think it anchors you in what you build on."
-practice*

family advisory committee to ensure that the needs of families are being met and to allow families to guide clinic operations. Committee members are parents of CYSHCN, parents of younger children, and parents of frequent health care users who are invited to participate in a non-paid position. Through the advisory committee, it was found that there were access issues for some families. In response, the clinic lobbied for city and state resources to

allow YCHC to offer expanded hours on weekday evenings and Saturdays.

Section III: Implications for Practice and Policy

KEY FINDINGS

The practices identified as exemplary medical homes in the provision of family-centered care represent a range of geographic locations, organizational structures, sizes, and patient panels (Appendix III). Of the 17 practices, 4 serve rural populations, 6 serve suburban populations, and 7 serve urban populations. Their organizational structures include community clinics or health centers, private practices, academic practices, health system-affiliated practices, and hospital-based practices. Approximately half of the practices (7 of 17 practices) predominantly serve patients with Medicaid insurance. The majority received recognition as a medical home by a national or state organization. The majority of practices also used EMRs and other supporting technology such as registries or patient portals. Only 10 of the 17 practices received support for family-centered processes and structures from external funding sources.

Practices reported specific processes and structures key to family-centered care within the pediatric medical home. General domains for these processes and structures include access, care management, collaborative learning with other practices, collaborative learning with patients and families, cultural diversity and sensitivity, mechanisms to gather feedback from patients and families, practice mission and culture, and practice quality improvement (Appendix IV). Within these domains, practices provided examples of specific features that emphasize the MCHB family-centered principles based on a partnership between families and professionals as described in the following list.

1. ACKNOWLEDGES THE FAMILY AS THE CONSTANT IN A CHILD'S LIFE.

Many of the practices (11 of 17 practices) recognize the role of families as the constant in a child's life, involve family members in the development of written care plans, and acknowledge their unique role in care of the child. For example, the practice of Hagan, Rinehart, and Connolly acknowledges the family as the constant in the child's life and promotes an individual and developmental approach in the creation of each care plan. A care coordinator organizes face-to-face collaborative meetings or "care conferences" which bring families, medical providers, educators, and other community service providers together to discuss care issues for CYSHCN. These meetings foster continuity of care and yield the shared benefits associated with creating family partnerships. The clinic believes, "when you build these teams of different people with different life experiences, you gain a lot of knowledge."

2. BUILDS ON FAMILY STRENGTHS.

All of the practices build on family strengths. Children's Medical Group-Southwest Pediatrics recognizes the strength of parents in serving as advisors to the practice and providing helpful information to other parents through a quarterly newsletter that families help to develop. In addition to informing other families about community resources and events, the newsletter includes an educational component, serial disease-specific columns, and articles written from patient or sibling perspectives. The WMPA recognizes the strength in families' abilities to self-manage illness. For example, at the 9-month and 18-month well-child visits, the practice provides oral steroids and instructions for their use in case the child experiences a croup attack. The practice also provides rapid Streptococcus test home kits for families to avoid unnecessary office visits.

3. SUPPORTS THE CHILD IN LEARNING ABOUT AND PARTICIPATING IN HIS/HER CARE AND DECISION-MAKING.

CentraCare offers patients over 12 years of age access to MyChart, a patient portal system with access to the patient's record and scheduling. The patients can also choose to grant their parents limited access to their medical records. This system allows older patients to communicate directly and confidentially with the provider and encourages youth to take a more active role in their own care, thus ultimately preparing them for the transition to adult care.

4. HONORS CULTURAL DIVERSITY AND FAMILY TRADITIONS.

While the majority of the practices (14 of 17 practices) provided access to translation or interpreter services for non-English-speaking families, several practices have implemented additional processes to honor the cultural diversity of their patients and families. For example, GCH experienced a large influx of Latino families seeking care in 2003 and responded by providing onsite beginning, intermediate, and advanced Spanish classes to providers and staff, as well as by making available to staff 12-week Spanish courses at local nonprofit agencies. As a result of the clinic's efforts, over 20 staff members in the practice, including community liaisons, front desk staff, providers, and nurses, are now conversant in medical Spanish. Also, as part of the Reach Out and Read program, which encourages families to read to children ages 0 to 5 years, the clinic offers books in English, Spanish, Cambodian, Vietnamese, Arabic, and French at each well-child visit. The staff further celebrates patient diversity by encouraging children to mark their country of birth on a large map in the practice.

5. RECOGNIZES THE IMPORTANCE OF COMMUNITY-BASED SERVICES.

Rainforest Pediatric Care routinely connects families with similar concerns or diagnoses with one another and refers family members to community support groups, such as new parent groups or a group geared specifically to fathers. The practice has also established communication lines with local daycare providers. With parental consent, the daycare provider and physician can communicate directly with one another during daytime hours, should a family member be unavailable. For families with non-emergent needs, physicians offer health coaching over the telephone. In addition, the practice regularly communicates with local school nurses and encourages them to contact the practice with concerns regarding patients, especially children with chronic health conditions.

Core Pediatrics–Exeter Pediatric Associates is also involved with educators and administrators from local elementary, junior high, and high schools, local pediatric mental health providers, and the director of the local early intervention center. The regular meetings between these community partners allow all parties to build a rapport, ultimately improving communication and collaboration between educators and health care providers and facilitating better continuity of care for children with learning and behavioral issues.

6. PROMOTES AN INDIVIDUAL AND DEVELOPMENTAL APPROACH.

Wishard Primary Care Pediatrics utilizes the Child Health Improvement Through Computer Automation system, a computer-based decision support system that uses pediatric preventive care guidelines to generate custom-tailored, scannable questionnaires for families to complete in the waiting room before a well-child visit. It allows the practice to generate questionnaires regarding topics including safety, risk factors, health protective factors, and child development that are custom-tailored and age-specific for each patient. It allows families and physicians to focus on the pediatric guidelines specifically pertaining to an individual child.

7. ENCOURAGES FAMILY-TO-FAMILY AND PEER SUPPORT.

Under the supervision of the parent consultant, Comprehensive Pediatric Care has created support groups for parents experiencing similar situations, including a Streptococcus-associated hyperactivity group and a group for new mothers. The Streptococcus-associated hyperactivity group was created with the hope that participating families will use each others' strengths to get through the day-to-day struggles in caring for a child with this illness. The group for new mothers was started in response to the many telephone calls the

practice receives from new mothers with questions about caring for their baby. In addition to being informative, these sessions introduce participating new mothers to one another and give them a forum to develop friendships with one another, potentially providing a valuable source of support during an often difficult adjustment period.

8. SUPPORTS YOUTH AS THEY TRANSITION TO ADULTHOOD.

Ten of the practices provided youth transition support for families, including information and resources, policies, practices, and systems that are family-friendly and family-centered. Young Children's Health Center sponsors teenager group sessions to address common adolescent interests and concerns. The sessions are run by nurses and a pediatrician who serves as the group facilitator.

9. DEVELOPS POLICIES, PRACTICES, AND SYSTEMS THAT ARE FAMILY-FRIENDLY AND FAMILY-CENTERED IN ALL SETTINGS.

The LINC program—in an attempt to serve the needs of the family as a whole—provides primary care for patients' healthy siblings. The goal is to prevent or minimize feelings of isolation or neglect experienced by the unaffected siblings due to the attention paid to the ill sibling and to decrease the number of clinic visits needed by a family, thereby alleviating potential stress on the family. The practice also routinely provides prolonged outpatient appointments (30-60 minutes). Home visits, palliative care, and vertically integrated care, including oversight of inpatient management for every child on every hospitalization, are provided by practice physicians when necessary.

10. CELEBRATES SUCCESSES.

Pediatric Partners' providers and staff make a point to "celebrate and brag about our newsworthy patients." Vaccinations are rewarded with a trip to the treasure chest, and children's achievements such as college acceptances, violin recitals, and scouting awards are acknowledged and celebrated through a "superstar" bulletin board.

FAMILY-PROFESSIONAL PARTNERSHIP

Family professional partnerships and family voice are key elements in a family-centered practice. As a physician in one exemplar practice states:

"We have put together a parent advisory group that has started meeting last year to kind of talk about a lot of systems issues. Are the after-hours care and access adequate? Is the phone system adequate? Are you getting what you need out of the advice nurses and so forth? Some of that came out of looking into some of the medical home definitions and knowing that we weren't involving parents in some of the aspects of care that they were utilizing the most frequently. We sort of assumed we knew what

their needs were, and so it was I think important to again make that shift and say, well, we think we're providing what the parents need, but let's actually ask them."

A physician in another exemplar practice describes the process of engaging families in this partnership:

"We meet once a month for an hour to discuss incremental improvements in care, and one thing we've always emphasized is that these are actually parent partners and not parent advisors. Parent partners are equal partners in these meetings, so their opinions are equally as valid as the doctors' or the care coordinators' opinions, so that they're really equal partners in making these changes in the practice."

Involving families in discussions about the medical home creates a family-centered atmosphere and addresses families' needs, and it has improved the quality and function of the practice. Participation in learning collaboratives—particularly state and national collaboratives to support the development of medical homes—also helped practices to develop a shared philosophy and mission and to test new strategies. Learning collaboratives also enabled some practices to financially support initial efforts in family professional partnerships. As one physician describes:

When I became part of this learning collaborative one of the things that came along with it was the ability to offer a stipend to families if we had a parent partner to pay them for their time. That's what finally pushed me over the edge so that I was able to compensate a family, a parent for their time.

Many practices quickly realize the contribution of families following the collaboratives and continue to support the family stipends from the clinic budgets. For example, GCH provides focus group participants with onsite childcare and gas vouchers or grocery store gift certificates that are paid from the clinic's general operating funds.

RESEARCH IMPLICATIONS

The case studies described in this monograph were identified through national pediatric and maternal and child health listserves and do not necessarily represent the breadth of pediatric practices across the United States. Still, they highlight a number of promising strategies and best practices in the provision of family-centered care. To understand how frequently these strategies occur in pediatric medical homes, a survey of practices could be conducted to assess the presence of these specific structures and processes across the country. However, as these practices were nominated due to their best practices in family-centered care, the domains or themes emerging from the key informant interviews may serve as a foundation for further exploration in more quantitative studies.

PRACTICE IMPLICATIONS

According to providers within the case studies, participation in learning collaboratives appears to be strongly asso-

ciated with the implementation of specific family-centered processes and structures within the medical home. Having a family-centered mission statement within the practice also appears highly associated with practice philosophy and provider and staff engagement with family professional partnerships. Finally, specific identifiable processes and structures within the domains of primary care or medical home, such as accessibility, care management, collaborative learning, and mission culture, appear associated with increased success in implementing family-centered care from both the practice and family perspective. Many of these processes and structures require little monetary investment and could be easily implemented. Several of the clinics mentioned greater efficiencies within their practice as a result of more family partnership and the participation of families in identifying processes to streamline clinic functions.

POLICY IMPLICATIONS

Dedicated funding is needed for family-centered care to be fully implemented in the medical home and health care system. Payers can provide per member per month payments to practices to engage and support family partners in practice quality initiatives. Continued support for both national and state learning collaboratives is essential. Learning collaboratives provide opportunities for both families and professional teams to work together to implement transformative activities within practices.

Family-to-Family Health Information Centers provide key resources for implementing family-centered care, such as support, information, and training around health issues. Specifically, F2F HICs provide assistance to families and professionals in navigating the health care systems, information, education, training, support, and referral services; outreach to underserved/underrepresented populations; guidance on health programs and policy; and evaluation and outcome assessment.

CONCLUSION

Medical homes can implement family-centered structures and processes to partner with families, gain efficiencies, and experience greater enjoyment and enhanced interactions with patients and families. Many of the domains related to family-centered care, such as accessibility, coordinated care, and cultural competence, are key domains of the pediatric medical home. Primary care practices functioning as medical homes can partner with both families and community resources to increase family-centeredness. Policymakers, payers, and purchasers can support medical homes in the provision of family-centered care through the funding of F2F HICs and learning collaboratives and by providing per member per month payments, other monthly stipends, or grants to support meaningful family partnership in the pediatric medical home.

Appendix I.

Desirable Characteristics of a Medical Home

ACCESSIBLE

Care is provided in the child's or youth's community.

All insurance, including Medicaid, is accepted.

Changes in insurance are accommodated.

Practice is accessible by public transportation, where available.

Families or youth are able to speak directly to the physician when needed.

The practice is physically accessible and meets Americans with Disabilities Act requirements.

FAMILY-CENTERED

The medical home physician is known to the child or youth and family.

Mutual responsibility and trust exists between the patient and family and the medical home physician.

The family is recognized as the principal caregiver and center of strength and support for child.

Clear, unbiased, and complete information and options are shared on an ongoing basis with the family.

Families, youth, and physicians share responsibility in decision making.

The family is recognized as the experts in their child's care, and youth are recognized as the experts in their own care.

COMPREHENSIVE

Care is delivered or directed by a well-trained physician who is able to manage and facilitate essentially all aspects of care.

Ambulatory and inpatient care for ongoing and acute illnesses is ensured, 24 hours a day, 7 days a week, 52 weeks a year.

Preventive care is provided that includes immunizations, growth and development assessments, appropriate screenings, health care supervision, and patient and parent counseling about health, safety, nutrition, parenting, and psychosocial issues.

Preventive, primary, and tertiary care needs are addressed.

The physician advocates for the child or youth and family in obtaining comprehensive care and shares responsibility for the care that is provided.

The needs of the child or youth, including medical, educational, developmental, and psychosocial needs, are identified and addressed.

Families of children with special health care needs receive information about private insurance and public resources including Supplemental Security Income, Medicaid, the state Children's Health Insurance Program, waivers, early intervention programs, and the Title V Maternal and Child Health Program.

Extra time for an office visit is scheduled for children with special health care needs, when indicated.

COORDINATED

A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the patient's care.

Care among multiple providers is coordinated through the medical home.

A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.

The medical home physician shares information among the child or youth, family, and consultant and provides a specific reason for referral to pediatric medical subspecialists, surgical subspecialists, and mental health/developmental professionals.

Families are linked to family support groups, parent-to-parent groups, and other family resources.

When a child or youth is referred for consultation or additional care, the medical home physician assists the child, youth, and family in communicating clinical issues.

The medical home physician evaluates and interprets the consultant's recommendations for the child or youth and, in consultation with subspecialists, implements recommendations that are indicated and appropriate.

The plan of care is coordinated with educational and other community organizations to ensure that special health needs of the individual child are addressed.

CONTINUOUS

The same primary pediatric health care professionals are available from infancy to adolescence and young adulthood.

Assistance with transitions, in the form of developmentally appropriate health assessments and counseling, is available to the child or youth and family.

The medical home physician participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider.

COMPASSIONATE

Concern for the well-being of the child or youth and family is expressed and demonstrated in verbal and nonverbal interactions.

Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth.

CULTURALLY EFFECTIVE

The family's cultural background, including beliefs, rituals, and customs, are recognized, valued, respected, and incorporated into the care plan.

All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of paraprofessional translators or interpreters, as needed.

Written materials are provided in the family's primary language.

Appendix II. Joint Principles of the Patient-Centered Medical Home

Personal physician	Each patient has an ongoing relationship with a personal physician trained to provide first contact and continuous and comprehensive care.
Physician-directed medical practice	The personal physician leads a team of individuals at the practice level who collectively take responsibility for the ongoing care of patients.
Whole-person orientation	The personal physician provides all of the patient's health care needs or takes responsibility for arranging care with other qualified professionals. Care for all stages of life (acute care, chronic care, preventive services, and end-of-life care) is provided or arranged.
Coordinated/integrated care	Care is coordinated and integrated across all elements of the health care system (eg, subspecialty care, hospitals, home health agencies, and nursing homes) and the patient's community (eg, family and public and private community-based services). Care is facilitated by registries, information technology, health information exchange, and other means to ensure that patients get the indicated care when and where they need and want it in a culturally and linguistically appropriate manner.
Quality and safety	<p>The medical home has the following hallmarks:</p> <ul style="list-style-type: none"> • Practices advocate for their patients to support the attainment of optimal, patient-centered outcomes that are defined by a care planning process driven by a compassionate, robust partnership between physicians, patients, and the patient's family. • Evidence-based medicine and clinical decision-support tools guide decision-making. • Physicians in the practice accept accountability for continuous quality improvement through voluntary engagement in performance measurement and improvement. • Patients actively participate in decision-making, and feedback is sought to ensure that patient expectations are being met. • Information technology is utilized appropriately to support optimal patient care, performance measurement, patient education, and enhanced communication. • Practices go through a voluntary recognition process by an appropriate nongovernmental entity to demonstrate that they have the capabilities to provide patient-centered services consistent with the medical home model. • Patients and families participate in quality improvement activities at the practice level.
Enhanced access	Enhanced access to care is available through systems such as open scheduling, expanded hours, and new options for communication between patients, their personal physician, and practice staff.
Payment	<p>The level of payment should reflect the added value provided to patients who have a patient-centered medical home.</p> <p>The payment structure should be based on the following framework:</p> <ul style="list-style-type: none"> • It should reflect the value of physician and non physician staff patient-centered care management that falls outside of the face-to-face visit. • It should pay for services associated with coordination of care both within a given practice and between consultants, ancillary providers, and community resources. • It should support adoption and the use of health information technology for quality improvement. • It should support provision of enhanced communication access, such as secure e-mail and telephone consultation. • It should recognize the value of physician work associated with remote monitoring of clinical data using technology. • It should allow for separate fee-for-service payments for face-to-face visits. (Payments for care management services that fall outside of the face-to-face visit, as described above, should not result in a reduction in the payments for face-to-face visits). • It should recognize case mix differences in the patient population being treated within the practice. • It should allow physicians to share in savings from reduced hospitalizations associated with physician-guided care management in the office setting. • It should provide additional payments for achieving measurable and continuous quality improvements.

Appendix III: Case Study Practice Descriptions

Practice Name	CentraCare Clinic-Women and Children Pediatrics	Child Health Clinic	Comprehensive Pediatric Care, PC	Core Pediatrics-Exeter Pediatric Associates	Guilford Child Health	Hagan, Rinehart & Connolly Pediatricians	Henry Ford Pediatrics New Center One	The LINGS Program at CHAM	North Arlington Pediatrics	Pecar Health Center	Pediatric Partners	Rain Forest Pediatric Care	Children's Medical Group- Southwest Pediatrics	The Children's Clinic, PC	Westwood-Mansfield Pediatric Associates, PC	Wishard Primary Care Pediatrics	Young Children's Health Center
Geographic location:	MN	MI	ND	NH	NC	VT	MI	NY	IL	IN	NC	AK	WI	OR	MA	IN	NM
Type of practice: (Sub=suburban)	Rural	Urban	Rural	Rural	Urban	Urban; serves rural areas	Urban	Urban	Sub	Urban	Sub	Sub	Sub	Sub	Sub	Urban	Urban
Organizational structure: (CC= community clinic; PP= private practice; AA=academic affiliation; HSA= health system affiliated; HB= hospital-based)	CC	AA	PP	HAS	CC	PP	HAS	HB	PP	CC, HSA, AA	PP	PP	PP	PP	PP	CC, HSA, AA	CC
Total patient panel:	26,000	4,000	6,000	12,000	39,000	4,000	N/A	300	12,005	3,500	2,675	N/A	13,000	50- 55,000	11,000	1,500/ FTE	5,000
Insurance ≥ 50% Medicaid?		X			X		X	X		X						X	X
Medical home recognition:	X	X	IP	X	X	X	X		X	X	X		X			X	X
EMR system:	X	X	X	X	X	X	X	X	X	X	X			X	X	X	X
Other information technology:	X	X	X	X		X	X		X	X	X		X	X		X	
Outside funding source:	X	X		X		X	X	X		X			X			X	X

Abbreviation: IP, in progress

Appendix IV: Case Study Practices' Family-Centered Processes and Structures

Strategies or Tools Utilized Targeting Areas of:	CentraCare Clinic-Women and Children Pediatrics	Child Health Clinic	Comprehensive Pediatric Care, PC	Core Pediatrics-Exeter Pediatric Associates	Guilford Child Health	Hagan, Rinehart & Connolly Pediatricians	Henry Ford Pediatrics New Center One	The LINGS Program at CHAM	North Arlington Pediatrics	Pecar Health Center	Pediatric Partners	Rain Forest Pediatric Care	Children's Medical Group- Southwest Pediatrics	The Children's Clinic, PC	Westwood-Mansfield Pediatric Associates, PC	Wishard Primary Care Pediatrics	Young Children's Health Center
ACCESS																	
Extended office hours-evenings or weekends	X		X	X			X		X	X	X	X	X	X	X	X	X
After-hours nursing line	X			X			X	IP		X	X		X	X	X	X	X
Extended on-call hours	X	X	X	X				X	X		X	X	X	X	X	X	X
Open-scheduling or equivalent	X	X		IP	X				X	X	X	X	X	X		X	X
Special accommodation for siblings of CYSHCN			X					X	X	X	X	X	IP				
CARE MANAGEMENT																	
Written care plans	X	X		X			X	X	X			X	X	X*	X	X**	
Standardized method of identifying and accommodating CYSHCN requiring pre-visit tasks and/or longer appointments	X	X	X	X	X		X	X	X	X	X	X	X	X	X		
Patient registries by diagnosis	X	X		X	X		X	X	X				X	X*	X	X	X
Designated care coordinator(s)	X	X	X	X	X		X	X	X				X	IP	X	X	X
Established workflow for identifying and completing care coordination and follow-up tasks	X	X		X	X		X	X	X				X	IP	X	X	X
Transportation coordination services	X			X	X					X		X	X	X		X	X
COLLABORATIVE LEARNING WITH OTHER PRACTICES & CLINICS																	
Participant in a medical home learning collaborative	X	X		X			X		X	X			X	X		X	X
Participation in other forums providing opportunities to share experiences and/or learn about other patient- and family-centered initiatives	X	X	X	X	X		X		X	X	X		X	X	X	X	X
COLLABORATIVE LEARNING WITH PATIENTS & FAMILIES																	
Offer support groups and/or regularly link families in similar situations		X	X				X	X	X	X		X	X		X	X	X
Host educational/informational sessions for families and/or community members	X			X	X		X	X		X	X		X		X	X	X

Appendix IV:
Case Study Practices' Family-Centered Processes and Structures, continued

Strategies or Tools Utilized Targeting Areas of:	CentraCare Clinic-Women and Children Pediatrics	Child Health Clinic	Comprehensive Pediatric Care, PC	Core Pediatrics-Exeter Pediatric Associates	Guilford Child Health	Hagan, Rinehart & Connolly Pediatricians	Henry Ford Pediatrics New Center One	The LINGS Program at CHAM	North Arlington Pediatrics	Pecar Health Center	Pediatric Partners	Rain Forest Pediatric Care	Children's Medical Group- Southwest Pediatrics	The Children's Clinic, PC	Westwood-Mansfield Pediatric Associates, PC	Wishard Primary Care Pediatrics	Young Children's Health Center
COMMUNICATION WITH PATIENTS & FAMILIES																	
Practice brochure outlining medical home services	X	X		X			X		X		X		X			X	X
Patient/family portal system	X		X	IP					IP	X	X			X	X	X	
Patient/family newsletter	X												X	X	X		X
Transition information/resources for patients/families	X	X		X			X	X	IP	X			X		X	X	X
Resource list or library	X	X		X	X		X	X		X			X	X	X	X	X
Bulletin board (with practice news, community resources, and events)	X	X		X					X	X	X		X		X		X
CULTURAL DIVERSITY & SENSITIVITY																	
Translation/interpreter services	X	X	X	X	X		X	X		X	X		X	X	X	X	X
Strategy for noting cultural, religious, or spiritual preferences of the patient and family	X	X		X	X					X	X	X	IP		X		X
Practice of incorporating flexibility into organizational policies, procedures, and provider practices to ensure services can be tailored to accommodate the needs, beliefs, and cultural values of each child/family	IP	X	X		X				X	X	X	X	X		X		X
GATHERING FEEDBACK FROM PATIENTS & FAMILIES																	
Engage parent/family partners (via parent advisory board or family partner who consults with staff/providers regularly)	X	X	IP	X	X		X	X	X	X	X		X	X	X	X	X
Patient/family experience questionnaire(s)	X	X	X	X	X		X	X	X	X	X		X	X	X	X	X

Appendix IV:
Case Study Practices' Family-Centered Processes and Structures, continued

Strategies or Tools Utilized Targeting Areas of:	CentraCare Clinic-Women and Children Pediatrics	Child Health Clinic	Comprehensive Pediatric Care, PC	Core Pediatrics-Exeter Pediatric Associates	Guilford Child Health	Hagan, Rinehart & Connolly Pediatricians	Henry Ford Pediatrics New Center One	The LINGS Program at CHAM	North Arlington Pediatrics	Pecar Health Center	Pediatric Partners	Rain Forest Pediatric Care	Children's Medical Group- Southwest Pediatrics	The Children's Clinic, PC	Westwood-Mansfield Pediatric Associates, PC	Wishard Primary Care Pediatrics	Young Children's Health Center
MISSION CULTURE																	
Job descriptions and hiring practices that underscore the expectation that staff and providers maintain a patient- and family-centered, service-oriented approach to patient care	X		X	X						X	X	X	X	X	X		X
Mission statement that embodies the principles inherent to providing patient- and family-centered care	X		X	X					X	X	X	X	X	X	X	X	X
PRACTICE QUALITY IMPROVEMENT																	
Regular meetings/forums for discussing quality improvement among providers and staff	X	X		X					X	X	X		X	X	X	X	X
Standardized method for allowing providers and staff to propose areas for focused quality improvement efforts and/or suggest potential solutions	X			X					X	X	X		X	X	X	X	X
Opportunities for providers and staff to recognize outstanding performance of coworkers	X	X		X						X			X	X	X	X	X

* = asthma patient only, ** = patients with developmental delays only

Abbreviations: CHAM, Children's Hospital at Montefiore; CYSHCN, children and youth with special health care needs; EMR, electronic medical record; FTE, full-time equivalent; IP, in progress; LINGS, Linking Individual Needs of Children with Services.

Appendix V.

References for Family-Centered Tools

CULTURAL COMPETENCY

Beach MC, Saha S, Cooper LA. *The Role and Relationship of Cultural Competence and Patient-Centeredness in Health Care Quality*. New York, NY: The Commonwealth Fund; 2006.

Silow-Carroll S, Alteras T, Stepnick L. *Patient-Centered Care for Underserved Populations: Definition and Best Practices*. Washington, DC: Economic and Social Research Institute; 2006. http://www.esresearch.org/documents_06/Overview.pdf. Accessed January 2, 2009.

Wynia M, Matiasek J. *Promising Practices for Patient-Centered Communication With Vulnerable Populations: Examples From Eight Hospitals*. New York: The Commonwealth Fund; 2006. http://www.commonwealthfund.org/publications/publications_show.htm?doc_id=397067.

COMMUNICATION

Cooley WC, McAllister JW, Sherrieb K, Khulthau K. Improved outcomes associated with medical home implementation in pediatric primary care. *Pediatrics*. 2009;124:358-364.

Coulter A, Ellins J. Effectiveness of strategies for informing, educating, and involving patients. *BMJ*. 2007;335:24-27.

Crocker L, Johnson B. *Privileged Presence: Personal Stories of Connections in Health Care*. Boulder, CO: Bull Publishing Company; 2006.

Young A, Flower L. Patients as partners, patients as problem-solvers. *Health Commun*. 2002;14(1):69-97.

Landon B, Gill J, Antonelli R, et al. Prospects for rebuilding primary care using the patient-centered medical home. *Health Aff*. 2010;29(5):827-834.

Pham H. Good neighbors: how will the patient-centered medical home relate to the rest of the health-care delivery system? *J Gen Intern Med*. 2010;25(6):630-634.

CARE COORDINATION

Klitzner TS, Rabbitt LA, Change RR. Benefits of care coordination for children with complex disease: a pilot medical home project in resident teaching clinic. *J Pediatr*. 2010;156(6):1006-1010. [http://www.jpeds.com/article/S0022-3476\(09\)01240-2/](http://www.jpeds.com/article/S0022-3476(09)01240-2/). Accessed March 19, 2010.

Antonelli RC, McAllister JW, Popp J. *Making Care Coordination a Critical Component of the Pediatric Health System: A Multidisciplinary Framework*. New York, NY: The Commonwealth Fund; 2009.

Palfrey JS, Sofis LA, Davidson EJ, Liu J, Freeman L, Ganz ML. The Pediatric Alliance for Coordinated Care: Evaluation of a medical home model. *Pediatrics*. 2004;113(5):1507-1516.

COLLABORATION

Dillon, AD. *Parent Partners: Creative Forces on Medical Home Improvement Teams*. Concord, NH: Center for Medical Home Improvement; 2003. <http://www.medicalhomeimprovement.org/pdf/CMHI-Parent-Partner-Guide.pdf> Accessed November 30, 2012.

Heisler, M. *Building Peer Support Programs to Manage Chronic Conditions: Seven Models for Success*. Oakland, CA: California HealthCare Foundation; 2006. <http://www.chcf.org/topics/chronicdisease/index.cfm?itemID=127997>.

Holman H, Lorig K. Patients as partners in managing chronic disease: partnership as a prerequisite for effective and efficient health care. *BMJ*. 2000;320(7234):526-527.

Family-Professional Partners Institute; Massachusetts Consortium for Children with Special Health Care Needs. *The Power of Partnership: Sixteen Family-Professional Partnerships That are Making a Difference for Children With Special Health Care Needs*. Boston, MA: New England SERVE; 2008. http://www.neserve.org/neserve/pub_pop.htm.

Sadof MD, Nazarian BL. Caring for children who have special health-care needs: a practical guide for the primary care practitioner. *Pediatr Rev*. 2007;28(7):e36-e42.

Shulman ST, Antonelli R, Turchi RM, eds. Medical home in pediatrics. *Pediatr Ann*. 2009;38(9, theme issue).

Hanson JL, Randall VF. *Patients as Advisors: Enhancing Medical Education Curricula*. Bethesda, MD: Uniformed Services University of the Health Sciences, Department of Medicine, Pediatrics, and Family Medicine; 2006.

Haskard KB, Williams SL, DiMatteo R, Rosenthal R, White MK, Goldstein MG. Physician and patient communication training in primary care: effects on participation and satisfaction. *Health Psychol*. 2008;27(5):513-522.

GENERAL

Conway J. Patients and families: Powerful new partners for healthcare and caregivers. *Healthcare Executive*. 2008;23(1):60-62.

Frampton SB, Charmel PA, Planetree Foundation, eds. *Putting Patients First: Designing and Practicing Patient-Centered Care*. 2nd ed. San Francisco, CA: Jossey-Bass; 2008.

Frampton S, Guastello S, Brady C, et al. *Patient-Centered Care Improvement Guide*. Derby, CT: Planetree; 2008.

References Cited

1. Sia C, Tonniges T, Osterhus E, Taba S. History of the medical home concept. *Pediatrics*. 2004;113(suppl 5): 1473-1478.
2. Starfield B. Access, primary care, and the medical home: rights of passage. *Med Care*. 2008;46(10):1015-1016.
3. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. *Milbank Q*. 2005;83(3):457-502.
4. Starfield B. *Primary Care: Balancing Health Needs, Services, and Technology*. New York, NY: Oxford University Press; 1998.
5. Rosenthal, TC. The medical home: growing evidence to support a new approach to primary care. *J Am Board Fam Med*. 2008;21(5):427-440.
6. Robert Graham Center. *The Patient Centered Medical Home: History, Seven Core Features, Evidence and Transformational Change*. Washington, DC: Center for Policy Studies in Family Medicine and Primary Care; 2007.
7. McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics*. 1998;102(1, pt 1):137-140.
8. American Academy of Pediatrics Ad Hoc Task Force on Definition of the Medical Home. The medical home. *Pediatrics*. 1992;90(5):774.
9. American Academy of Pediatrics Medical Home Initiatives for Children With Special Needs Project Advisory Committee. The medical home. *Pediatrics*. 2002;110(1, pt 1):184-186.
10. AAP publications reaffirmed and retired. *Pediatrics*. 2008;112:184-186.
11. American Academy of Family Physicians; American Academy of Pediatrics; American College of Physicians; American Osteopathic Association. *Joint Principles of the Patient-Centered Medical Home*. Patient-Centered Primary Care Collaborative, <http://www.pcpc.net/content/joint-principles-patient-centered-medical-home>, 2007
12. Fine MJ, Simpson RL, eds. *Collaboration With Parents and Families of Children and Youth With Exceptionalities*. Nerand, Australia, Pro-ed Australia, 2000
13. Committee on Children With Disabilities. Role of the pediatrician in family-centered early intervention services. *Pediatrics*. 2001;107(5): 1155-1157.
14. Wells N. Historical perspective on family-centered care. *Acad Pediatr*. 2011;11(2):100-102.
15. Brewer EJ Jr, McPherson M, Magrab P, Hutchins V. Family-centered, community-based, coordinated care for children with special health care needs. *Pediatrics*. 1989;83(6):1055-1060.
16. Bishop K, Woll J, Arango P. *Family/Professional Collaboration for Children With Special Health care Needs and their Families*. Burlington, VT: University of Vermont, Department of Social Work; 1993.
17. Bishop K, Woll J, Arango P. *Family-Centered Care Projects 1 and 2 (2002-2004)*. Algodones, New Mexico: Algodones Associates; 2004.
18. Maternal and Child Health Bureau Division of Services for Children With Special Health Needs. *Definition of Family-Centered Care*. 2005. <http://www.medicalhomeimprovement.org/pdf/MCHB-Family-Centered-Care.pdf>
19. Maternal and Child Health Bureau Division of Services for Children with Special Needs. *Principles of Family-Centered Care for Children*. 2005. <http://www.medicalhomeimprovement.org/pdf/MCHB-Family-Centered-Care.pdf>
20. *Patient- and family-centered care*. Institute for Patient and Family Centered Care, 2007. <http://www.familycenteredcare.org/pdf/CoreConcepts.pdf>.
21. American Academy of Pediatrics Committee on Hospital Care. Family-centered care and the pediatrician's role. *Pediatrics*. 2003;112(3, pt 1):691-697.
22. American Academy of Pediatrics Committee on Hospital Care and Institute for Patient- and Family-Centered Care. Patient- and family-centered care and the pediatrician's role. *Pediatrics*. 2012;129(2):394-404.
23. *Patient-Centered Care 2015: Scenarios, Vision, Goals and Next Steps*. Camden, ME: Picker Institute; 2004.
24. Institute of Medicine Committee on Quality of Health Care in America. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.
25. Johnston AM, Bullock CE, Graham JE, et al. Implementation and case-study results of potentially better practices for family-centered care: the family-centered care map. *Pediatrics*. 2006;118(suppl 2):S108-S114.
26. Muething SE, Kotagal UR, Schoettker PJ, Gonzalez del Rey J, DeWitt TG. Family-centered bedside rounds: A new approach to patient care and teaching. *Pediatrics*. 2007. 119(4):829-832.
27. Heller R, McKlinton D. Families as "faculty": parents educating caregivers about family-centered care. *Pediatric Nursing*. 1996;22(5):428-431.
28. Kuo DZ, Frick KD, Minkovitz CS. Association of family-centered care with improved anticipatory guidance delivery and reduced unmet needs in child health care. *Matern Child Health J*. 2011;15(8): 1228-1237.

29. Kuo DZ, Bird TM, Tilford JM. Associations of family-centered care with health care outcomes for children with special health care needs. *Matern Child Health J.* 2011;15(6):794-805.
30. Kuhlthau KA, Bloom S, Van Cleave J, et al. Evidence for family-centered care for children with special health care needs: a systematic review. *Acad Pediatr.* 2011; 11(2):136-143.
31. *Healthy People 2010.* Washington DC: US Dept of Health and Human Services; 2000.
32. van Dyck PC, Kogan MD, McPherson MG, Weissman GR, Newacheck PW. Prevalence and characteristics of children with special health care needs. *Arch Pediatr Adolesc Med.* 2004;158(9):884-890.
33. Guerrero AD, Chen J, Inkelas M, Rodriguez H, Ortega A. Racial and ethnic disparities in pediatric experiences of family-centered care. *Med Care.* 2010;48(4): 388-393.
34. Montes G, Halterman JS. White-black disparities in family-centered care among children with autism in the United States: evidence from the NS-CSHCN 2005-2006. *Acad Pediatr.* 2011; 11(4): 297-304.
35. Zickafoose JS, Gebremariam A, Clark S, Davis M. Medical home disparities between children with public and private insurance. *Acad Pediatr.* 2011;11(4):305-310.
36. Zickafoose JS, Gebremariam A, Davis MM. Medical home disparities for children by insurance type and state of residence. *Matern Child Health J.* 2012;16(suppl 1):178S-187S.

