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A Review of the Evidence for the Medical Home for Children With Special Health Care Needs

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ABSTRACT

CONTEXT. The receipt of health care in a medical home is increasingly touted as a fundamental basis for improved care for persons with chronic conditions, yet the evidence for this claim has not been systematically assessed.

OBJECTIVE. Our goal was to determine the evidence for the federal Maternal and Child Health Bureau recommendation that children with special health care needs receive ongoing comprehensive care within a medical home.

METHODS. We searched the nursing and medical literature, references of selected articles, and requested expert recommendations. Search terms included children with special health care needs, medical home-related interventions, and health-related outcomes. Articles that met defined criteria (eg, children with special health care needs, United States–based, quantitative) were selected. We extracted data, including design, population characteristics, sample size, intervention, and findings from each article.

RESULTS. We selected 33 articles that reported on 30 distinct studies, 10 of which were comparison-group studies. None of the studies examined the medical home in its entirety. Although tempered by weak designs, inconsistent definitions and extent of medical home attributes, and inconsistent outcome measures, the preponderance of evidence supported a positive relationship between the medical home and desired outcomes, such as better health status, timeliness of care, family centeredness, and improved family functioning.

CONCLUSIONS. The evidence provides moderate support for the hypothesis that medical homes provide improved health-related outcomes for children with special health care needs. Additional studies with comparison groups encompassing all or most of the attributes of the medical home need to be undertaken. *Pediatrics* 2008;122:e922–e937

THE MATERNAL AND Child Health Bureau (MCHB) defines children with special health care needs (CSHCN) 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.” More than 12 million US children meet this definition.¹

Research over 3 decades demonstrates that CSHCN and their families have substantial unmet health care needs, and that these needs are more similar than different across different health conditions.^{2–8} These data and the experience of families led to the formulation of a model of family-centered, community-based care for CSHCN termed “the medical home” (MH).^{9–11} The attributes of care provided through an ideal MH are “accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.”¹²

The MCHB developed an integrated set of 6 core objectives for CSHCN that form the basis for measuring the performance of state Title V programs and are reflected in the nation's Healthy People 2010 goals. These objectives specify that:

- families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive;
- children and youth with special health care needs receive coordinated ongoing comprehensive care within an MH;

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Key Words

medical home, special needs children, systematic review, family-centered care

Abbreviations

MCHB—Maternal Child Health Bureau

CSHCN—children with special health care needs

MH—medical home

FCC—family-centered care

CINAHL—Cumulative Index to Nursing

and Allied Health Literature

RCT—randomized, controlled trial

NSCSHCN—National Survey of Children

With Special Healthcare Needs

BTS—Breakthrough Series Collaborative

PCP—primary care provider

ED—emergency department

PACC—Pediatric Alliance for Coordinated Care

HMO—health maintenance organization

USC—usual source of care

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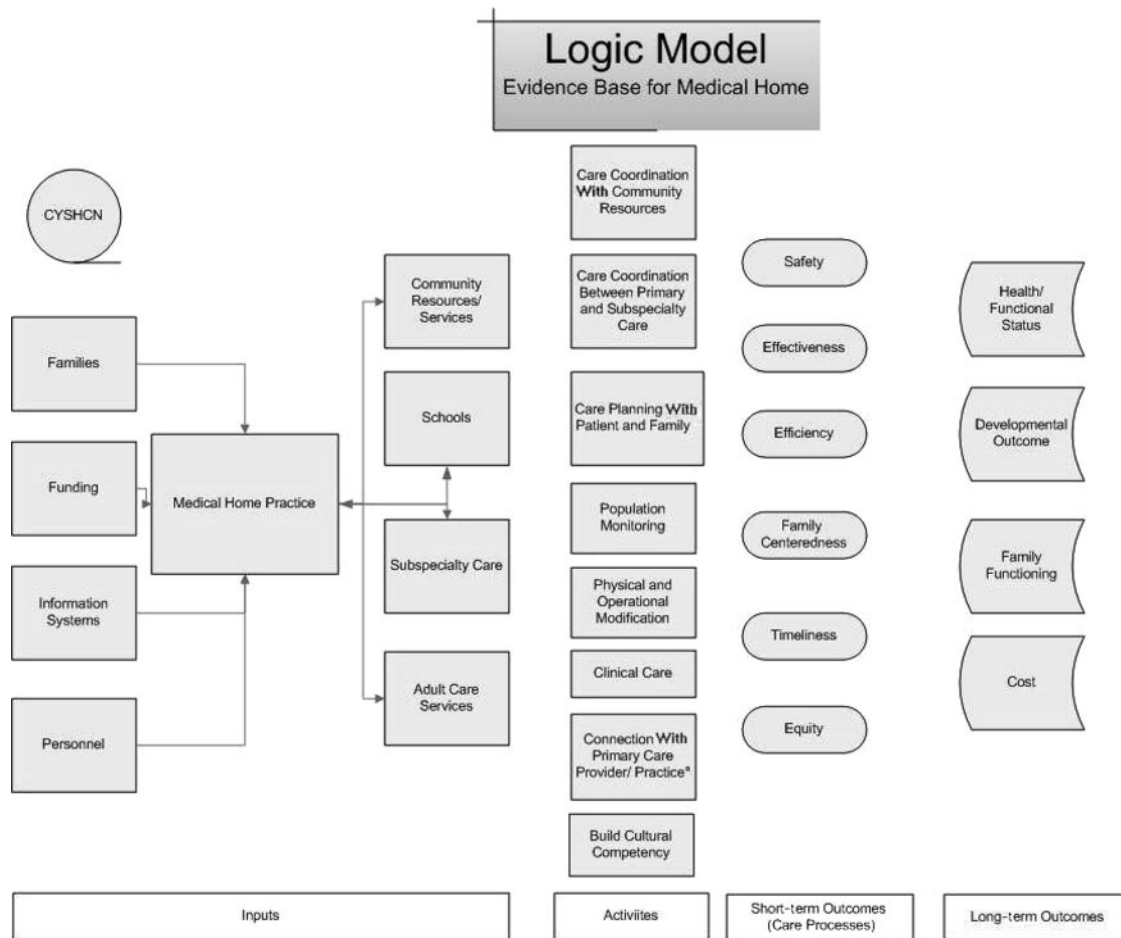


FIGURE 1
MH logic model.

- families of CSHCN have adequate private and/or public insurance to pay for the services they need;
- children are screened early and continuously for special health care needs;
- community-based services for children and youth with special health care needs are organized so families can use them easily; and
- youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.

This article focuses on the MH objective and examines the existing evidence on the impact of the MH on health and other related outcomes for CSHCN. Our research questions were as follows: Does having an MH change important outcomes? To what extent does undertaking more activities to achieve more of the attributes of the MH influence these outcomes for CSHCN? We hypothesized that having an MH would be associated with improved short- and long-term outcomes, and that programs undertaking more activities would have better outcomes than programs undertaking fewer.

ORGANIZATION OF THE REVIEW

A logic model (ie, a diagram that illustrates how resources relate to program activities and how these activities relate to expected outcomes) framed the search strategy and analysis of the review (Fig 1). The activities of the logic model were based on those specific actions required to create an MH with the desired attributes (eg, care coordination as an activity to produce coordinated care; care planning to produce family-centered care [FCC]). We considered short-term “outcomes” as the characteristics of the processes of care delivered to or received by the family. We used the Institute of Medicine’s aims for the health care system,¹³ a standard framework for assessing quality of care. These outcomes included: safety (of the patient when interacting with the health care system); effectiveness (provision of evidence-based care); efficiency (best use of resources); FCC (family-provider partnership, experience of care); timeliness (minimizing delays to receiving care); and equity (benefits of the health system for all people). We chose these dimensions of care because they are increasingly accepted as cross-cutting aims of a high-quality health system and provide the framework for national

TABLE 1 Search Terms

Condition	Activity	Outcome
General	MH	Safety
Developmental disabilities	Primary health care	Safety management
Disabled children	Quality of health care	Medical errors
Chronic disease	Care coordination	Patient safety
Chronic illness	Comprehensive health care	Efficiency
Chronic conditions	Patient-centered care	Emergency service, hospital
Special needs	Progressive patient care	Length of stay
Special health care needs	Continuity of patient care	Child, hospitalized
Catastrophic illness	Health services accessibility	Office visits
Specific	Disease management	Timeliness
Cerebral palsy	Long-term care	Timeliness
Asthma	Chronic care	Wait
HIV/AIDS	Case management	Waiting lists
Epilepsy	Planned care	Timeliness
Diabetes mellitus	Continuity of care	Equitable
Spina bifida	Continuous care	Equity
Down syndrome	Physical and operational modification	Disparities
Sickle cell anemia	Health services accessibility	FCC/family outcome
Cystic fibrosis	Care planning	Patient-centered care
Autism	Patient care planning	Progressive patient care
Obesity	FCC	Comprehensive health care
ADHD	Professional–family relations	FCC
	Professional–patient relations	Family participation
	Compassionate care	Patient satisfaction
	Build cultural competency	Comprehensive health care
	Cultural competence	Health/functional status/developmental
	Culturally competent care	Quality of life
	Connection to PCP	Health status
	Usual source of care	Cost
	Clinical care	Health care costs
	Accessible care	Direct service costs
	Delivery of health care	Drug costs
	Well-child visit	Hospital costs
	Preventive health services	Indirect cost
	Population monitoring	
	Registry	

ADHD indicates attention-deficit/hyperactivity disorder.

reports on quality of care.^{14–16} We considered longer term outcomes as the substantive impact of care on the well-being of the child or the performance of the health care system.

The distinction between the MH activity of “care planning with child/family” and the indicators of “family centeredness” is subtle. We considered the elements of care planning, such as collaborative goal setting and the preparation of written management plans, as MH activities in this domain. We considered parent reports of an enhanced experience of care or documentation that a care plan was in place indicators of care being more family centered—an outcome of medical homes.

We conducted a systematic search of the medical literature through Medline and nursing/ allied health literature through Cumulative Index to Nursing and Allied Health Literature (CINAHL). Inclusion criteria specified that studies need to be quantitative, focused on populations of CSHCN aged 0 to 18 years of age residing in the United States, published between 1986 and November 2006 in a peer-reviewed journal that included abstracts, written in English, and based on primary or

secondary data analysis. Studies could include adults but were required to report data on children separately. We disregarded findings reported by studies that included only children with asthma where the study design was a pre-post intervention without comparison group design because children with asthma, particularly those selected based on illness severity, tend to improve over time regardless of intervention¹⁷ making it difficult to attribute findings from these studies to the intervention. We also reviewed references of selected articles and relevant reviews, and consulted with experts for recommendations of relevant articles.

Search terms were divided into 3 categories: condition, activity, and outcome (Table 1). Activity and outcome terms were based on the logic model. All terms in each category were separated by “or,” and the 3 categories were joined by an “and” condition. Some terms were duplicated in the intervention and outcome term lists to ensure that the search yielded as many relevant articles as possible.

Two reviewers screened one third of titles and abstracts for inclusion. Differences in determination of el-

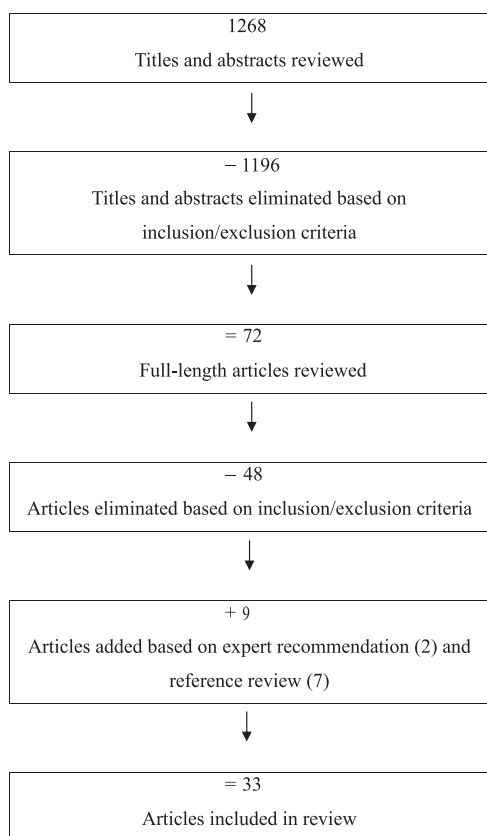


FIGURE 2
Article selection.

igibility were reviewed and discussed. One reviewer screened the remaining titles and abstracts. The project lead (CH), also an MH expert, reviewed any questionable titles and abstracts to determine eligibility. Study design, population characteristics, sample size, intervention, and findings were abstracted into a Microsoft Access database. Quality was assessed by categorizing the study design according to widely established hierarchies of study design quality (eg, randomized, controlled trials [RCTs]; pre-post intervention with comparison group; pre-post intervention without comparison group; cohort; and cross-sectional).

RESULTS

We selected 33 articles reporting on 30 distinct studies. Figure 2 shows the selection process. The studies used the following designs: rRCTs ($n[r] = 6$), pre-post intervention with comparison (ie, comparison group intervention) ($n = 1$), pre-post intervention without comparison (ie, noncomparison group intervention) ($n = 4$), cohort ($n = 3$), and cross-sectional ($n = 16$). Seven studies analyzed data from the National Survey of Children with Special Health care Needs (NSCSHCN). Eleven articles studied children with asthma.

The MH-related activities observed in each article are shown in Table 2. Articles are ordered by the number of activities observed, starting with those studying the most activities. Over half the articles studied ≤ 2 MH activities.

Only 9 studies observed ≥ 4 MH activities. No articles studied all of the MH activities included in the logic model. Only 1 article studied an intervention specifically modeled after the MH concept.¹⁸ Table 3 shows how we categorized specific indicators found in the articles under the logic model outcomes. The outcome most frequently studied was FCC ($n = 18$). Twenty-eight articles found some significant relationships between MH activities and positive outcomes.

Findings are summarized below by outcome, with an emphasis on comparison group studies. We first present the RCT and comparison group intervention studies followed by noncomparison group intervention, cohort, and cross-sectional studies. Key findings can be found in Table 4; Table 2 summarizes the results as determined by both significance and direction of findings. We describe findings in a desired direction (eg, improved outcomes) as positive, nondefinitive findings as not significant, and findings in an undesired direction as adverse. We did not define direction on clinic visits because it is unclear whether a change in this outcome implies a desired impact; however these findings are included in Table 4.

Effectiveness

Half of the comparison group studies investigating effectiveness resulted in positive findings. Two studies based on the same RCT investigated the effects of a planned care intervention on children with asthma. One study, which collected parent interview data, found greater frequency of controller use in the intervention group than in the control group. However, the other study, which collected claims data, found no significant difference in purchase of medication, an indicator of medication use.^{19,20} One asthma-focused Breakthrough Series collaborative (BTS) intervention study found that patients at intervention sites improved more in asthma process of care.²¹ An asthma-focused BTS RCT found no differences in appropriate asthma medication use.²²

Both associational studies on effectiveness found some positive results. Families who received asthma care from a primary care provider (PCP) were more likely than those getting care from the emergency department (ED) to measure peak flow and to use inhaled β agonists.²³ Physician rating of a treatment alliance scale with adolescents was associated with adherence to medication use; however, associations were not found when analyzing parent or adolescent treatment alliance scale ratings.²⁴

Efficiency

Three of 6 comparison group studies investigating impact of MH on efficiency found positive effects of MH activities. One RCT studied an intervention targeting high-risk infants, where participants received acute care, well-child care, and social services. Fifty-seven percent fewer infants in the intervention group were admitted into the ICU; infants who were admitted to the ICU spent 42% fewer days there. The increase in follow-up care costs was offset by the decrease in ICU costs but did not result in overall cost savings.²⁵ Two analyses of a

TABLE 2 MH Activities and Outcomes in Selected Articles

Author Design	Single (S)/ Multiple (M) Conditions	MH Activities											Outcomes							
		MH Activities											Outcomes							
		Care Coordinated With Community Resources	Care Coordinated With Subspecialty Care	Care Plan With Patient and Family	Pop Monitoring	Physical and Operational Mod	Clinical Care	Cultural Competence	Connection With PCP/ Practice	Safety	Effectiveness	Efficiency	Family Centeredness	Timeliness	Equity	Health/ Functional Status	Developmental	Family Function	Cost	
Homer et al ²² ; RCT	S	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Mangione-Smith et al ²¹ ; pre- post with comparison	S	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Palfrey et al ¹⁶ ; pre-post- without comparison	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Berman et al ¹⁸ ; pre-post without comparison	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Farmer et al ²³ ; pre-post without comparison	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Jessop et al ¹⁵ ; RCT	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Stein et al ¹⁸ ; RCT	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Strickland et al ¹⁶ ; cross- sectional	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Lotstein et al ¹⁶ ; cross- sectional	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Baruffi et al ¹⁶ ; cross- sectional	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Damiano et al ¹⁴ ; cross- sectional	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Smith et al ¹⁵ ; RCT	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Heslin et al ¹⁸ ; cross- sectional	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Smaldone et al ¹⁷ ; cross- sectional	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Williams et al ¹² ; cross- sectional	S	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Broyles et al ¹⁵ ; RCT	S	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Finkelstein et al ¹⁹ ; RCT	S	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Lozano et al ¹⁹ ; RCT	S	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Ngui et al ¹¹ ; cross- sectional	M	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

TABLE 2 Continued

Author Design	Single (S)/ Multiple (M) Conditions	MH Activities										Outcomes									
		Care Coordinated With Community Resources	Care Coordinated With Subspecialty Care	Care Plan With Patient Family	Pop Monitoring	Physical and Operational Mod	Clinical Care	Cultural Competence	Connection With PCP/ Practice	Safety	Effectiveness	Efficiency	Family Centeredness	Timeliness	Equity	Health/ Functional Status	Developmental	Family Function	Cost		
Scal et al ¹⁸ ; cross- sectional	M			X																	
Lipiak et al ¹⁹ ; pre-post without comparison	M	X	X																		
Christakis et al ¹¹ ; cohort	S																				
Denboba et al ²⁰ ; cross- sectional	M			X																	
Dinkevich et al ²¹ ; cross- sectional	S																				
Finkelstein et al ¹⁵ ; cohort	S																				
Kelley et al ¹⁶ ; cross- sectional	M																				
Lafata et al ²² ; cohort	S																				
Kieckhefer et al ¹³ ; cross- sectional	S																				
Gavin et al ¹⁴ ; cross- sectional	S			X																	
Freeman et al ¹⁰ ; cross- sectional	S			X																	
Van Riper ⁴ ; cross- sectional	S			X																	
Clark et al ²² ; RCT	S			X																	
Clark et al ¹⁵ ; RCT	S			X																	

O indicates no significant findings (eg, not definitive); +, significant positive findings in the desired direction; *, positive findings but no measure of significance.

TABLE 3 Indicators of Impact of MH in the Desired Direction

Logic Model Outcome	Indicator
Effectiveness	Better processes of care Better adherence to medication use
Efficiency ^a	Fewer ED visits Fewer hospitalizations
Family-centered care	Decreased short-term costs Increased self-management Increased care planning Increased satisfaction and improved experience of care Better transition to adult care
Timeliness	Less time to get an appointment Less time to have telephone calls returned Improved access to care Less delayed or forgone care
Health/functional status	Improved health status Fewer missed school days Fewer unmet needs Fewer missed work days
Family functioning	Better family functioning Less need for financial and social support
Cost	Decreased long-term costs

Safety, equity, and developmental are not included because no articles were found that addressed these outcomes.

^a Defined as the best use of resources.

single intervention, 1 short-term and 1 long-term follow-up, assessed the impact of an intervention in which physicians attended educational seminars focused on the development of provider-family partnerships for children with asthma. The long-term follow-up study found that children in the intervention group had fewer hospitalizations, but neither study found any difference in ED visits.^{26,27} An RCT observing the effects of an asthma-focused BTS resulted in a difference in ED visits in children who came from the subset of practices that participated in the full BTS. Fifty-one percent of children in the intervention group required an ED visit before the intervention compared with only 22% after the intervention. However, no difference was found when comparing children from all practices involved in the collaborative with the control group. Hospitalizations did not differ between groups.²² No impact on cost was found in a community-based care coordination RCT study.²⁸ A comparison group study examining the effects of another asthma-focused BTS found no difference in acute service use.²¹

Two of 3 noncomparison intervention studies found associations between MH activities and efficiency. After an intervention where resources were allocated to subspecialty divisions for care coordination expansion as determined by the division, annual hospital admissions and median hospital length of stay decreased.²⁹ A study examining the Pediatric Alliance for Coordinated Care (PACC) intervention, where a nurse practitioner visited children with severe needs at home to coordinate care, found fewer hospitalizations but no change in ED visits.¹⁸ Berman and colleagues found that a decrease in inpatient costs immediately after the implementation of a hospital-based primary care intervention did not offset

an increase in outpatient costs to the hospital resulting in overall increased hospital costs. Also, no differences were found in ED visit or hospitalization rates.³⁰

Two of 5 associational studies found positive relationships between MH and efficiency. Decreased continuity of care was related to increased hospitalizations among children seen at a health maintenance organization (HMO).³¹ ED risk decreased with each asthma-related PCP visit in children seen at a large multi-specialty group.³² No association was found between having a usual source of care (USC) and ED visits for children with asthma.³³ A survey of Iowa Medicaid enrollees found no relationship between degree of medical homelessness (based on the MH Index) and cost.^{28,34} Connection with a PCP was not associated with adherence to keeping a follow-up appointment after an asthma-related ED visit.³⁵ Ratings on a physician-family goal alliance scale was not associated with ED use or hospitalizations.²⁴

Family Centeredness

Six studies with comparison groups examined family centeredness, with 4 finding positive effects. Families of children participating in a home care intervention were significantly more likely to feel that their provider listened to their concerns. However, no differences were found in the 5 other experience of care measures.³⁶ Families seeing physicians participating in an FCC educational program reported higher rates of satisfaction both immediately after and 2 years after the intervention.^{26,27} After an asthma-focused BTS intervention, families were more likely to receive self-management education, a written action plan, instruction on inhaled medication use, peak flow measurement, and collaborative goal setting, but were not more satisfied with services.²¹ No difference in percentages of children with written care plans was found after another asthma-focused BTS intervention.²² No difference was found in satisfaction after a care coordination RCT.²⁸

Two noncomparison group intervention studies resulted in positive associations. An increase in written care plans, goal setting, and viewing of medical charts but no difference in satisfaction was found after the PACC intervention.¹⁸ After an intervention targeting rural CSHCN, care coordination satisfaction was higher, but no change in satisfaction with other services was found.³⁷

Cross-sectional studies, including 4 using the NSCSCHN and 5 other studies, found generally positive associations between MH activities and FCC. Parent-provider relationship was associated with smooth transition into adult health care³⁸ and satisfaction.³⁹ Parent-provider discussions about transition-related issues was generally associated with having an MH.⁴⁰ Ratings on 4 of 5 family-centeredness factors were associated with satisfaction.⁴¹

Parent assessment of a multidisciplinary epilepsy clinic indicated that staff attitudes and provision of information about seizures were related to higher quality ratings.⁴² Having a USC was associated with greater satisfaction.⁴³ In a survey of mothers of children with Down Syndrome, less discrepancy between expectation of ver-

TABLE 4 Key Findings from Selected Articles

Author/Design	Sample Size/Population Characteristics	Interventions/Independent Variables	Significant Findings
Baruffi et al ⁴⁶ (2005); cross-sectional	449 CSHCN residing in Hawaii	Coordinated care in an MH	More families who received coordinated care in an MH responded positively to ease of use of comm. services [88.4% said yes and 52.6% said no; $P < .0001$; OR 2.95 (CI: 1.33–6.58)]
Berman et al ³⁰ (2005); pre-post without comparison	175 children ≥ 4 y with multisystem disorders who received services from the special primary care clinic	Special primary care clinic—care coordination and case management	Inpatient hospital payments covered approximately one third of outpatient per child-year losses based on total costs. No significant differences in ancillary service use, ED visits, hospitalizations, average length of stay, or direct costs per patient hospitalized
Broyles et al ²⁵ (2000); RCT	High-risk, inner-city infants in Dallas County, TX; 395 in comprehensive care; 388 in routine care	Comprehensive care group—5 d/wk follow-up routine and acute care, primary caregiver (NP or PA) available 24/7 for acute issues. Routine follow-up group—follow-up care 2 mornings per week. Taught mothers signs of acute illness and told where to seek care	Comprehensive care group had 3.1 more outpatient visits and 6.7 more telephone contacts ($P < .001$). In the comprehensive care group, 48% fewer life-threatening illnesses (33 vs 63; $P < .001$), 57% fewer ICU admissions (23 vs 53; $P = .003$), and 42% fewer total days in a the PICU (254 vs 440; $P = .003$). Increase in follow-up care costs was offset by the decrease in ICU costs
Christakis et al ³¹ (2001); cohort	Children < 18 continuously enrolled in large HMO for 2 y with at least 4 clinic visits; subset of children with asthma—3559	Decreased continuity of care for children with asthma	Asthma subset: decreased continuity of care for all children with asthma was associated with increased hospitalizations (HR: 2.12 [1.87–2.42]). No relationship between COC and ED use
Clark et al ²⁶ (1998); RCT	74 of 1276 invited general pediatricians. 637 children aged 1–12 y with asthma and no other chronic disorder with pulmonary complication	An interactive seminar based on theory of self-regulation guiding MDs to examine ways to develop a partnership with their patients. It focused on using interactive methods, helping MDs create interactive conversation between self and patient	Parent survey results: Significant difference between intervention and control in views of 4 of 6 MD performance measures: reassuring and encouraging, looked into how family managed day to day, described how child should be fully active, gave info to relieve specific worries ($P = .007$ –.02). Utilization: difference in asthma visits (planned 1.24 for intervention and 2.25 for control $P = .005$; unplanned 0.94 for intervention and 1.61 for control $P = .005$). No difference in ED visits and hospitalizations
Clark et al ²⁷ (2000); RCT	67 (34 experimental; 33 control); 369 children with asthma and no other chronic disorder with pulmonary complication (202 experimental; 167 control)	An interactive seminar based on theory of self-regulation guiding MDs to examine ways to develop a partnership with their patients. Focused on using interactive methods, helping MDs create interactive conversation between self and patients	Parent survey results: 6 of 7 measures of MDs behavior were significantly different when comparing intervention and control groups ($P = .00$ –.04). Utilization: patients seen by MDs in intervention group had fewer hospitalizations ($P = .03$). No difference in ED visits or office visits
Damiano et al ³⁴ (2006); cross-sectional	1140 Iowa Medicaid enrollees between 6 mo and 12 y	Medical homeness	For 26% of the sample who were CSHCN, medical homeness did not have an impact on cost
Denboba et al ³⁹ (2006); cross-sectional	38866 CSHCN in United States	Families feeling like a partner	Families never or sometimes feeling like a partner were ~ 10 times more likely to be dissatisfied with services, ~ 3 times more likely to have unmet needs. Families never/sometimes feeling like a partner were $\sim 1.5\times$ more likely to miss school
Dinkevich et al ²³ (1998); cross-sectional	398 children < 18 y presenting with a wheezing episode at an ED	Receiving asthma care from a PCP	Children who received asthma care from their PCP were significantly more likely to: have access to after hours telephone number (66% vs 43%; $P < .0001$), be asked to call the office regarding concerns (55% vs 34%; $P = .015$), get a same-day appointment with doctor (89% vs 67.3%; $P < .0001$), measure peak flow (32% vs 15%; $P < .003$), use inhaled β -agonists (95% vs 82%; $P < .04$); for those with severe asthma, use cromolyn sodium (56.3% vs 17.5%; $P < .001$). Families who saw PCP were more likely to report higher quality care on the following measures: asked parent to call after an asthma exacerbation (55% vs 34%), given written management plan (59% vs 37%; $P = .0005$), instruction on peak flow monitoring (34% vs 17%; $P = .003$), child-specific trigger avoidance (68% vs 52%; $P = .015$). No differences were found in discussion of avoiding smoking, cats and dogs, reported days or nights of cough, nights of poor sleep, school days missed, or asthma management behaviors

TABLE 4 Continued

Author/Design	Sample Size/Population Characteristics	Interventions/Independent Variables	Significant Findings
Farmer et al ³⁷ (2005); pre-post without comparison	83 of 149 children with complex chronic health conditions who were eligible from 3 PCP practices in central Midwest state	Care team provided care coordination, resource/service info, emotional support and encouragement, empowerment, needs assessment, goal setting. NP had regular contact with physicians and nurse at each office for problem-solving ways to improve MH	Improved access to mental health services (29% before vs 45% after; $P < .05$), decrease in PCP visits (>8 visits in previous 12 mo, 32% before vs 12% after; $P = .0013$) and specialty visit frequency (>6 visits in previous 12 mo—56% vs 35%; $P = .0028$); improvement in care coordination activity satisfaction, reduction in total family needs, less need for social support, financial/material assistance, family functioning; decrease in family strain; fewer missed >13 d of school (28% before, 14% after; $P = .025$); fewer moms missed >10 d of productive activities (38% before, 22% after; $P = .03$). Slight decrease in satisfaction with PCP but still "very good." No change in utilization, satisfaction with other medical services, therapies and medical equipment, or preventive care indicators
Finkelstein et al ³⁵ (1996); cohort	448 patients presenting to an ED in 1 of 2 urban teaching hospitals with 1 of the following complaints: wheezing/asthma, diarrhea or vomiting, or abdominal pain. Excluded those with severe chronic illness or those who were critically ill, previously enrolled, or admitted to the hospital from the ED	Connection with a PCP	Connection with a PCP was not associated with adherence to follow up
Finkelstein et al ²⁰ (2005); RCT	Analyses of medications used the automated pharmacy data from all patients in the 40 enrolled practices ($N = 5169$; children enrolled in practices and insured by health plan for full baseline year with at least 1 encounter for asthma) 638 enrolled in trial	3 groups: (1) peer leader intervention practices: selected MD champion of asthma care; (2) planned care intervention practices: peer leaders and asthma nurse educator to support care planning and self-management; and (3) usual care	No differences between intervention and control groups in purchase of medication, asthma exacerbations, hospitalizations
Freeman et al ⁵⁰ (2004); cross-sectional	87 families of children diagnosed with brain or spinal cord tumor in past 10 y and receiving care or living in the northeast of the United States	Perceived family-provider relationship	Association between family stress and lack of availability of a doctor/nurse, lack of info concerning stopping treatment significant in bivariate (range: $P = .01-.04$), inappropriate manner in which doctor shared prognosis significant in bivariate ($P = .003$) and multivariate ($P < .05$); lack of information on lifetime expectations significant in bivariate ($P = .04$) and multivariate ($P < .05$). Lack of communication and information around diagnosis not associated with family stress
Gavin et al ²⁴ (1999); cross-sectional	60 adolescents with severe chronic asthma hospitalized in the adolescent inpatient service at National Jewish Med and Research Center tertiary care center with a respiratory specialty. 70% response rate. Only 30 children at 1-y follow-up	Goal alliance scale rating	Parent rating of family functioning scale was associated with physician goal alliance ($r = 0.09, P < .05$). Adherence with asthma meds was related to the physician's goal alliance rating of the teen at discharge and to the MD treatment defeating rating. ($r = 0.28, P < .05; r = 0.34, P = .01$) Follow-up adherence also related to physicians rating of goal alliance and physician defeat rating ($r = 0.60, P < .001; r = 0.54, P < .01$). Physicians' ratings of goal alliance and defeating scales were both negatively associated with sick/urgent office visits ($r = -0.42, P < .05; r = -0.40, P < .05$). No difference in ED use or hospitalizations. No associations were found with parent or teen goal alliance scales
Heslin et al ⁴⁹ (2006); cross-sectional	14 070 CSHCN who needed eyeglasses or vision care in the previous year; nationally representative sample	Provider sensitivity to family customs	Respondents who felt that their providers were never sensitive to their customs were 2 times more likely to have unmet needs than those who felt their provider was always sensitive to customs ($P = .02$)

TABLE 4 Continued

Author/Design	Sample Size/Population Characteristics	Interventions/Independent Variables	Significant Findings
Homer et al ²² (2005); RCT	43 practices with 13 878 pediatric patients with 1 asthma visit without another complicating respiratory condition randomized to intervention and control groups. 631 completed baseline interview, 490 completed second interview	Practices participated in a BTS collaborative where they were asked to collect baseline data on "performance gaps" in their practice, trained on a comprehensive method to care for patients with asthma	No significant findings on receipt of appropriate asthma medication, written care plans, or hospitalizations. Significant difference in ED visits in children that came from practices which participated in the full collaborative ($P = .01$). 51% of children coming from these practices required an ED visit before the intervention compared to only 22% after the intervention
Jessop et al ³⁶ (1994); RCT	219 children aged birth to 11 y with chronic physical conditions; 188 completed 6 mo and 181 completed 1 y	Pediatric Home Care program—multidisciplinary team members monitored condition, delivered direct care, ongoing primary care, specialized care in conjunction with specialist, coordination of services, patient education and advocacy. Involved family in management and decision-making and serves as liaison between pediatric services and outside agencies	Difference in "listen to concerns" measure (64% in home care vs 33% in standard care; $P < .001$). No difference in 3 other FCC measures (discussion of family risk, explanation of illness, general advice)
Kelley et al ⁴³ (1991); cross-sectional	Final sample size 140 (53 children in allergy clinic and 87 in orthopedic clinic)	Relationship with a USC	General satisfaction associated with relationship over time with a USC (>1 y) ($P \leq .001$)
Kieckhefer et al ³³ (2005); cross-sectional	1726 children with asthma aged 0–17; national sample	Identification of a USC	Respondents identifying physician as the USC reported higher scores on the 10-item MH index. Identifying a USC was related to a 2× greater likelihood of making a wellness visit ($P = .015$) and 2× greater likelihood to have a rescue bronchodilator fill/refill ($P = .017$) but not related to asthma-related ED use
Lafata et al ³² (2005); cohort	194 children aged 5–14 receiving care at large multispecialty group who incurred 1 hospitalization or 2 outpatient encounters for asthma per year of sample inclusion and 1 office visit to 1 of the 33 pediatricians enrolled in an affiliated HMO	PCP visit frequency	ED visit risk decreased significantly with each visit a child made to a primary care physician for asthma care (OR: 0.82 [CI 0.7–0.96]; $P = .01$). From med record abstraction: no relationship between PCP visit frequency and documented rates of care plan review, referral for asthma education, ed regarding prevention of triggers. The more primary care visits for asthma care incurred during baseline year, more likely the child was to have a review of symptoms ($P < .01$), to review of peak flow diary ($P < .01$), to receive education on peak flow meter use ($P < .01$), education on medication use ($P < .01$) and asthma ($P < .05$)
Liptak et al ²⁹ (1998); pre-post without comparison	10715 children <18 with ≥ 1 chronic conditions seen at a tertiary care center	Expansion of care coordination and wrap around services; subspecialty areas were allocated funds to hire personnel to coordinate care	Median length of stay for children with chronic conditions admitted to CHAS decreased from 83.9 to 10.6 d ($R^2 = 0.83$, $P < .001$); annual admissions decreased from 2796 to 1622 ($R^2 = 0.83$, $P < .001$). Adjusted hospital inpatient charges for chronic conditions fell from \$26.2 million in 1984 to \$14.6 million in 1995 but no test for significance
Lotstein et al ⁴⁰ (2005); cross-sectional	5333 youth aged 13–17	Having an MH	Youth with an MH were more likely to have discussed changing needs with their providers (57.0% vs 44.0%; $P = .000$). 59.3% of the 50% who reported discussing changing needs reported having developed a plan with their child's physicians to address these needs. Of those who discussed changing needs in adulthood, those with an MH were more likely to have a plan (63.5% vs 55.5%; $P = .023$). 42% of those who reported having discussed changing needs also had discussed shifting their child's care to an adult provider. No difference in groups that did and did not have an MH on this measure

TABLE 4 Continued

Author/Design	Sample Size/Population Characteristics	Interventions/Independent Variables	Significant Findings
Lozano et al ¹⁹ (2004); RCT	638 3- to 17-y-old children with mild-to-moderate persistent asthma completed baseline interviews (64% of those screened and deemed eligible)	3 groups: (1) peer leader intervention practices: selected MD champion of asthma care; (2) planned care intervention practices: peer leaders and asthma nurse educator to support care planning and self-management; and (3) usual care	Children in planned care arm experienced an additional reduction of 13.3 (95% CI: -24.7 to -2.1) fewer asthma symptom days per year of intervention relative to children in usual care (represents 12% reduction). When adjusting for controller use at baseline, planned care subjects had greater frequency of regular controller use during follow-up period compared with usual care (rate ratio: 1.05 [95% CI: 1.00-1.09]). Children in planned care had 39% less rate of oral steroid bursts per year than usual care
Mangione-Smith et al ²¹ (2005); pre-post with comparison	Survey data from-385-intervention; 126-control. Medical charts data from 348 intervention; 153-control. Children with asthma seen in 9 organizations in United States	Breakthrough Series learning collaborative to improve care for children with asthma	Medical chart abstraction: Patients seen at intervention sites improved significantly more on 6 of 8 quality indicators than those seen at control sites, Summary score [intervention group + 13%; $P < .0001$]. No difference in prescription of β -2 agonist, follow-up visit within 6 weeks for patients whose medication changed. Survey results: children receiving care at an intervention site were also more likely to be monitoring peak flows (70% vs 43%; $P < .0001$), have a written action plan (41% vs 22%; $P = .001$) than those seen at control site. No differences between control and intervention were seen in goal setting or level of asthma-specific knowledge. Children receiving care at intervention site had significantly higher scores on the Peds QL 3.0 SF-22 asthma module treatment problems scale (88.6 vs 85.3; $P = .03$). Score difference in general health related quality of life scale was nearly significant (80.2 vs 77; $P = .05$). Care at intervention site was not associated with impact of the child's asthma on family functioning, satisfaction of care, acute care service use, missed school or work for parent
Ngui et al ⁴¹ (2006); cross-sectional	36 238 CSHCN; national sample	Time spent with provider, amount of information given to families, provider listening skills, partnership with families, sensitivity to family values and customs	FCC associated with satisfaction of care. Specific factors associated with dissatisfaction of care—inadequate time spent with provider, amount of information given providers to families, provider listening skills, partnership with families (OR: 1.74–2.63; $P < .01$). FCC factors except for sensitivity to family values and customs associated independently with satisfaction with care. Inadequate family-centered care associated with reports of services not being easy to use (range of OR: 1.57–2.52; $P < .01$)
Palfrey et al ¹⁸ (2004); pre-post without comparison	150 CSHCN residing in Massachusetts of 222 invited	PACC-Ped NP provided home visit to understand context of child's life; sick visits at home; systems to streamline ordering of meds and supplies; coordinated appointments to minimize burden; development of individual health plan in collaboration with family; local parent consultant provided peer support and community resources information; newsletter provided in Spanish and English; improvement of language proficiency of staff members	Families reported that during PACC, it was easier on the following survey items: having the same nurse to talk to, getting letters of medical necessity, getting early care when child is sick, having telephone calls returned, appointments, communicating with doctor, getting referrals to specialists, getting resources for child, forming a relationship with doctor, understanding condition, prescriptions filled, setting goals for child (range: 51.8%–68.4%). Differences in parents' missed workdays: 26% missed >20 d before compared with 14% after ($P = .02$), and hospitalizations 58% before and 43% after ($P < .01$). Significantly more families had written health plan (29.9% before vs 47.4% after; $P < .01$). No differences in satisfaction
Scal et al ³⁸ (2005); cross-sectional	4,332 CSHCN; national sample	Parent-provider relationship; having a personal doctor	Of those who received health care transition (HCT) services, parent-provider relationship was associated with higher score on the HCT scale ($P < .01$), but having a personal doctor was not
Smaldone et al ⁴⁷ (2005); cross-sectional	748 CSHCN in New York state	Time spent with family, provider listening skills, cultural sensitivity, information provided to family	Lower ratings of FCC indicators (eg, spends enough time, listens, sensitive to culture, gives information) were associated with higher rates of delayed or forgone care (adjusted OR range: 6.5–8.6; $P = .01$ to $< .001$)

TABLE 4 Continued

Author/Design	Sample Size/Population Characteristics	Interventions/Independent Variables	Significant Findings
Smith et al ²⁸ (1994); RCT	Families of CSHCN aged 0–6, mostly Hispanic, working/middle class	Expanded care group received needs assessment and resource identification at home. Community care coordinator was responsible for implementation of plan; regular communication with parents; monthly reevaluation and revisions of plan as needed. Control group received only administrative case management	No significant results in illness status, cost of care, satisfaction, number of school days missed
Stein et al ⁴⁸ (1991); RCT	Original sample—81 families enrolled in Pediatric Home Care program; follow-up sample—68% of original 81 families	Pediatric Home Care program: Multidisciplinary team members monitored condition, delivered direct care, ongoing primary care, specialized care in conjunction with specialist, coordination of services, patient education and advocacy. Involved family in management and decision-making and serves as liaison between pediatric services and outside agencies	Long-term follow up findings: difference remained on adjustment of the groups for initial differences (mean: 74 home care vs 67 standard care; $P = .009$)
Strickland et al ⁴⁵ (2004); cross-sectional	38866 CSHCN in United States	Having an MH	Greater % of children without an MH (13.9%) had forgone or delayed care vs children with an MH (5.9%). Children without an MH are 2× more likely to experience delayed or forgone care. Greater percentage of children without an MH (23%) had unmet health care need vs children with an MH (9.9%). Children without an MH are >2× as likely to have unmet health care needs than those with an MH. Of those reporting unmet needs for family support services, 7.9% among children without an MH vs 2.2% with an MH. Children without an MH were 3× more likely to have unmet needs for family support services. No difference in missed school
Van Riper ⁴⁴ (1999); cross-sectional	89 children with Down Syndrome	Beliefs about family-provider relationship	Correlations between mothers who reported less discrepancy between their family's relationship with the health care provider and what they wanted reported more satisfaction ($r = 0.56$; $P \leq .01$) with care and higher levels of individual and family functioning ($r = 0.22$; $P < .05$) but not with depression. Beliefs about family provider relationship were related to feelings of satisfaction, intentions to seek help, family functioning, and overall psychological well-being
Williams et al ⁴² (1995); cross-sectional	533 children and teens with epilepsy seen at a multidisciplinary clinic (Satisfaction data based on 136 patients who returned the survey)	Seizure information, staff attitude, seizure frequency, medication information, time with staff	Staff attitude and amount of information on seizures were found to be significant predictors of parental rating of overall quality of multidisciplinary clinic ($P = .004$ and $P < .001$, respectively).

OR indicates odds ratio; CI, confidence interval; COC, continuity of care.

sus actual relationship with provider showed associations with greater satisfaction with care.⁴⁴ Families who saw a PCP for asthma were more likely to receive a written management plan, instruction on peak flow monitoring, and child-specific trigger avoidance.²³ The more asthma-related PCP visits, the more likely the child was to have a review of symptoms and peak flow diary, to receive education on peak flow meter use, medication use, and asthma.³²

Timeliness

Seven studies, none with comparison groups, found positive associations between MH and timeliness of care.

After the PACC intervention, parents reported having telephone calls returned on a timely basis.¹⁸ Rural families reported improved access to mental health services after receiving intensive care coordination and social support.³⁷ More children receiving asthma care from their PCP were able to get a same-day appointment and received an after-hours telephone contact than those receiving asthma care from the ED.²³

Four studies using data from the NSCSHCN analyzed outcomes related to timeliness. Not having an MH was related to likeliness to delay or forgo care.⁴⁵ Ease of service use was associated with FCC factors and having an MH.^{41,46} Lower ratings of FCC factors (ie, provider

spends enough time, listens) by families from New York state were associated with higher rates of delayed or forgone care.⁴⁷

Health/Functional Status

Half of the comparison group studies found that MH-related interventions had a strong effect on health status. One RCT studied health status several years after the implementation of a pediatric home care intervention which involved care coordination and social support. At a 4- to 5-year follow-up, patients participating in the program had higher scores on a child mental health measure.⁴⁸ Another found that 48% fewer infants receiving an acute and chronic care intervention had life-threatening illnesses.²⁵ Studies on the planned asthma care intervention RCT resulted in inconsistent findings. One study found that children in the intervention group experienced fewer asthma symptom days per year and had a higher reduction of oral steroid bursts per year.¹⁹ However, the other study found no difference in asthma exacerbations.²⁰ A community-based care coordination intervention had no impact on illness status or missed school days.²⁸ An asthma-focused BTS intervention comparison group study had no impact on missed school/ work days or β 2 agonist prescriptions, an indicator of poor asthma control.²¹

Two noncomparison group intervention studies found relationships with MH activities and better functional status. Fewer parents of children participating in the PACC intervention missed >20 work days after the intervention, but no difference was found in missed school days.¹⁸ A decrease in missed school days was found after an intensive care coordination intervention targeting rural families.³⁷

All NSCSHCN studies and 1 of 2 other cross-sectional studies found results in the hypothesized direction (ie, better health status associated with having an MH). Children in families who never or sometimes felt like a partner with their provider were more likely to miss school and have unmet needs.³⁹ Over twice as many families without an MH reported having unmet needs but no associations were found between missed school days and having an MH.⁴⁵ Decreased provider sensitivity to family values and customs was related increased unmet needs in families with children who needed vision care.⁴⁹ Having a USC was found to be associated with filling or refilling a rescue bronchodilator.³³ Connection with a PCP was not found to be associated with functional morbidity, days/nights with a cough or poor sleep, or missed school days.²³

Family Functioning

One noncomparison group intervention study and 3 cross-sectional studies observing family functioning found an association in the desired direction. Family strain and need for financial and social support was lower after participation in an intervention targeting CSHCN in rural areas.³⁷ In a survey of mothers of children with Down Syndrome, less discrepancy between expectation of versus actual relationship with a provider

showed associations with higher levels of family functioning.⁴⁴ Poor family centeredness was associated with increased family stress in families of children diagnosed with a brain or spinal tumor.⁵⁰ Physician treatment alliance scale rating was associated with parent rating on a family functioning scale.²⁴

Cost

One study that assessed an intervention where subspecialty programs at a children's hospital were provided resources to enhance care coordination at their discretion found a positive impact on cost; however, significance was not measured. Adjusted hospital inpatient charges for chronic conditions fell from \$28.1 million in 1989 when the intervention was implemented to \$14.6 million in 1995.²⁹

DISCUSSION

The evidence in this review supports our hypothesis that CSHCN receiving care in an MH experience better outcomes than children receiving care in non-MH settings. Although results were not universal, positive impacts were found for MH activities on each outcome studied. Outcomes with the most compelling positive results included family centeredness, effectiveness, timeliness, health status, and family functioning. Inconsistencies in the definition of MH activities and in the assessment of outcomes preclude our ability to answer the second study question of whether programs undertaking more activities have better outcomes than programs undertaking fewer such activities.

Several factors could explain the inconsistency of findings across studies. Some studies assessed interventions seeking to improve the function of practices or the clinicians in those practices through efforts to change their behavior or organization through training (a BTS or a seminar for providers on enhancing FCC); the effectiveness of these interventions depends on whether the intervention changed provider/practice behavior, whether the change was well implemented, and whether the desired implementation had the potential to be effective. Other studies examined more direct interventions, such as hiring a care coordinator or extending hours/accessibility of a practice. In these latter studies, the element of whether a change was implemented is assured; effectiveness only depends on the quality of the change and its efficacy. Other potential causes of nonsignificant findings might include ceiling effects, imprecise measures and an inadequate amount of time between implementation of the change and assessment of effectiveness.

In including studies with only 1 or 2 elements of the MH, we were clearly assuming that "medical homes" is not an all or none phenomenon, but that there are degrees to which the idealized concept is realized in practice. That we found an association between individual elements and broader outcomes suggests this framing is helpful and that practices can start to see better results without full scale implementation.

One could legitimately ask whether the MH as as-

essed through this review is different from primary care per se, as many of the specific activities studied—such as identification of a continuous provider over time—are indistinguishable from primary care. In our view, the MH concept and the definition of primary care differ little.⁵¹ However, because the reality of primary care has come to differ so broadly from its ideal definition, and because the elements required to make primary care effective in improving outcomes for persons with chronic illness have been clarified, the reframing of primary care as the MH serves a useful purpose. These elements include resources required for care coordination, training and tools for care planning, patient registries, and others. Many of the intervention studies here (excepting the quality improvement interventions) entailed special grant or organizationally funded services (such as a care coordinator). These studies do not of themselves inform questions of sustainability or the feasibility of implementation in real world settings with readily available resources. The quality improvement intervention studies and the cross sectional analyses, however, all should inform effectiveness (versus efficacy).

The review has several methodologic limitations. After assuring consistency with a second, expert reviewer, only 1 reviewer screened articles for inclusion. The selected studies are diverse and often difficult to compare. As a result, we could not pool data for meta-analysis. Much of this review reports findings from cross-sectional, cohort, and noncomparison group intervention designs, none of which provide strong evidence of causality. One third of these studies observe children with asthma, with unknown generalizability to the larger population of CSHCN. The frequency of targeting children with asthma is likely because asthma is a common condition seen in primary care settings and therefore a good target for study.

Even with these limitations, this evidence review indicates the impact of ≥ 1 MH activities on outcomes for CSHCN. Including separate MH activities allowed us to collect important information on which have been studied and what they found. Finally, we included noncomparison group intervention studies, cohort, and cross-sectional studies because we correctly predicted that there would be few studies with comparison groups examining the impact of MH attributes on outcomes of CSHCN. Although results in noncomparison group intervention studies cannot control for secular trends, they can indicate potential impacts on outcomes. Similarly, cohort and cross-sectional designs allow researchers to collect data on a large sample to guide the focus of future research.

Evidence exists supporting the benefits of MH and related interventions, such as care coordination, in the adult population.^{51–53} A study conducted on a quality improvement intervention on adults and children with diabetes, asthma, and hypertension found a positive effect on processes of care for asthma and diabetes.⁵⁴ There is also evidence supporting the positive impact of key aspects of the MH, such as continuity of care, in children without special health care needs.^{55–57} An ED diversion

program that provided care coordination, multiple locations and extended office hours targeting children without chronic conditions on Medicaid found that children in the intervention visited the ED fewer times than children in the control group.⁵⁸

Additional research on the impact of MH on CSHCN is recommended. We suggest that research be conducted on interventions that encompass the full MH construct; on interventions targeting aspects of the MH not or only minimally studied to date (eg, physical/operational modification, population monitoring, and cultural competency); and incorporate key outcomes not yet studied (eg, safety, equity, developmental, family, and cost). Moreover, the field would benefit from more rigorous study methods that incorporate experimental or quasi-experimental designs, using standardized and consistent measures, conducting long-term follow-up studies, and examining a more diverse population in terms of diagnoses. Additional mixed methods research, combining qualitative and quantitative methods, should explore the practice characteristics that can successfully take on the attributes of the “medical home,” as well the types of interventions and supports that are needed to facilitate the creation of these practices and sustain them over time. In addition, additional research needs to explore how to identify and establish the appropriate balance in services between comprehensive specialty-based services for children with specific uncommon chronic conditions—such as cystic fibrosis and sickle cell disease—and the primary care MH. Taking these steps would allow for a richer evidence base supporting the benefits of the MH.

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