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Medical Home Disparities Are Not Created Equal: Differences in the Medical Home for Children from Different Vulnerable Groups

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Abstract

Objective—To identify components of the medical home that contribute to medical home disparities for vulnerable children.

Methods—Cross-sectional analysis of 2007 National Survey of Children’s Health. Prevalence of components of the medical home were estimated by special health care needs (SHCN), race/ethnicity, primary language, and health insurance.

Results—Medical home disparities for children with SHCN were driven by differences in getting help with care coordination, when needed (71% vs. 91% children without SHCN, $p<.001$). Medical home disparities for other groups were largely attributable to less family- centered care (Hispanic 49% and African American 55% vs. White 77%, $p<.001$; non- English primary language 37% vs. English 72%, $p<.001$; uninsured 45% and publicly insured 57% vs. privately insured 75%, $p<.001$).

Conclusions—The components of the medical home that contribute to medical home disparities differ between groups of vulnerable children. Medical home implementation may benefit from focusing on the specific needs of target populations.

Keywords

Pediatrics; medical home; disparities; health policy; National Survey of Children’s Health

The medical home model has become central to efforts to improve primary care for children. The American Academy of Pediatrics (AAP) defines a medical home as a regular source of primary care that is “accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective.”[1] Although the medical home was initially developed for and applied to children with special health care needs (CSHCN), it is now promoted as a model of care for all children [1,2] and has been integrated into a large number of state and national health care reform efforts.[3–5] Information on the specific needs of diverse populations of children could be used to help guide these implementation efforts and improve their effectiveness.

However, as illustrated by the AAP definition, the medical home is a complex concept that encompasses multiple aspects of clinical care.[1,6–8] Studies using parent- report measures of the medical home have identified significant medical home disparities for several

vulnerable groups of children,[9] including those who have special health care needs,[10,11] are racial/ethnic minorities,[11–14] live in a non- English primary language household, [11,15,16] are uninsured,[11] or have public insurance.[17,18] The parent- report measures used in these studies incorporate multiple components of the medical home,[19] but this body of research frequently focuses on a single dichotomous indicator of the presence or absence of a medical home with less attention to the components of the medical home that contribute to differences between groups.

Efforts to promote the medical home among diverse groups will require more detailed information about the specific components of the medical home that must be addressed to reduce disparities. This study seeks to inform efforts to decrease medical home disparities by addressing the following question: Which components of the medical home contribute to reported disparities in the medical home for children with different vulnerable characteristics? Based on the literature, we hypothesized that medical home disparities for CSHCN would be driven by challenges in care delivery, such as care coordination, for this high needs population, while disparities for minority and other underserved populations would be driven by the challenges of delivery family- centered care across social and cultural differences.

METHODS

Data Source

The 2007 National Survey of Children’s Health (NSCH) is a nationally representative telephone survey of households with children ages 0–17 years. Households were sampled as part of the State and Local Area Integrated Telephone Survey Program and sampling is stratified by state to allow for national and state-level estimates of parental report of a wide variety of child health indicators and sociodemographic characteristics. Interviews were performed in English, Spanish, Mandarin, Cantonese, Vietnamese, and Korean. The NSCH is sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration. The 2007 NSCH had a final sample size of 91,642 children (overall response rate 66%), including children from all 50 states and the District of Columbia.[20] Further details of the survey methodology are available from other sources.[20] We used a publicly- available version of the dataset that contained the original survey response data, as well as derived variables used to construct the medical home composite.

Dependent Variable: Medical Home Composite

The medical home composite is a dichotomous indicator of parental report of a medical home.[19] The composite is constructed from 18 questions in the 2007 NSCH to reflect multiple aspects of the 2002 AAP definition of the medical home. For a child to have a medical home, the parent must indicate the presence of each of five components: 1) a usual source of care that is not an emergency department; 2) a provider they consider their child’s personal doctor or nurse; 3) family- centered care; 4) help with care coordination, if needed; and 5) no difficulty getting referrals, if needed (Table 1).[19] If any component is absent, the child is considered not to have a medical home. Family- centered care questions were asked for any child who had one or more health care provider visits in the last year. Five questions

were applicable for all respondents, including whether the provider: 1) spent enough time; 2) listened carefully; 3) was sensitive to family values and customs; 4) provided enough information; and 5) partnered in care (Table 1). There was an additional question about getting help from interpreters, if needed. If any single component was missing, the entire medical home composite was considered missing; the medical home composite variable was missing in 3.9% of the sample.

Independent Variables

All sociodemographic and health characteristics were determined by parental report at the time of the interview for the 2007 NSCH. Characteristics of interest for this study were special health care needs, race/ethnicity, primary language, and health insurance. Special health care needs were identified in the survey using the Children with Special Health Care Needs Screener, a widely-used five question screener designed to identify children with increased physical, mental, behavioral, or other health care needs.[21] Child race was categorized using U.S. Census categories. To protect the confidentiality of respondents in several smaller categories, these were collapsed into White, African American or Black, other race, and multiple races. These categories were then combined with an ethnicity question (Hispanic or non-Hispanic) to create four mutually exclusive race/ethnicity categories (White, non-Hispanic; African American, non-Hispanic; Hispanic; and multiple/other). Primary language in the household was categorized as English or non-English. Insurance status was determined at the time of interview and identified as private insurance, public insurance (Medicaid, CHIP, or other public plan), or uninsured.

Analysis

We estimated the national prevalence of a medical home for children in each sociodemographic category and then calculated medical home disparities within each category. We then estimated the proportion of each group within each sociodemographic category that did not meet each of the five medical home components.

Bivariate comparisons were conducted using the chi-square test. We then fit multivariable logistic regression models for the medical home composite and each of the five components to assess the independent associations with special health care needs, race/ethnicity, household primary language, and health insurance, after adjusting for child age, parent-rated child health, household income, household education, and highest level of parent/guardian education.

All statistical analyses were performed using Stata/IC version 10.1 (StataCorp LP, College Station, TX). The original data file was obtained in SAS format and converted to Stata format using StatTransfer (Circle Systems, Seattle, WA). Survey commands were used in all analyses to account for the complex survey design, including stratification by state and random selection of one child within the household, and non-response. We utilized sampling weights included in the dataset. Statistical significance was determined at $p < .05$; results also meeting stricter significance criteria are indicated in the text and tables.

As a secondary analysis of de-identified survey data, this study was exempt from human subjects review.

Results

Overall, 58% of children in the United States reported care consistent with a medical home. There were significant disparities in the overall medical home measure (Table 2) and its components (Table 3) by special health care needs, race/ethnicity, primary language, and health insurance, as described below.

Medical Home Disparities by Special Health Care Needs

CSHCN were less likely to have a medical home than those without special needs (50% vs. 59%, $p < .001$). For CSHCN, the medical home component with the largest disparity was in getting needed care coordination (Table 3); 29% of all CSHCN reported not getting needed help with care coordination compared with 9% of children without special needs ($p < .001$). A slightly higher proportion of CSHCN had problems getting referrals their parents felt were needed (7% vs. 2%, $p < .001$). Otherwise, CSHCN did not significantly differ from other children in measures of the medical home. In multivariable analyses adjusting for other sociodemographic characteristics, CSHCN remained significantly less likely to report receiving needed help with care coordination (adjusted odds ratio [aOR]: 0.55 [95% CI or confidence interval 0.49–0.63]) and less likely to get needed referrals with no problems (aOR: 0.76 [95% CI 0.59–0.98]) (Table 4).

Medical Home Disparities by Race/Ethnicity

Minority children were much less likely to report a medical home than White, non-Hispanic children (39% Hispanic; 44% African American, non-Hispanic; 56% multiracial/other race; 68% White, non-Hispanic; $p < .001$). Family-centered care was the medical home component that the lowest proportions of minority children reported receiving and that had the largest disparities between groups (Table 3). When we examined the five family-centered care questions asked of all respondents who used health care in the last year, minority children were significantly less likely to report their provider taking enough time, listening carefully, being sensitive to family values, providing needed information, or partnering in care (Table 5). Of these, the lowest proportions of parents reported that their children's providers spent enough time.

Minority children were also less likely to have a usual source of care or a personal doctor/nurse (Table 3). Although statistically significant, absolute differences by race/ethnicity were small in the overall percentage that had problems getting referrals or did not get needed care coordination. These differences remained significant in multivariable analyses (Table 4).

Medical Home Disparities by Primary Language

Children who spoke a non-English primary language (NEPL) were significantly less likely to report a medical home than those who spoke English (29% vs. 62%, $p < .001$). Family-centered care was the medical home component that NEPL children were least likely to report and that had the largest disparity (Table 3). While 72% of families who spoke English as a primary language reported receiving family-centered care, 37% of NEPL children received family-centered care ($p < .001$). When we examined the five family-centered care

questions, NEPL children were significantly less likely to report their provider taking enough time, listening carefully, being sensitive to family values, providing needed information, or partnering in care (Table 5). Of these, the lowest percentages of children reported that their provider spent enough time. Non- English- primary- language children were also significantly less likely than others to have a usual source of care or to have a personal doctor/nurse (Table 3). Although statistically significant, absolute differences by primary language were small in the overall percentage that did not get needed care coordination. Differences by primary language were not significant for problems with getting referrals.

In multivariable analyses, NEPL children were significantly less likely to have a usual source of care (aOR: 0.65 [95% CI 0.47–0.91]) and to receive family- centered care (aOR: 0.43 [95% CI 0.35–0.52]) (Table 4). They were also slightly less likely to receive needed care coordination (aOR: 0.76 [95% CI 0.58–1.00]) and to get needed referrals without problems (aOR: 0.68 [95% CI 0.47–1.00]).

Medical Home Disparities by Health Insurance

Uninsured children and children with public insurance were less likely to have a medical home than children with private insurance (36% vs. 45% vs. 67%, respectively; $p < .001$). Family- centered care was the medical home component that uninsured children and children with public insurance were least likely to report and that had the largest disparity (Table 3). When we examined the five family- centered care questions, uninsured and publicly- insured children were significantly less likely to report their provider spending enough time, listening carefully, being sensitive to family values, providing needed information, or partnering in care (Table 5). Of these, the lowest percentages of children reported that their provider spent enough time.

Uninsured children were also much less likely to have a usual source of care or not have a personal doctor/nurse than other children with coverage (Table 3). Although statistically significant, absolute differences by health insurance were small in the overall percentage of children that did not get needed care coordination or had problems getting needed referrals.

In multivariable analyses, the only component with significant differences for children with public *versus* private insurance was in getting needed referrals with no problems (aOR: 0.68 [95% CI 0.49–0.95]) (Table 4). Uninsured children were significantly less likely than privately insured children to meet criteria for each of the five components (Table 4).

Discussion

Consistent with prior studies,[9–18] we found significant disparities in a parent- reported measure of the medical home for each of the vulnerable groups of children that were examined. However, the key insight from this analysis of national data is that the components of the medical home that drive disparities were different among the groups. For CSHCN, overall medical home disparities were modest and primarily driven by differences in care coordination, with very small differences in the other medical home components. This finding suggests that medical home programs that focus on or include a large

proportion of CSHCN will need to invest in addressing challenges in care coordination through interventions promoting care managers, health information technology to support care management, improved communication between primary care and specialists, therapists, and schools, and incentives to encourage these interventions.[22,23] Additionally, many CSHCN receive the majority of their care from specialists rather than through their primary care providers (e.g., pediatric pulmonologists for children with cystic fibrosis). Medical home programs could explore models that encourage specialists and primary care providers to explicitly define roles in preventive, acute, and chronic care, including care coordination, for these children.

In contrast, medical home disparities for racial/ethnic minorities, non- English primary language speakers, and uninsured children were driven primarily by large differences in family- centered care. While these characteristics are frequently correlated, we found that each was an independent predictor of lower odds of parents reporting family- centered care. Disparities in family- centered care have been described previously for several sociodemographic groups,[18,24–26] and these results are consistent with those findings. The findings in our study suggest that many pediatric providers are not meeting the challenge of effective communication with parents of some of the most vulnerable groups of children, such as spending enough time, listening carefully, being sensitive to family values, providing needed information, and working together with parents in providing care. To date, it has been unclear to what degree disparities in responses to these types of questions are driven by patient expectations versus provider behaviors. The results of a recent study in adults suggested that individuals from racial/ethnic minority groups have similar expectations for family- centered care from physicians and that measured disparities are likely driven by differences in physician behavior.[27] A key driver of many of the family- centered care disparities was parents' reporting that providers did not spend enough time. Future research will be needed to clarify whether this reflects the actual time spent with providers or the quality of the communication that occurs in the time that parents and providers have together.

The effects of interventions to promote family- centered care are just beginning to be explored and could include practice systems to enhance communication outside the office visit, such as through telephone care or an online portal, continuing medical education regarding communication skills for providers, or provider incentives based on measures from patient experience surveys.[28]

In this study, we also found disparities in having a usual source of care and a personal doctor or nurse. For uninsured children, these disparities were marked, reflecting more traditional barriers to primary care. They should continue to be addressed through efforts to promote health insurance coverage for children and ongoing support for safety- net providers, such as community health centers. It is encouraging to note that there were not significant differences between children with public *versus* private insurance in report of a usual source of care or a personal doctor/nurse. There were also significant, but more modest, disparities for children who were from racial/ethnic minorities or spoke a non- English primary language. Further research is needed to understand the barriers to a usual source of care or personal doctor/nurse for these populations independent of insurance status.

The medical home model was initially developed for CSHCN but is now promoted for all children.[1,2] While many medical home programs continue to focus on CSHCN, other large medical home projects target broad populations of primarily healthy children.[29,30] The results of this study suggest that medical home programs must act strategically in implementing components of the medical home based on the needs of their target populations.

It is important to note several limitations to the findings in this study. All measures used in this study were by parent report and could be influenced by both differences in provider behaviors and parents' expectations, particularly the measure of family-centered care. Further work is needed to understand the relative influences of provider behaviors and parents' expectations on parent-reported measures of the medical home.

Additionally, although the medical home measure used in this study has been incorporated in some of the largest surveys of children's health in the United States,[19] little is known about the relationships between patient-reported measures of the medical home, primary care practice certification as a medical home, and, ultimately, clinical outcomes for children. [31] Additionally, the wording and importance of a question about a personal doctor or nurse in medical home measures must be investigated as medical home programs emphasize the use of team-based care, including the use of other providers such as nurse practitioners and physician assistants. Lastly, the sampling frame for the 2007 NSCH only included landline telephones, which may miss populations in households with intermittent service or those that use cell phones only; the administrators of the survey plan to include sampling of cellular telephone numbers in future iterations.[32]

In conclusion, there are significant medical home disparities for large groups of vulnerable children, including CSHCN, racial/ethnic minorities, those whose primary language is not English, and those with public or no health insurance. However, the components of the medical home that contribute to these disparities differ between groups, with a lack of care coordination being central for children with special health care needs and a lack of family-centered care being key for the other groups. Medical home programs should avoid one-size-fits-all approaches and work with their patient populations to identify specific needs and prioritize the implementation of medical home services to meet those needs.

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Abbreviations

AAP	American Academy of Pediatrics
CSHCN	children with special health care needs
NSCH	National Survey of Children's Health

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Table 1

The Medical Home Composite, 2007 National Survey of Children's Health

Component	Criteria to be Considered a Medical Home ^a
Usual Source of Care	Yes and not an emergency department
Personal doctor or nurse	Yes
Family centered care	Provider usually/always <ul style="list-style-type: none"> • spent enough time • listened carefully • was sensitive to family values and customs • provided needed information • partnered in care Usually/always able to get someone other than a family member to help interpret (if needed)
Care coordination (if needed) ^b	Usually/always get help coordinating care Usually/always satisfied with communication among providers Usually/always satisfied with communication between providers, school, and other programs
No problems getting referrals (if needed)	Getting a referral not a problem

^a Children must meet each of the 5 components to be considered to have a medical home. All questions asked regarding 12 months prior to the survey

^b Only asked of children using two or more health services (preventive medical care, preventive dental care, mental health, or a specialist)

Table 2

Sample Characteristics, Medical Home Prevalence, and Medical Home Disparities for Selected Sociodemographic Characteristics, 2007 National Survey of Children's Health

	Unweighted n	Weighted %	Medical Home, ^a %	Medical Home Disparity, %
Total	91,642	--	58	--
Special health care needs				
No special health care need	73,290	81	59 ^b	Ref
CSHCN	18,352	19	50	-10
Race/ethnicity				
White, non-Hispanic	61,377	56	68 ^b	Ref
Hispanic	11,523	20	39	-29
African-American, non-Hispanic	8,873	14	44	-24
Multi/other	8,323	9	56	-12
Household primary language				
English	84,943	87	62 ^b	Ref
Non-English	6,643	13	29	-33
Health insurance				
Private	64,165	62	67 ^b	Ref
Public	19,748	29	45	-21
Uninsured	6,808	9	36	-31

^aMet all 5 components of medical home composite: usual source of care, person doctor/nurse, family-centered care, no problems getting referrals (if needed), care coordinator (if needed)

^bDifferences significant at $p < .001$

CSHCN = Children with special health care needs

Table 3

Proportion of Children Meeting Components of the Medical Home for Selected Sociodemographic Groups, 2007 National Survey of Children's Health

	USC, %	PDN, %	FCC, %	CC, % ^a	No problem getting referral, % ^b
Total population	93	92	67	87	97
Special health care needs					
No special health care need	93 ^c	92 ^c	68 ^c	91 ^c	98 ^c
CSHCN	95	95	66	71	93
Race/ethnicity					
White, non-Hispanic	97 ^c	96 ^c	77 ^c	89 ^c	98 ^c
Hispanic	85	86	49	84	97
African-American, non-Hispanic	89	89	55	85	96
Multi/other	93	92	64	88	97
Household primary language					
English	95 ^c	94 ^c	72 ^c	88 ^c	97
Non-English	81	83	37	84	98
Health insurance					
Private	96 ^c	95 ^c	75 ^c	89 ^c	98 ^c
Public	91	91	57	84	96
Uninsured	80	75	45	87	97

^aPercentage of each group that reported a need for care coordination and usually or always receive help with care coordination. Overall, 41% of parents reported a need for care coordination.

^bPercentage of each group that reported a need for a referral and had no problem getting a referral. Overall, 17% of parents reported a need for a referral.

^cDifferences significant at $p < .05$

USC = Usual source of care

PDN = Personal doctor or nurse

FCC = Family-centered care

CC = Care coordination

CSHCN = Children with Special Health Care Needs

Table 4

Adjusted Odds of Children Meeting Criteria for the Medical Home Composite and Each Component for Selected Sociodemographic Groups, 2007 National Survey of Children's Health

	Adjusted Odds Ratios ^a					
	Medical Home ^b	USC	PDN	FCC	No problem getting needed referral	Received needed care coordination
Special health care needs (ref = no SHCN)						
SHCN	0.71 (0.65-0.78)*	1.36 (1.07-1.73)***	1.75 (1.43-2.13)*	0.96 (0.86-1.06)	0.76 (0.59-0.98)***	0.55 (0.49-0.63)*
Race/ethnicity (ref = White, non-Hispanic)						
Hispanic	0.60 (0.52-0.69)*	0.54 (0.40-0.74)*	0.64 (0.49-0.83)**	0.61 (0.52-0.71)*	0.78 (0.55-1.10)	0.73 (0.58-0.92)**
African-American, non-Hispanic	0.51 (0.46-0.56)*	0.41 (0.32-0.51)*	0.55 (0.45-0.67)*	0.46 (0.42-0.52)*	0.87 (0.62-1.22)	0.78 (0.65-0.92)**
Multi/other	0.68 (0.59-0.79)*	0.53 (0.38-0.73)*	0.62 (0.48-0.79)*	0.61 (0.53-0.71)*	0.84 (0.63-1.12)	0.85 (0.70-1.03)
Household primary language (ref = English)						
Non-English	0.48 (0.40-0.59)*	0.65 (0.47-0.91)***	0.79 (0.59-1.05)	0.43 (0.35-0.52)*	0.68 (0.47-1.00)***	0.76 (0.58-1.00)***
Health insurance (ref = private)						
Public	0.84 (0.75-0.94)**	0.97 (0.77-1.23)	1.03 (0.84-1.27)	0.94 (0.83-1.07)	0.68 (0.49-0.95)***	0.92 (0.77-1.09)
Uninsured	0.52 (0.45-0.60)*	0.37 (0.29-0.48)*	0.30 (0.25-0.37)	0.52 (0.45-0.61)*	0.44 (0.28-0.69)*	0.47 (0.37-0.60)*

^a Adjusted for special health care needs, race/ethnicity, household primary language, health insurance, child age, parent-rated child health, household income, household education, and highest level of parent/guardian education

^b Met all 5 components of medical home composite: usual source of care, person doctor/nurse, family-centered care, no problems getting referrals (if needed), care coordination (if needed)

* p<.001

** p<.01

*** p<.05

SHCN = Children with special health care needs

USC = Usual source of care

PDN = Personal doctor or nurse

FCC = Family-centered care

Table 5

Proportion of Children Meeting Components of Family-Centered Care for Selected Sociodemographic Groups, 2007 National Survey of Children's Health

	Time ^a	Listened ^b	Sensitive to values ^c	Information ^d	Partnered ^e
Total population	79	89	89	85	88
Special health care needs					
No special health care need	79	90 ^f	89	85 ^f	88 ^f
CSHCN	80	88	89	83	86
Race/ethnicity					
White, non-Hispanic	88 ^f	93 ^f	94 ^f	90 ^f	92 ^f
Hispanic	62	81	79	77	81
African-American, non-Hispanic	70	86	83	80	83
Multi/other	78	89	88	79	84
Household primary language					
English	83 ^f	91 ^f	91 ^f	87 ^f	89 ^f
Non-English	53	78	74	70	76
Health insurance					
Private	86 ^f	93 ^f	94 ^f	89 ^f	91 ^f
Public	71	86	84	81	85
Uninsured	58	77	77	70	76

^aSpent enough time;

^bListened carefully;

^cWas sensitive to family values and customs;

^dProvided needed information;

^ePartnered in care.

^fDifferences significant at $p < .05$

CSHCN = Children with special health care needs