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Alexy Arauz Boudreau, Elizabeth Goodman, Daniel Kurowski, James M. Perrin, W. Carl Cooley and Karen Kuhlthau

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# Care Coordination and Unmet Specialty Care Among Children With Special Health Care Needs



**WHAT'S KNOWN ON THIS SUBJECT:** Parents of children with special health care needs and low-income children report more unmet specialty care needs. Care coordination is associated with increased and decreased referrals to specialty care, but whether care coordination is related to unmet needs is unknown.



**WHAT THIS STUDY ADDS:** Among children with special health care needs, care coordination is associated with lower odds of unmet specialty care needs regardless of whether care coordination was received within a medical home. This association was independent of household income.

## abstract

**OBJECTIVES:** Care coordination and the medical home may ensure access to specialty care. Children with special health care needs (CSHCN) have higher rates of specialty care use and unmet need compared with the general pediatric population. We hypothesized that care coordination, regardless of whether it was provided in a medical home, would decrease unmet specialty care needs among CSHCN and that the effect of care coordination would be greater among low-income families.

**METHODS:** Secondary data analysis of participants in the 2009–2010 National Survey of CSHCN who reported unmet specialty care needs and for whom care coordination and medical home status could be determined ( $n = 18\,905$ ). Logistic regression models explored the association of unmet need with care coordination and medical home status adjusting for household income.

**RESULTS:** Approximately 9% of CSHCN reported having unmet specialty care needs. Care coordination was associated with reduced odds of unmet specialty care need (without a medical home, odds ratio: 0.63, 95% confidence interval: 0.47–0.86; within a medical home, odds ratio: 0.22, 95% confidence interval: 0.16–0.29) with a greater reduction among those receiving care coordination within a medical home versus those receiving care coordination without a medical home. We did not find differences in the impact of care coordination by percentage of the federal poverty level.

**CONCLUSIONS:** Care coordination is associated with family report of decreased unmet specialty care needs among CSHCN independent of household income. The effect of care coordination is greater when care is received in a medical home. *Pediatrics* 2014;133:1046–1053

**AUTHORS:** Alexy Arauz Boudreau, MD, MPH,<sup>a,b</sup> Elizabeth Goodman, MD, MPH,<sup>a,b</sup> Daniel Kurowski, MS,<sup>c</sup> James M. Perrin, MD,<sup>a,b</sup> W. Carl Cooley, MD,<sup>d,e</sup> and Karen Kuhlthau, PhD<sup>a,b</sup>

<sup>a</sup>Division of General Academic Pediatrics / Center for Child and Adolescent Health Research and Policy, MassGeneral Hospital for Children, Boston, Massachusetts; <sup>b</sup>Harvard Medical School, Pediatrics, Boston, Massachusetts; <sup>c</sup>Visiting Nurse Service of New York Center for Homecare Policy & Research, New York, New York; <sup>d</sup>Crotched Mountain Foundation and Rehabilitation Center, Greenfield, New Hampshire; and <sup>e</sup>Department of Pediatrics, Geisel School of Medicine at Dartmouth, Hanover, New Hampshire

### KEY WORDS

medical home, health care delivery/access, quality of care, children

### ABBREVIATIONS

AAP—American Academy of Pediatrics

CSHCN—children with special health care needs

FPL—federal poverty level

NS-CSHCN—National Survey of Children with Special Health Care Needs

Dr Arauz Boudreau conceptualized and designed the study, oversaw and participated in the analysis, and drafted the initial manuscript; Dr Goodman advised on the design and analytical approach of the study and critically reviewed and revised the manuscript; Mr Kurowski carried out the initial analyses and reviewed and revised the manuscript; Dr Perrin participated in conceptualizing the study and reviewed the manuscript; Dr Cooley critically reviewed and revised the manuscript; Dr Kuhlthau participated in the conceptualization and design of the study, advised on the analytical approach of the study, and critically reviewed and revised the manuscript; and all authors approved the final manuscript as submitted.

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Address correspondence to Alexy D. Arauz Boudreau, MD, MPH, MassGeneral Hospital for Children, Center for Child and Adolescent Health Research and Policy, 15th Floor—C100, 100 Cambridge St, Boston, MA 02114. E-mail: [aaaruz@partners.org](mailto:aaaruz@partners.org)

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Estimates of specialist use among the pediatric population vary between 13% to 22% but are highest among children with chronic conditions.<sup>1–3</sup> National estimates of unmet need for specialty care are 6%<sup>2</sup> with higher rates among children with special health care needs (CSHCN; 7.2%).<sup>4</sup> Specialty care use also varies, with lower rates of use among minorities, uninsured children, those with less than high school–educated parents, and children in low-income households regardless of insurance type.<sup>1,4–7</sup> In addition, low-income families and less educated families report less perceived need for specialist visits even though they report their children have more severe functional limitations than higher-income parents.<sup>8</sup> Among CSHCN, care coordination has been identified as a potential mechanism to decrease unmet specialty care needs.<sup>9</sup> The American Academy of Pediatrics (AAP) defines care coordination as “a process that links children and youth with special health care needs and their families with appropriate services and resources in a coordinated effort to achieve good health.”<sup>10</sup> Care coordination aims to enhance health and reduce cost.<sup>10,11</sup> It has been associated with fewer problems obtaining referrals to specialists and reduced emergency department visits, hospital admissions, length of hospital stay, and inpatient charges. Patient satisfaction, family-provider relationships, the financial burden of health costs and the impact of children’s health on parental work have also been positively associated with care coordination.<sup>12–16</sup> However, the association between care coordination and improved health outcomes is inconsistent,<sup>17</sup> and the relationship between care coordination and health-related outcomes for CSHCN is not known.<sup>18</sup> Queries of large national surveys to examine the association between care coordination and obtaining family-perceived needed specialty care are currently lacking.

Fewer CSHCN with adequate care coordination are publicly insured or uninsured compared with CSHCN with inadequate care coordination. Among those reporting inadequate care coordination, families with lower socioeconomic status report using fewer services compared with families with higher socioeconomic status<sup>13</sup>; studies exploring if care coordination could mitigate the difference in services used based on income are needed.

The medical home has been proposed as model of primary care to improve health care delivery and outcomes, including effectiveness, safety, timeliness, and patients’ experience of care.<sup>15</sup> By definition, a medical home provides care coordination and other important functionalities.<sup>19</sup> Lack of a medical home has been associated with increased risk of forgone or delayed care among children<sup>20</sup> and, for families of CSHCN, increased out-of-pocket health-related costs<sup>21</sup> and fewer referrals to needed specialty care.<sup>12</sup> Conversely, rates of visits to specialists have been demonstrated to decrease among CSHCN in medical homes.<sup>22</sup> This inconsistent association between the medical home and health-related outcomes for CSHCN highlights the need for additional studies.<sup>23–25</sup>

Our study examines the association of care coordination, a key component of the medical home, with family-perceived unmet specialty care needs for CSHCN. We hypothesize that having care coordination will be associated with decreased likelihood of unmet specialty care needs for CSHCN and that this decrease in unmet need will be enhanced if the care coordination is provided within a medical home. We further examine whether these associations are moderated by household income, positing that the association of care coordination and unmet specialty care will be greater for children living in low-income families than children living in higher income families.

## METHODS

### Sample

In this cross-sectional study, we conducted analyses of data from the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN).<sup>26,27</sup> The NS-CSHCN is a nationally representative randomly selected telephone survey sponsored by the Maternal Child Health Bureau and conducted by the National Center for Health Statistics of the Centers for Disease Control and Prevention.<sup>28</sup> The parent or guardian of 40 242 CSHCN (67.1% of those contacted) between the ages of 0 and 17 years completed a 25- to 30-minute telephone interview. Data collection occurred between July 2007 and March 2011. The NS-CSHCN identified CSHCN using the Children With Special Health Care Needs Screener.<sup>29</sup> Data documentation and additional details on the sampling methodology are available elsewhere.<sup>26</sup> Our analysis only included CSHCN whose parent or guardian reported the child needed specialty care and whose care coordination and medical home status could be determined as reported in the NS-CSHCN (unweighted  $N = 18\,905$ , 47.0%).

### Main Variables (Unmet Need, Care Coordination, and Medical Home)

Unmet specialty care was determined by family report on the NS-CSHCN of not having received all needed care from specialty doctors. A child was determined to have “effective care coordination” using the Child and Adolescent Health Measurement Initiative algorithm.<sup>30</sup> The criteria for effective care coordination are met if (1) the family usually or always receives sufficient help coordinating care when needed and (2) the parent/guardian was very satisfied with communication between the specialist/specialty program and the provider if needed (specific wording of questions are in Table 1).

**TABLE 1** NS-CSHCN 2009–2010 Items Used to Define Effective Care Coordination

Care Coordination Component	NS-CSHCN Question	Response Category
Family usually or always receives sufficient help coordinating care when needed	C5Q12: Does anyone help you arrange or coordinate [SC]'s care among the different doctors or services that [he/she] uses?	Yes (vs no)
	C5Q17: [During the past 12 mo/since [his/her] birth], have you felt that you could have used extra help arranging or coordinating [SC]'s care among these different health care providers or services?	Yes (vs no)
	C5Q09: [During the past 12 mo/since [his/her] birth], how often did you get as much help as you wanted with arranging or coordinating [SC]'s care? Would you say never, sometimes, or usually?	Usually (vs sometimes or never)
The parent/guardian was very satisfied with communication between the specialist/specialty program and the provider if needed	C5Q10: Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with the communication among [SC]'s doctors and other health care providers?	Very satisfied (vs somewhat satisfied, dissatisfied, or very dissatisfied); No communication needed or wanted; excluded
	C5Q05: Do [SC]'s doctors or other health care providers need to communicate with [his/her] school, early intervention program, child care providers, vocational education or rehabilitation program?	Yes (vs no)
	C5Q06: Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied with that communication?	Very satisfied (vs somewhat satisfied, dissatisfied, or very dissatisfied)

SC, selected child.

Medical home status was operationalized per the Child and Adolescent Health Measurement Initiative algorithm<sup>50</sup> used by the Maternal Child Health Bureau with the National Survey of Children's Health and NS-CSHCN.<sup>20,21,28,31–34</sup> This medical home measure uses the AAP definition of the medical home, representing 5 of 7 elements of the AAP criteria medical home criteria. The 5 component variables are constructed from a total of 22 NS-CSHCN survey items. They include (1) personal doctor or nurse, (2) usual source for sick and well care, (3) family-centered care, (4) problems getting needed referrals, and (5) effective care coordination when needed (as defined earlier). To qualify as having a medical home, children's parent or guardian must report the child having a personal doctor or nurse, a usual source for care, receiving family-centered care (usually or always), having no problem obtaining needed referrals, and receiving effective care coordination when needed.<sup>35</sup> Because care coordination could occur for a family on

its own or within the context of medical home, we created a 3-category variable to describe care coordination status: no care coordination, care coordination without a medical home, or care coordination within a medical home.

Candidate control variables were chosen based on previous research.<sup>5,36</sup> These included child's age, gender, race/ethnicity (Hispanic; non-Hispanic, white; non-Hispanic, African American; other), primary household language (English or other), highest parental education level (less than high school, high school graduate, and more than high school), type of insurance (public, any private, uninsured), insurance status in the past 12 months (insured or not insured at any time), whether the child received routine preventative care in the past 12 months, whether the child's health was causing financial problems, and federal poverty level (FPL) categorized into 4 levels:  $\leq 100\%$ , 100% to 199%, 200% to 399%, and above 400% of FPL. Both primary household language and household

FPL were imputed for missing responses by the National Center for Health Statistics.<sup>37</sup>

### Analytic Strategy

Initially, descriptive statistics for the dependent and independent variables were completed, including the percentage of children with unmet and met specialty care at each FPL by their care coordination status: no care coordination, care coordination without a medical home, and care coordination within a medical home. Second, unadjusted and adjusted multivariable logistic regression models were developed to model unmet specialty care need with care coordination status. The model measured the odds of a child having an unmet specialty care need, adjusting for all covariates.  $\chi^2$  statistics were used to test the association between each control variable and unmet specialty care. Only variables at a 0.10 significance level in the  $\chi^2$  statistics were kept in the final model. Multicollinearity analysis was done to ensure chosen predictor variables were

not highly correlated with other variables or groups of variables. After the final multivariable model was developed, the interaction between FPL and care coordination was tested. All analysis controlled for the complex sampling strategy per National Center for Health Statistics guidelines; analyses were done using SAS SURVEY PROCEDURES v9.2 (SAS Institute, Cary, NC).

## RESULTS

### Demographic Characteristics

Most children were white non-Hispanic (64.8%) and had at least 1 parent with more than a high school education (75.6%; Table 2). Approximately one-third lived in households with a FPL >400%. Nearly 9% of children reported unmet specialty care needs. Of respondents in our sample, 16% responded that their family usually or always had care coordination without a medical home, whereas 39% reported receiving care within a medical home.

Table 3 shows the percentage of CSHCN with unmet and met specialty care needs at each FPL for all children in our sample by care coordination status for the whole sample. In all 3 categories of care coordination (no care coordination, care coordination without a medical home, and care coordination within a medical home) with each increase in FPL category, the percentage of families reporting unmet specialty care is smaller. In addition, at each FPL category, the percentage of families reporting unmet specialty care needs was smallest among those with care coordination within a medical home compared with the other 2 categories of care coordination.

### Multivariable Logistic Regression Analyses

In both unadjusted and adjusted analyses, receiving care coordination without and within a medical home was

**TABLE 2** Children With Special Health Care Needs: Demographics, Care Coordination, Medical Home, and Unmet Specialty Care Needs

Demographic Characteristic	Unweighted <i>N</i>	% (95% CI)
Gender		
Male	11 079	57.9 (56.6–59.2)
Female	7796	42.1 (40.8–43.4)
Age (y)		
0–5	3974	23.5 (22.4–24.6)
6–11	6947	35.6 (34.3–36.8)
12–17	7984	40.9 (39.6–42.1)
Race/ethnicity		
Hispanic	1962	15.5 (14.4–16.6)
Non-Hispanic, white	13 896	64.8 (63.5–66.1)
Non-Hispanic, African American	1392	12.1 (11.1–13.1)
Other	1655	7.5 (6.8–8.3)
Primary language spoken at home		
English	18 298	93.9 (93.1–94.7)
Other than English	607	6.1 (5.3–6.9)
Parental highest education		
Less than high school	689	8.2 (7.2–9.2)
High school	2221	16.2 (15.1–17.2)
More than high school	15 995	75.6 (74.3–76.9)
Type of insurance at time of survey		
Public	4635	32.1 (30.8–33.5)
Any private	13 140	64.9 (63.5–66.2)
Uninsured	439	3.0 (2.5–3.5)
Insurance status		
Not insured anytime (past 12 mo)	1286	9.2 (8.2–10.1)
Insured (past 12 mo)	17 571	90.8 (89.9–91.8)
Routine preventive medical care in past 12 mo		
Received a preventive well visit	15 166	79.5 (78.4–80.6)
Did not receive a preventive well visit	3618	20.5 (19.4–21.6)
FPL		
<100%	2545	17.8 (16.7–18.8)
100%–199%	3353	20.7 (19.6–21.9)
200%–399%	6034	29.4 (28.3–30.6)
≥400%	6973	32.1 (30.9–33.2)
Causing financial problems		
Yes	5144	29.8 (28.5–31.0)
No	13 671	70.2 (70.0–71.5)
Care coordination and medical home		
Care coordination, no medical home	2734	15.9 (14.9–16.9)
Care coordination, medical home	8117	39.3 (38.1–40.5)
No care coordination, no medical home	8054	44.8 (43.5–46.1)
Outcome		
Received needed care from a specialist		
Yes	17 560	91.3 (90.3–92.0)
No	1345	8.8 (8.0–9.7)

CI, confidence interval.

significantly associated with reporting unmet need compared with families reporting no care coordination (care coordination without medical home adjusted odds ratio: 0.63 (95% confidence interval 0.47–0.86); care coordination with medical home adjusted odds ratio: 0.22 (95% confidence interval 0.16–0.29; Table 4). After adjusting for a child's age, gender, race/ethnicity, insurance type, continual in-

urance throughout the year, medical expenses posing a family financial burden, having preventative care in the past 12 months, and primary language spoken at home, parents of CSHCN with care coordination without a medical home were one-third less likely to report unmet specialty care needs compared with those without care coordination. Similarly, parents of CSHCN who had care coordination within a medical

**TABLE 3** Percentage of Children With Unmet and Met Specialty Care at Each FPL by Care Coordination Received

Care Coordination Category	FPL											
	<100%			100%–199%			200%–399%			≥400%		
	N	%	(95% CI)	N	%	(95% CI)	N	%	(95% CI)	N	%	(95% CI)
All CSHCN												
With unmet specialty care need	358	16.7	(14.0–19.4)	358	12.2	(10.0–14.5)	398	7.9	(6.5–9.3)	231	3.1	(2.5–3.7)
With met specialty care need	2187	83.3	(80.6–86.0)	2995	87.8	(85.5–90.0)	5636	92.1	(90.7–93.5)	6742	96.9	(96.3–97.5)
No care coordination												
With unmet specialty care need	251	22.2	(18.2–26.1)	239	17.4	(13.6–21.3)	293	13.4	(10.8–16.0)	178	6.0	(4.6–7.4)
With met specialty care need	1013	77.8	(73.9–81.8)	1250	82.6	(78.7–86.4)	2251	86.6	(84.0–89.2)	2579	94.0	(92.6–95.4)
Care coordination without medical home												
With unmet specialty care need	62	18.5	(11.1–25.9)	67	14.6	(8.8–20.4)	53	7.3	(4.1–10.6)	15	1.2	(0.4–2.0)
With met specialty care need	413	81.5	(74.1–88.9)	521	85.4	(79.6–91.2)	798	92.7	(89.4–95.9)	805	98.8	(98.0–99.6)
Care coordination within medical home												
With unmet specialty care need	45	6.2	(3.7–8.7)	52	3.5	(1.6–5.3)	52	2.3	(0.9–3.7)	38	1.1	(0.6–1.6)
With met specialty care need	761	93.8	(91.3–96.3)	1224	96.5	(94.7–98.4)	2587	97.7	(96.3–99.1)	3358	98.9	(98.4–99.4)

Ns are unweighted. CI, confidence interval.

home were three-fourths less likely to report unmet specialty care needs compared with children without care coordination. Hence, the presence of care coordination was associated with decreased unmet specialty care needs, regardless of medical home status. However, children whose care coordination was delivered within a medical home were significantly less likely by a third to have reported unmet specialty care needs compared with those receiving care coordination without a medical home, adjusting for all covariates.

In unadjusted and adjusted analysis, CSHCN living in lower-income households had a greater likelihood of having unmet specialty care needs than those living in higher-income households (Tables 3 and 4). CSHCN in FPL 100% to 199% were >25% less likely to have unmet need compared with those living in households <100% FPL, whereas those in households with incomes >400% FPL had nearly a two-thirds reduction in their likelihood of unmet needs compared with children in households <100% FPL (Table 4). In the multivariable model, there was no significant interaction between FPL and care coordination (*P* interaction term = .0756).

## DISCUSSION

Nationally care coordination within the medical home has been embraced as a key process to improve health care outcomes. The Children's Health Insurance Program Reauthorization Act of 2009, the Patient Protection and Affordable Care Act of 2010, and numerous state and medical professional associations have instituted efforts to promote care coordination and the adoption of the medical home model. Our findings support the notion that care coordination and the medical home may improve access to care. We show that the provision of care coordination to CSHCN is associated with decreased unmet specialty care needs. Furthermore, we demonstrate that the likelihood of family-reported unmet specialty care need is smallest among those whose care coordination is provided in the context of a medical home. Importantly, the beneficial association of delivering care coordination persists across all income levels.

Care coordination and the medical home are thought to improve care by ensuring familiarity between a family and the health care system, making families partners in their children's care, improving information sharing, and facilitating and tracking navigation

of the health care system. Low-income families and less educated families report decreased perceived specialty care needs.<sup>8</sup> The information sharing that occurs in a medical home during care coordination may increase families' awareness of needs and availability of services, increasing the likelihood of successful connections especially for families with low-socioeconomic status. Previous research has shown that care coordination and the medical home are associated with reports of obtaining needed referrals for care.<sup>13</sup> Our study moves downstream in the care process to show that the provision of care coordination to CSHCN is associated with receiving specialty health care that families perceive as needed. Studies have shown both increased<sup>38</sup> and decreased<sup>22</sup> specialty visits for CSHCN receiving care coordination, presumably due to increased access and the elimination of unneeded visits. However these studies do not assess family satisfaction with the increase or decrease in visits or whether such reductions were medically appropriate. In a fee-for-service environment, the medical home can foster trust, allowing a family to follow through with a referral even at an additional cost or come to understand and accept that a denied referral is not

**TABLE 4** Unadjusted and Adjusted Association of Unmet Specialty Care With Care Coordination Received and Federal Poverty Level

	Unadjusted Odds Ratio	Adjusted Model <sup>a</sup> Odds Ratio
No care coordination or medical home	Reference	Reference
Care coordination without a medical home	0.71 (0.52–0.96)	0.63 (0.47–0.86)
Care coordination within a medical home	0.17 (0.12–0.22)	0.22 (0.16–0.29)
FPL <100%	Reference	Reference
FPL 100%–199%	0.70 (0.53–0.94)	0.77 (0.56–1.09)
FPL 200%–399%	0.43 (0.33–0.57)	0.62 (0.44–0.89)
FPL ≥400%	0.16 (0.12–0.21)	0.30 (0.20–0.44)

<sup>a</sup> Results from logistic regression controlling for child age, gender, race/ethnicity, primary language spoken at home, insurance type, continual insurance throughout the year, medical expenses posing a financial burden to the family, and having preventative care in the past 12 months.

necessary, trusting the clinical judgment of their usual provider, resulting in more appropriate referrals. Recognizing the potential disconnect between referrals to specialty care and the delivery of appropriate care, our study addressed the qualitative family experience of care rather than the quantitative numbers of specialty referrals or visits. Additional studies that use individual patient medical information are needed to address whether care coordination without or within the medical home is associated with improved medical appropriateness of specialty visits.

The best strategies to implement care coordination and deliver care within a medical home are still being determined, and efforts to determine the elements that offer the greatest health care benefits are ongoing.<sup>14,39</sup> Our study aligns with national efforts to implement medical homes to reduce unmet specialty care. However, our findings suggest the implementation of care coordination is an effective means to decrease family-perceived unmet need as an interim step on the journey to comprehensive medical home transformation. As the ACA drives primary care toward using a medical home model, focusing on care coordination may deliver substantial early benefits to this arduous process.

Children living at lower FPLs are known to have greater unmet needs in health

care and poorer quality of care,<sup>40</sup> as was also shown in this study. Children at all income levels show a beneficial association between the provision of care coordination and reductions in unmet specialty care needs. Although families with higher incomes may have greater resources to act upon the assistance that care coordination provides (factors such as transportation, work flexibility and understanding of the health care system), care coordination appears to help low income families access family perceived needed specialty care at approximately the same rate.

The potential for the medical home to reduce health care disparities among low socioeconomic and minority populations has been demonstrated<sup>41,42</sup>; children with a medical home show a smaller disparity in care received compared with low socioeconomic and minority children without a medical home.<sup>14</sup> Our study reveals income-related disparities in reporting unmet specialty care needs. CSHCN in lower-income households may report higher percentages of unmet specialty needs due to lack of financial resources, lack of knowledge as to how to access specialists, availability of specialists or perceived need, or lack of transportation or ability to navigate the health care system. Cost of services, followed by health plan issues were the top reported reasons for unmet specialty need in previous studies.<sup>8</sup> However, at each FPL, CSHCN receiving care

coordination were more likely to report decreased unmet specialty care needs than those low-income children without care coordination.

This study has several limitations. We are unable to assess if specialty care was medically needed, and we are limited to testing the association of family-perceived unmet specialty care needs. However, consumer-based perception of quality and need of care are widely used measures of health care delivery. Although numerous publications define the medical home as we have done with the NS-CSHCN,<sup>20,21,36,41,43,44</sup> the items included to meet these criteria do not capture all activities of the medical home or care coordination (such as patient registries, team based care, comanagement arrangements with specialists, and other concepts of the patient-centered medical home).<sup>45</sup> However, the items used to define the constructs of the medical home and care coordination are aligned with the AAP definitions.<sup>31,32</sup> Finally, as with all cross-sectional survey studies, we can only report an association and not causality; it may be that families able to access needed specialty care are also more able to secure a medical home and care coordination.

## CONCLUSIONS

Care coordination without and within a medical home is associated with decreased odds of unmet specialty care needs among CSHCN who needed a specialty care referral regardless of household income. The decrease in unmet specialty care needs is larger among those receiving care coordination within a medical home compared with those receiving care coordination without a medical home. Although children living in higher income brackets may be better equipped to harness benefits provided by care coordination, low-income children may gain improved access to needed specialty

care with access to care coordination within and even without a medical home. Additional work is needed to elucidate the directionality of these associations, the mechanisms through which the associ-

ations act, and the essential elements of care coordination that are associated with improved access. Furthermore, substantial payment reform will be needed for care coordination to become

widely available. Improved training and revisions to professional standards will also be needed to ensure that the benefits of care coordination are available to all.

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Alexy Arauz Boudreau, Elizabeth Goodman, Daniel Kurowski, James M. Perrin, W. Carl Cooley and Karen Kuhlthau

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