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# Medical Homes for Children With Autism: A Physician Survey

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## What's Known on This Subject

Primary care physicians are important in the care of children with autism. Parents of children with autism have reported a lack of medical homes and low physician confidence. In previous studies, physicians reported a need for improved knowledge of autism.

## What This Study Adds

Information regarding physicians' experiences caring for children with autism could inform physician education, practice parameters, and models of primary care which have the potential to improve physician knowledge, parent satisfaction and medical home care for children with autism.

## ABSTRACT

**BACKGROUND.** Primary care physicians can enhance the health and quality of life of children with autism by providing high-quality and comprehensive primary care.

**OBJECTIVE.** To explore physicians' perspectives on primary care for children with autism.

**METHODS.** National mail and e-mail surveys were sent to a random sample of 2325 general pediatricians and 775 family physicians from April 2007 to October 2007.

**RESULTS.** The response rate was 19%. Physicians reported significantly lower overall self-perceived competency, a greater need for primary care improvement, and a greater desire for education for children with autism compared with both children with other neurodevelopmental conditions and those with chronic/complex medical conditions. The following barriers to providing primary care were endorsed as greater for children with autism: lack of care coordination, reimbursement and physician education, family skeptical of traditional medicine and vaccines, and patients using complementary alternative medicine. Adjusting for key demographic variables, predictors of both higher perceived autism competency and encouraging an empirically supported therapy, applied behavior analysis, included having a greater number of autism patient visits, having a friend or relative with autism, and previous training about autism.

**CONCLUSIONS.** Primary care physicians report a lack of self-perceived competency, a desire for education, and a need for improvement in primary care for children with autism. Physician education is needed to improve primary care for children with autism. Practice parameters and models of care should address physician-reported barriers to care. *Pediatrics* 2009;123:966–971

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### Key Words

autism, medical home, physician survey, primary care

### Abbreviations

CAM—complementary alternative medicine

CME—continuing medical education

ABA—applied behavior analysis

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**P** RIMARY CARE PROVIDERS play an important role in the care of children with autism. On average, primary care providers care for at least 10 patients with autism.<sup>1</sup> Children with autism visit their physicians more frequently<sup>2</sup> and have increased rates of comorbid medical conditions, mental health problems, behavioral concerns, and developmental delays.<sup>2–11</sup> Primary care providers are called on to provide comprehensive medical home care<sup>12</sup> and guide parents through a growing and shifting array of medical subspecialty care, psychopharmacologic and/or behavioral interventions, educational and rehabilitation therapies, and complementary and alternative medicine (CAM) treatments.<sup>13</sup> Unfortunately, parents of children with autism report that their children are less likely to have medical home care compared with parents of children with other special health care needs.<sup>14</sup> In addition, some parents of children with autism express low confidence and dissatisfaction with physicians' abilities to care for their children.<sup>15,16</sup> Furthermore, primary care models are often not adequately structured to provide comprehensive care for children with complex health care needs, such as those with autism. This can lead to fragmented care delivery.<sup>17</sup>

Physicians play an integral role in primary care, yet there is little information available regarding physicians' experiences and perceived challenges specifically for children with autism. Physicians in previous small, regional studies have demonstrated deficits in autism screening and knowledge.<sup>1,18</sup> In addition, physicians have reported challenges to providing coordinated care for all children with special health care needs.<sup>19</sup> The physicians' perspective could inform physician education, practice parameters, and models of primary care factors, which have the potential to improve parent satisfaction and medical home care for children with autism.

This study sought to examine physicians' perspectives regarding primary medical care for children with autism. We hypothesized that physicians would report lower competency, a greater need for primary care improvement, a greater desire for education, and greater barriers to care for children with autism compared with children with other neurodevelopmental conditions and children with chronic/complex medical conditions.

## METHODS

### Study Sample

We drew a national random sample of 15 000 physicians from the American Medical Association Masterfile, the most comprehensive physician listing of all licensed physicians in the United States, including both American Medical Association members and nonmembers. The sample included allopathic and osteopathic physicians in office-based, direct patient care whose board certification and self-described primary specialty was pediatrics or family medicine. We excluded physicians with a sub-board or secondary specialty, and those who were >70 years of age, resident physicians, or practicing at military or federal facilities. From the original sample of 15 000 physicians, the survey was sent to a random sample of 3100 physicians (75% pediatricians and 25% family medicine physicians). Approximately three fourths of office visits by patients <18 years of age are with pediatricians and approximately one fourth are with family physicians.<sup>20</sup> Medical Marketing Service Inc, a contracted vendor, obtained the e-mail and mailing addresses of participants through publisher/association data that is updated monthly. The University of Minnesota institutional review board approved the study.

### Survey Instrument and Administration

We developed an instrument consisting of 27 items regarding demographics (10), and questions regarding self-perceived competency (4), perceptions of primary care in the United States (1), barriers to care (9), applied behavior analysis (ABA) treatment recommendations (1), and desire for autism training (2). Demographic data included: specialty, degree, years out of residency, age, gender, number of patient visits per year, having a friend/relative with autism, and whether autism training was obtained in continuing medical education (CME), residency, or medical school. The instrument consisted of multiple-choice questions and Likert scales of agreement. Likert response categories ranged from 1, representing "poor, never, or strongly disagree," to 7, representing "excellent, always, or strongly agree," depending on the item. Physicians identified "barriers that I experience when caring for children in my practice" from a list of potential barriers. Regarding ABA, we divided physicians into 2 groups: those who encouraged ABA and those who did not encourage ABA (including those who "discouraged, were not knowledgeable enough to advise," or "accepted a family's decision if already using it"). Autism included all the autism spectrum disorders: classic autism, Asperger syndrome, and pervasive developmental disorder—not otherwise specified.

We compared children with autism to children with other neurodevelopmental conditions and those with chronic/complex medical conditions. Examples of neurodevelopmental conditions listed were: hypoxic ischemic encephalopathy, cerebral palsy, mental retardation, and attention-deficit/hyperactivity disorder. Examples of chronic/complex medical conditions given were: congenital heart disease, chronic asthma, early cystic fibrosis, and diabetes. We conducted pilot testing on a convenience sample of 15 pediatric and family medicine physicians and revised the survey to ensure clarity and ease of administration. The survey took ~10 minutes to complete and is available on request to the author. We sent the e-mail survey 3 times in April, May, and June of 2007. The chance to win a \$200 Amazon gift certificate was provided as an incentive. The survey was mailed once in October 2007 following the e-mailed surveys. A letter explaining the purpose of the study and contact information for the first author accompanied all surveys.

### Data Analysis

Dichotomous demographic variables were compared for respondents and nonrespondents by using the  $\chi^2$  statistic. Mean scores (1–7) were calculated for Likert items regarding competency, evaluation of primary care, and desire for additional training. Questions regarding capacity, resources, trust, and satisfaction were combined into an overall competency scale. Internal consistency of scales was evaluated with Cronbach's  $\alpha$ . *T* tests were used to compare mean scores for competency items, desire for education, evaluation of primary care, and reported barriers for the 3 medical conditions: autism, neurodevelopmental conditions, and chronic/complex medical conditions. Frequencies of reported barriers were compared between the 3 conditions by using McNemar's test. Linear regression models were used to evaluate predictors of overall autism competency while adjusting for key variables. Logistic regression was used to evaluate predictors of encouraging ABA while adjusting for key variables. All analyses were conducted by using SAS 9.1 (SAS Inc, Cary, NC).

## RESULTS

Responses totaled 539 (346 e-mail and 193 mailing) from 2801 eligible physicians resulting in a 19% response rate. Ninety percent of respondents were pediatricians.

Respondents were more likely to be pediatricians rather than family physicians, have an MD degree rather than a DO degree, be older, and have more years from residency training than nonrespondents, as seen in Table 1. Respondents and nonrespondents did not differ significantly on gender. Study respondents reported an average of 37 visits with patients with autism per year, 98 visits with patients with neurodevelopmental conditions, and 145 visits with patients with chronic/complex conditions. Overall, 167 (13%) of respondents reported having a close friend or relative with autism. Respondents indicated that they had obtained specific autism training in the following settings: medical school (37%

**TABLE 1 Demographic Characteristics of Physician Respondents and Nonrespondents**

| Demographic Characteristics                                      | Respondents | Nonrespondents | <i>P</i> < .001 |
|--|-------------|----------------|-----------------|
| Pediatrician, <i>n</i> (%) (vs family physician)                 | 449 (90)    | 1796 (73)      | <.001           |
| Medical doctor, <i>n</i> (%) (vs doctor of osteopathic medicine) | 468 (93)    | 2215 (90)      | .04             |
| Mean age, y  | 47          | 45             | <.001           |
| Mean postresidency duration, y                                   | 15          | 13             | <.001           |
| Male, <i>n</i> (%)   | 237 (50)    | 1255 (51)      | .87             |

[*n* = 199]), residency (57% [*n* = 309]), and continuing medical education (CME) (70% [*n* = 377]).

As shown in Table 2, physicians reported their overall competency in providing primary care as significantly lower for children with autism as compared with children with neurodevelopmental conditions and chronic/complex medical conditions. Cronbach's  $\alpha$  for this competency scale was 0.86. Lower overall autism competency was reported for all 4 scale components: capacity to provide primary care, availability of resources to answer a family's questions, family trust, and family satisfaction. Physicians rated all 4 components as significantly lower for children with autism compared with that for children with neurodevelopmental conditions and chronic/complex medical conditions.

Physicians were significantly more likely to report that "primary care in the United States needs improvement" regarding the care of children with autism when compared with children with neurodevelopmental and chronic/complex medical conditions (Table 2).

Physicians reported a significantly greater desire for primary care and CAM training for children with autism compared with similar training for children with neurodevelopmental and chronic/complex medical conditions (Table 2).

Barriers to providing primary care are reported in Table 3. Barriers noted as significantly greater for children with autism compared with barriers for children with both neurodevelopmental and chronic/complex

medical conditions included: lack of coordination, reimbursement and physician education, families being skeptical of traditional medicine and vaccines, and patients' frequent CAM use.

Controlling for gender, age, years out of residency, specialty, and degree, significant predictors of higher self-perceived competency were a greater number of autism patient visits and receiving education about autism in residency. Autism education through CME and having a friend or relative with autism approached significance with *P* < .07. In addition, being a pediatrician rather than family physician and being male were significantly associated with higher self-perceived autism competency in each of the multivariate models. Controlling for the same demographic factors, significant predictors of encouraging empirically supported ABA treatment were a greater number of autism patient visits, receiving CME about autism, having a friend or relative with autism, and higher self-perceived competency in caring for children with autism.

## DISCUSSION

Consistent with the parents of children with autism who expressed low confidence<sup>15</sup> and dissatisfaction<sup>16</sup> with their children's physicians, physicians in this survey reported feeling less competent providing primary care for children with autism compared to children with neurodevelopmental conditions and chronic/complex conditions. Physicians reporting greater competency were

**TABLE 2 Items Regarding Providing Primary Care for Patients With Autism and Neurodevelopmental and Chronic/Complex Conditions**

| Items  | Patients With Autism (Reference Group), Mean (SD) | Patients With Neurodevelopmental Conditions, Mean (SD) | Patients With Chronic/Complex Conditions, Mean (SD) |
|--|---|--|---|
| I have the capacity to provide primary care for these pediatric patients (poor to excellent)                                       | 4.80 (1.37)                                       | 4.88 (1.31) <sup>a</sup>                               | 5.24 (1.26) <sup>a</sup>                            |
| I have the resources to answer a family's questions related to the child's condition (strongly disagree to strongly agree)         | 4.68 (1.48)                                       | 4.82 (1.40) <sup>a</sup>                               | 5.17 (1.35) <sup>a</sup>                            |
| Pediatric patients and their families trust me and will follow my instructions or advice (strongly disagree to strongly agree)     | 5.31 (1.22)                                       | 5.52 (1.06) <sup>a</sup>                               | 5.67 (1.04) <sup>a</sup>                            |
| Pediatric patients and their families are satisfied with the primary care I provide (strongly disagree to strongly agree)          | 5.41 (1.24)                                       | 5.55 (1.14) <sup>a</sup>                               | 5.69 (1.10) <sup>a</sup>                            |
| Autism competency (overall score; above 4 components combined)   | 4.92 (1.16)                                       | 5.18 (1.05) <sup>a</sup>                               | 5.43 (1.03) <sup>a</sup>                            |
| In general, primary care in the United States needs improvement for these pediatric patients (strongly disagree to strongly agree) | 6.18 (1.05)                                       | 6.08 (1.09) <sup>a</sup>                               | 5.91 (1.19) <sup>a</sup>                            |
| Do you desire more primary care training for these pediatric patients (never to always)?   | 5.82 (1.34)                                       | 5.60 (1.41) <sup>a</sup>                               | 5.47 (1.49) <sup>a</sup>                            |
| Do you desire more complementary alternative medicine training for these patients (never to always)?                               | 4.94 (1.82)                                       | 4.84 (1.81) <sup>a</sup>                               | 4.81 (1.81) <sup>a</sup>                            |

All items were rated on a 1 to 7 Likert scale.

<sup>a</sup> *P* < .001.

**TABLE 3 Physician-Reported Barriers to Providing Primary Care for Patients With Autism and Neurodevelopmental and Chronic/Complex Conditions**

| Barrier   | % Reporting as Barrier for Patients With Autism (Reference Group) (n = 539) | % Reporting as Barrier for Patients With Neurodevelopmental Conditions (n = 539) | % Reporting as Barrier for Patients With Chronic/Complex Conditions (n = 539) |
|---|---|--|---|
| Lack of care coordination   | 60  | 51 <sup>a</sup>  | 53 <sup>b</sup>   |
| Lack of reimbursement   | 60  | 40 <sup>a</sup>  | 40 <sup>a</sup>   |
| Family is skeptical of traditional medicine   | 43  | 23 <sup>a</sup>  | 25 <sup>a</sup>   |
| Family is skeptical of vaccines   | 66  | 22 <sup>a</sup>  | 12 <sup>a</sup>   |
| Patient's frequent use of complementary alternative medicine                          | 48  | 19 <sup>a</sup>  | 10 <sup>a</sup>   |
| Lack of practice guidelines   | 48  | 42 <sup>a</sup>  | 47  |
| Lack of time during office visit  | 65  | 57 <sup>a</sup>  | 65  |
| Patient's use of outside providers (eg, specialty doctors, therapists, chiropractors) | 24  | 25   | 21  |
| Lack of provider education about the disorder   | 30  | 35 <sup>b</sup>  | 26 <sup>b</sup>   |

<sup>a</sup>  $P < .001$ .

<sup>b</sup>  $P < .05$ .

more likely to encourage empirically supported ABA treatment,<sup>21,22</sup> providing some validation of the competence measure.<sup>23</sup> In our study, greater autism experience, including more patient visits, previous education about autism, and having a friend or relative with autism, was associated with greater competence and encouraging ABA. Physicians in this study affirmed that primary care for children with autism in the United States needs improvement, suggesting that physicians are aware of the medical home deficiencies reported by parents of children with autism.<sup>14</sup>

Physicians in this study reported a great desire for autism education, a likely means to improved competency. These findings reaffirm the need for autism education shown in a 2004 Delaware and Maryland survey in which physicians reported unfamiliarity with screening tools, and only 8% screened specifically for autism spectrum disorders.<sup>1</sup> In another survey, primary health care providers and residents from 1 hospital differed with personnel from the Center for Autism-Related Disabilities and autism specialists on statements regarding autism prognosis, course, and treatment.<sup>18</sup> Our survey results suggest that CME and residency autism education are effective; these were related to higher autism competency and encouraging ABA. It is promising that over half of primary care physicians in this survey reported receiving previous education about autism in residency and more than two thirds reported such training through CME. The 2008 American Academy of Pediatrics Guidelines on Management of Autism Spectrum Disorders<sup>13</sup> and *Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Physicians*<sup>23</sup> are examples of recent educational materials and guidelines for primary care physicians. Future studies should assess the impact of physician education interventions on physician attitudes and practices.

Most physicians reported that care coordination and reimbursement present challenges, which are greater, when caring for children with autism. Children with autism have more medical comorbidities, medical visits, and 3 times the medical care costs than children without

autism.<sup>13,24</sup> Primary care providers are expected to coordinate a growing and shifting array of autism specialty services, providers, and treatments.<sup>13,25</sup> Our survey results echo those of a national survey where only 25% of parents of children with autism reported that their children received ideal medical home care compared with 42% of parents of children with other special health care needs.<sup>14</sup> Innovative models of coordination and reimbursement are needed, particularly to meet the complex needs and high medical costs of children with autism. Proposed approaches include care teams and specialty medical homes that collaborate with primary care physicians.<sup>26,27</sup>

Physicians reported that the medical home components of family trust and satisfaction were lower among families of children with autism than other medical conditions. These results resonate with those of parents of children with autism, who provided poorer assessments of their physicians' abilities to answer questions, manage their child's condition, and understand how the child's condition affected the family compared with parents of children with other special health care needs.<sup>16</sup> Similarly, in another survey, three quarters of parents of children with autism expressed a lack of confidence regarding their child's physician.<sup>15</sup>

Perhaps related to family trust and satisfaction, physicians reported that families of children with autism were more likely to be "skeptical of vaccines and traditional medicine" and noted these as greater barriers to caring for children with autism than with other medical conditions. Parents of children with autism and conventional medicine have sometimes been at odds in areas such as the prevalence of autism, its etiology, and the search for specific medical interventions in autism.<sup>28</sup> The American Academy of Pediatrics advocates for family-centered care, including sensitivity, respect, and open communication when confronting differences in opinions around treatments, vaccines, or philosophy.<sup>25,29</sup>

Physicians reported that CAM use was a greater barrier to providing primary care for children with autism compared with children with neurodevelopmental and

chronic/complex conditions. Surveys suggest that over half of all children with autism are being treated with CAM.<sup>30</sup> CAM may be particularly challenging when a physician believes the treatment is not in the best interest of the child, often because of a lack of research or the potential for adverse effects.<sup>15,25,31</sup> Furthermore, CAM physician education is typically not part of traditional medical training. In a previous study, more than three fourths of physicians were found to desire general pediatric CAM education.<sup>32</sup> Physicians in the present study reported a greater desire for CAM education specifically for children with autism compared with those with other medical conditions. Both clinical infrastructure (eg, clinical guidelines, reference manuals, patient education materials) and physician education are necessary for physicians to adequately weigh and discuss the potential risks and benefits of treatments that are not clearly supported by empirical evidence or practice parameters.<sup>25</sup>

It is important to note the limitations of this study. Our response rate was lower than other surveys by using the American Medical Association Masterfile, which yielded response rates ranging from 57% to 63%.<sup>33,34</sup> These studies provided individual monetary incentives to participants. Overall, physician response rates are typically low.<sup>35</sup> Small financial incentives have been shown to increase physician survey response rates.<sup>35</sup> Our study did not include individual financial incentives, but rather offered a chance to win 1 larger financial incentive. Endorsements by legitimizing professional associations also increase physician survey response rates.<sup>35</sup> The cover letter for our survey documented a university affiliation but was not endorsed by another organized medical group. In addition, mailed physician surveys tend to yield higher response rates compared with Web-based approaches.<sup>35</sup> Our study used a combination of these 2 approaches. Despite studies showing that the differences between physician respondents and nonrespondents are typically smaller than anticipated,<sup>35</sup> responder bias is a potential study limitation. Although respondents were more likely to be pediatricians, which was a predictor of higher competency, they still reported low autism competency. Competency in this study was based on a self-report measure.

## CONCLUSIONS

Similar to the responses of parents of children with autism, primary care physicians in this study support the need to improve primary care for children with autism. Although physicians express less competence in caring for children with autism, they also express a greater desire to obtain additional autism education. CME and residency education seem to be effective in improving physician competence. Unique models of autism care should address effective coordination and ample reimbursement. Practice parameters and organized medical groups must continue to address the challenging subjects of both CAM and family skepticism of vaccines and traditional medicine. Physicians should continue to collaborate with families to enhance family trust and satisfaction. Such efforts may result in improved parental

satisfaction and medical home care and, ultimately, enhanced health and quality of life for children with autism. Future studies should assess the impact of educational and clinical interventions on physician knowledge and practices regarding autism primary care.

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