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# The Pediatric Alliance for Coordinated Care: Evaluation of a Medical Home Model

Judith S. Palfrey, MD; Lisa A. Sofis, MPA; Emily J. Davidson, MD; Jihong Liu, PhD;  
Linda Freeman, MS, MBA; and Michael L. Ganz, PhD

**ABSTRACT.** *Objectives.* The American Academy of Pediatrics recommends a medical home for children with special health care needs (CSHCN). In the Pediatric Alliance for Coordinated Care (PACC), 6 pediatric practices introduced interventions to operationalize the medical home for CSHCN. The intervention consisted of a designated pediatric nurse practitioner acting as case manager, a local parent consultant for each practice, the development of an individualized health plan for each patient, and continuing medical education for health care professionals. The objectives of this study were 1) to characterize CSHCN in the PACC, 2) to assess parental satisfaction with the PACC intervention, 3) to assess the impact on hospitalizations and emergency department episodes, and 4) to assess the impact on parental workdays lost and children's school days lost for CSHCN before and during the PACC intervention.

*Methods.* A total of 150 CSHCN in 6 pediatric practices in the Boston, Massachusetts, area were studied. Participants were recruited by their pediatricians on the basis of medical/developmental complexity. Physicians completed enrollment information about each child's diagnosis and severity of condition. Families completed surveys at baseline and follow-up (at 2 years), assessing their experience with health care for their children.

*Results.* A total of 60% of the children had >5 conditions, 41% were dependent on medical technology, and 47% were rated by their physician as having a "severe" condition. A total of 117 (78%) families provided data after the intervention. The PACC made care delivery easier, including having the same nurse to talk to (68%), getting letters of medical necessity (67%), getting resources (60%), getting telephone calls returned (61%), getting early medical care when the child is sick (61%), communicating with the child's doctor (61%), getting referrals to specialists (61%), getting prescriptions filled (56%), getting appointments (61%), setting goals for the child (52%), understanding the child's medical condition (56%), and relationship with the child's doctor (58%). Families of children who were rated "severe" were most likely to find these aspects of care "much easier" with the help of the pediatric nurse practitioner. Satisfaction with primary care delivery was high at baseline and remained high throughout the study. There was a statistically significant decrease in parents missing >20 days of work (26% at baseline; 14.1% after PACC) and in hospitaliza-

tions (58% at baseline; 43.2% after PACC). The approximate cost per child per year of the intervention was \$400.

*Conclusions.* The PACC medical home intervention increases parent satisfaction with pediatric primary care. Those whose needs are most severe seem to benefit most from the intervention. There are some indications of improved health as well as decreased burden of disease with the intervention in place. The PACC model allows a practice to meet many of the goals of serving as a medical home with a relatively small financial investment. *Pediatrics* 2004;113:1507-1516; children with special health care needs, medical home.

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ABBREVIATIONS. CSHCN, children with special health care needs; AAP, American Academy of Pediatrics; PCP, primary care physician; PACC, Pediatric Alliance for Coordinated Care; PNP, pediatric nurse practitioner; IHP, individualized health plan; CME, continuing medical education; LPC, local parent consultant; SES, socioeconomic status; ICD-9, *International Classification of Diseases Ninth Revision*.

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The past 3 decades have heralded enormous technologic advances in the care of children with special health care needs (CSHCN). Neonatal intensive care, microsurgery, parenteral nutrition, transplantation, immunosuppression, cancer chemotherapy, dialysis, and many other technologies have become routine practice in pediatrics. As a result of these breakthroughs, children with complex genetic disorders, congenital anomalies, extreme prematurity, severe chronic disease, and disability are living longer lives, with many now surviving into adulthood.<sup>1-10</sup> With these advances in care, the number of CSHCN is now estimated at 5% to 18% of the pediatric population, with ~5% to 6% of children having severe involvement.<sup>11,12</sup> Physicians who care for children with complex medical conditions often find themselves out on the frontier, learning together with the patient and the family about the natural history of the child's disorder and the emerging treatment modalities necessary to manage the child's condition.

In 1992, the American Academy of Pediatrics (AAP) published a statement calling on all primary care physicians (PCPs) to establish medical homes within their practices.<sup>13</sup> The components of such medical homes are 1) the provision of preventive care, 2) the assurance of ambulatory and inpatient care 24 hours a day, 3) continuity of care from infancy through adolescence, 4) appropriate use of subspecialty consultation and referrals, 5) interaction with school and community agencies, and 6) a cen-

From the Division of General Pediatrics, Children's Hospital Boston, and the Departments of Society, Human Development, and Health and Population and International Health, the Harvard School of Public Health, Boston, Massachusetts.

Reprint requests to (J.S.P.) 300 Longwood Ave, Boston, MA 02115-5724. E-mail: palfrey@fas.harvard.edu  
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tral record and database that contains all pertinent medical information. The medical home concept recognizes that the family is the child's primary source of strength and support. The AAP recently published a new policy statement reinforcing the importance of the medical home for CSHCN and calling on pediatricians to increase the involvement of families of CSHCN in medical decision making and comprehensive, life-long planning.<sup>14</sup>

In the new partnerships, clinicians involve parents more fully in decision making by offering a range of options.<sup>15</sup> With a freer level of exchange, parents often feel more comfortable disclosing more of their personal concerns and desires.<sup>16,17</sup>

The medical home model for CSHCN has garnered a good deal of attention over the past few years among policy makers and parent advocates. The US Maternal and Child Health Bureau, for instance, has incorporated the medical home model into Healthy People 2010.<sup>18</sup> The Family Voices web site provides descriptions of the medical home in English<sup>19</sup> and Spanish.<sup>20</sup> The Center for Health Care Strategies is examining how health plans can incorporate the medical home principles as part of their Best Clinical and Administrative Practices activity.<sup>21</sup> Although the term "medical home" does not appear officially in the federal Medicaid Bureau's new rules governing managed care, a number of the medical home quality concepts have found a prominent place in the policy discussions and commentary.<sup>22-24</sup>

On a practical level, however, PCPs still face serious challenges when they try to establish medical homes for CSHCN.<sup>25</sup> Managing complex patients requires knowledge of medical and community resources. PCPs who attempt to deliver high-quality care to CSHCN report that it is very time-consuming to offer comprehensive care delivery. Much of the time that they spend cannot be reimbursed under the current insurance systems. The physicians find it difficult to coordinate their patients' many health care needs, especially for children with conditions that affect multiple organ systems, such as cerebral palsy, cancer, and acquired immunodeficiency syndrome. One of the biggest burdens is the redundant paperwork required by health insurance providers to justify that nursing care, drugs, and equipment are "medically necessary." When the time comes to plan transition services for older adolescents and young adults, PCPs confront additional serious obstacles. Despite these financial and systems problems, pediatricians nationwide are working hard to improve the care of CSHCN in their practices by offering the type of care recommended in the medical home statements.<sup>26</sup> Moreover, the Future of Pediatric Education II is recommending that all pediatricians in training be prepared to deliver such care in their practices.<sup>27</sup> It therefore is critically important to determine whether it is possible to implement a medical home program given adequate structure and supports.

## METHODS

To assess the feasibility of establishing medical homes for CSHCN, a group of 6 community-based pediatric practices joined

together in a pilot project to launch the Pediatric Alliance for Coordinated Care (PACC).<sup>14,28</sup> This article details the project and presents evaluation data collected from the parents and guardians of the children who were enrolled in the project over a 2-year period (1998-2000).

## Intervention Model

The PACC consortium of pediatric primary care health professionals and specialists worked together to create an integrated system of care for CSHCN<sup>28</sup> based on principles of family-centered care and the medical home.<sup>14,18,29,30</sup> The PACC grew out of an extensive planning effort that involved a comprehensive literature review and focus group discussions with parents, as well as multiple interviews with health care professionals and payers. A multidisciplinary advisory board helped shape the PACC model and set the goals for the project. Six pediatric primary care practices (4 private practices and 2 neighborhood health centers) volunteered to participate in the consortium. Each practice designated a lead physician to work with the coordinating staff based at the Children's Hospital in Boston, Massachusetts.

The overarching goals of PACC were to provide comprehensive care at the community level and to improve the coordination and communication among PCPs, subspecialists, and families. The PACC model emphasized family-centered care with the maximization of family participation in care and care decisions. Specific family goals were elicited to ensure integration of health and other services (eg, education, social services, recreation).

In 1998, with the modest addition of resources, the PACC practices augmented and standardized several components of primary care: 1) the services of a designated pediatric nurse practitioner (PNP), 2) consultation from a local parent of a child with special health care needs, 3) modifications of office routines, 4) implementation of an individualized health plan (IHP), 5) regularly scheduled continuing medical and nursing education, and 6) expedited referrals and communication with specialists and hospital-based personnel.

At the outset of the project, each PACC physician designated in his or her practice a group of ~40 children who had serious medical, developmental, and/or emotional problems that required ongoing monitoring or intervention. A few of the children were selected for the intervention because social and behavioral difficulties seriously compounded their medical problems. The 6 PACC physicians met together periodically to discuss practice-based management. They also received semiannual continuing medical education (CME) training arranged through the coordinating group at the hospital.

Each practice chose one of their PNPs to be assigned as the PACC PNP. The lead physician arranged the PNP's schedule to include 8 hours per week devoted to the management of CSHCN. The PNPs received special bimonthly training arranged by the hospital-based coordinating group. As part of the project, the PNP visited each child who was enrolled in PACC at home to get a fuller understanding of the context of the child's life, including the resources and needs apparent in the child's environment. The PNPs were able to conduct sick visits at home. The PNPs developed systems to streamline the ordering of medications and supplies and worked to coordinate patient appointments so that family burden was minimized.

Central to the PACC process was the development of an IHP for each child. The PNP worked with the family to put in one accessible place the clinical information most relevant to be shared with other child health professionals. The IHPs were created and maintained on a word processing template on personal computers in the child's primary care office. With parental consent, the IHP could be faxed to subspecialists, emergency departments, intensive care units, schools, etc, to facilitate information sharing and referrals.

Each community practice site was given a stipend for a local parent consultant (LPC) to join the PACC team. The addition of this family member was a first step toward establishing a family-professional partnership. Because they themselves were parents of CSHCN, the LPCs could provide peer support to other PACC families and steer them to community resources in their area. The LPCs met regularly as a group along with a family coordinator based at the hospital to share resources and plan informational and recreational events for families. To enhance further the family-centered aspects of care, the coordinating group at the hospital

sponsored outreach and social activities and published a newsletter for PACC families several times each year. Within each practice, the LPCs worked directly with office staff to try to improve their understanding of and responsiveness to CSHCN. On occasion, the LPCs would meet with the clinical staff to work through issues in the practice that families identified as problematic for their children and themselves.

### Study Hypotheses

At the outset of the PACC intervention, the following hypotheses were proposed:

1. Relative to baseline, the PACC families will report improvement in obtaining health care services during the intervention.
2. The PACC families will report improved communication with their PCP and PNP as a result of the intervention.
3. The satisfaction level with the addition of a designated, specially trained PNP will be high.
4. There will be no disparity in the reports based on race, socioeconomic status (SES), or language spoken at home.
5. Families of younger children will have more favorable reports about the service coordination than will families of older children.
6. There will be greater impact of the intervention on families whose PCPs rate their child's problems as "severe" than on those whose problems are rated "moderate" or "mild."

### Sample

Children were eligible for the PACC study when they were 1) Massachusetts residents; 2) born on or after June 1, 1979; and 3) designated by their PCP as meeting any of the criteria listed in Fig 1. In the fall of 1997, each practice selected children with the most difficult situations to participate in the program. The intervention was offered to 222 children. The families of 150 met the program criteria, agreed to enroll, and provided informed consent. A total of 117 children had data available at the 2-year evaluation point.

Each child was assigned a primary diagnosis by his or her PCP at enrollment. On the basis of these diagnoses, 5 groups were created: mental disorders (*International Classification of Diseases, Ninth Revision* [ICD-9] values 290-319); diseases of nervous system/sense organs (ICD-9 values 320-389); congenital anomalies (ICD-9 values 740-759); conditions originating in perinatal period (ICD-9 values 760-779); and symptoms, signs, ill-defined conditions, and organ-specific conditions (ICD-9 values 780-799, 001-289, 390-739, 800-999, and V42.7). A post hoc review by staff using questions from the Questionnaire for Identifying Children With Chronic Conditions<sup>31</sup> demonstrated that all of the children in the sample would be identified as having a chronic condition by that measurement. By parent report, 62% of the children had at one time been on Supplemental Security Income. During the PACC project, 62% of the children were on Medicaid as either their primary or secondary health insurer. The average annual health

expenditure for the children on Medicaid was ~\$37 000 with a median of \$5600 and 10th and 90th percentiles of \$500 and \$116 000, respectively.

Family SES was measured by the educational status of the child's mother ( $\geq$ high school and  $\geq$ high school graduate) and family income ( $\leq$ \$19 000, \$20 000–\$39 999, \$40 000–\$74 999, and  $\geq$ \$75 000). Because a high proportion of families did not report income, missing income was treated as a separate category in the analyses rather than imputing it. Education and occupation were combined to form a modified Hollingshead Index<sup>32</sup> as another measure of SES. An ethnicity measure grouped into white and nonwhite (including black, Hispanic, and other) as well as a measure of the primary language spoken at home (English and non-English) were included. The children were separated by age into 2 levels (0-5 years and 6-18 years) at enrollment. The PCP report of the severity of the child's condition (mild, moderate, or severe) was used. The number of conditions was calculated from a checklist completed by families that included 21 specific conditions (eg, asthma, diabetes, learning problems) as well as an "other" category. Finally, the parents' categorization of their children's conditions as "a physical condition or disease," "an emotional or behavioral problem," and/or "a cognitive impairment or mental retardation" was used.

### Questionnaires

Data about the children and their families were collected directly by the PACC program using physician and family surveys at baseline (T1) and after 2 years of the intervention (T2). At the beginning of the program, the pediatricians reported on each child's diagnoses, medical conditions, use of medical technology, and the severity of the child's condition. At enrollment, the child's family reported on the health conditions, days missed from school, satisfaction with health care, use of services provided by their PCPs, use of specialty care, and family demographics. In the case of the 29 siblings enrolled in the program, the family submitted separate surveys for each child.

At baseline (T1) and at follow-up (T2), families completed a 96-item questionnaire based largely on the survey developed by New England SERVE.<sup>33</sup> This survey taps the following domains: child health status, health care provision (primary care, emergency department, specialty care, and hospitalizations), health insurance coverage, family involvement in the child's health care/decision making, and need for and access to other support services. After the intervention, families completed a 14-item questionnaire to assess their satisfaction with specific elements of the intervention. Families were asked whether various factors were "much worse," "worse," "no change," "better," and "much better" than before PACC.

### Statistical Analysis

To assess the differences between groups in the sample, we used the Pearson  $\chi^2$  test (or Fisher exact test when appropriate) for

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1. Biologically based health problem involving >1 body system
  2. Have a severe single system disorder
  3. Have simultaneous involvement with >1 medical specialist with each referral expected to last >12 months
  4. Have had >3 hospitalizations in the prior year or a hospitalization that lasted >15 days
  5. Be dependent on medical technology\*
  6. Be dependent on a wheelchair
  7. Have an ongoing need for home- or school-based health care services
  8. Have early intervention involvement for biological risks and/or developmental impairment (for children <3 years)
  9. Have great difficulty in coordinating treatment and rehabilitation due to complexity of the child's care needs.
- 

\*Medical technology includes gastrostomy, tracheostomy, continuous positive airway pressure, oxygen, ventilator, mechanical hospital bed.

Fig 1. PACC clinical selection criteria.

categorical data and the independent-sample *t* test for continuous data. To assess the differences across time periods, we used the McNemar test (exact when appropriate) for categorical data and the paired-sample *t* test for continuous data. For each variable, we performed our analyses on all available cases, and when comparisons were made across time, we selected those cases that had data available at both times. All tables presented here contain the results of bivariate analyses. We controlled for the simultaneous effects of race, age, severity, and PNP involvement on access to different components of care by estimating a logistic regression model containing all of these factors. The results of the logistic regressions are not different from the bivariate results, so they are not presented here.

Because the intervention was based in each of 6 distinct practices and because there were a number of siblings in the sample, we needed to take clustering into consideration. We present in

Tables 1 and 2 the *P* values that are corrected for clustering on the practice and family levels.<sup>34</sup> Because it is not possible to correct the *P* values from the McNemar tests, we present the uncorrected *P* values in Tables 3 and 4. It should be noted that the effects of the clustering as reported in Tables 1 and 2 were small; hence, it is unlikely that our conclusions based on the uncorrected *P* values in Tables 3 and 4 will be qualitatively different. We consider differences at *P* < .05 to be statistically significant.

## RESULTS

Table 1 demonstrates that the children in PACC had substantial disability. More than 60% of the children had 5 or more problems, and nearly 41% were dependent on medical technology. The male:female

**TABLE 1.** Characteristics of Study Samples Before (T1) and After (T2) PACC Intervention

Characteristic	Cases at T1 (N = 150; %)	Cases at T1 and T2 (N = 117; %)	Cases Not in T2 (N = 33; %)	<i>P</i> *
Age at enrollment, y				
0-5	56.0	55.6	57.6	.83
6-18	44.0	44.4	42.4	
Age at enrollment (y; mean ± SD)	5.6 ± 4.5	5.7 ± 4.5	5.4 ± 4.7	.71
Gender				
Male	66.7	66.7	66.7	1.00
Female	33.3	33.3	33.3	
Race/ethnicity				
White	58.7	62.4	45.5	.08
Nonwhite	41.3	37.6	54.6	
Language spoken at home				
English	81.3	82.1	78.8	.69
Non-English	18.7	17.9	21.2	
Family income				
<\$19 000	23.3	24.8	18.2	.12
\$20 000-\$39 999	16.0	15.4	18.2	
\$40 000-\$74 999	26.7	28.2	21.2	
\$75 000 and above	7.3	9.4	0.0	
Missing	26.7	22.2	42.4	
Mother's education				
<High school	12.7	13.7	9.1	<.01
High school and above	64.7	71.8	39.4	
Missing	22.7	14.5	51.5	
Mother's Hollingshead Index				
V (lowest)	16.0	15.4	18.2	.15
IV	42.0	41.9	42.4	
III	5.3	5.1	6.1	
II	18.0	20.5	9.1	
I (highest)	6.0	7.7	0.0	
Missing	12.7	9.4	24.2	
Number of conditions				
1	6.7	6.9	6.0	.54
2	10.7	11.9	6.1	
3	10.7	8.6	18.2	
4	12.0	11.1	15.2	
5 and more	60.0	61.5	54.6	
Types of conditions†				
Having cognitive conditions	46.0	45.3	48.5	.59
Having emotional conditions	28.0	28.2	27.3	.64
Having physical conditions	78.0	78.6	75.8	.64
Having at least 2 of the above conditions	45.3	46.2	42.4	.63
Diagnostic group				
Mental disorders	12.0	12.8	9.1	.59
Diseases of nervous system/sense organs	13.3	13.7	12.1	
Congenital anomalies	31.3	30.8	33.3	
Conditions originating in perinatal period	16.0	17.9	9.1	
Symptoms, signs, ill-defined, or organ-specific conditions	27.3	24.7	36.3	
Severity rating				
Severe	47.3	44.4	57.6	.19
Not severe	52.7	55.6	42.4	
Dependent on medical technology	41.3	38.5	51.5	.20

\* *P* values based on Pearson  $\chi^2$  test for all comparisons except average age at enrollment, for which independent sample *t* test was used. All *P* values are corrected for clustering on the practice and family levels.

† These conditions are not mutually exclusive.

**TABLE 2.** Ease of Care Access as Compared With Before PACC, by Race, Age, Severity, and Nurse Involvement (*N* = 117)

Items	Total	% of Positive Answers*											
		Race			Age			Severity			Nurse Very Involved?†		
		Nonwhite	White	<i>P</i> ‡	0–5	6–18	<i>P</i> ‡	Severe	Not Severe	<i>P</i> ‡	No	Yes	<i>P</i> ‡
Getting my telephone calls returned	61.2	69.1	56.8	.23	61.5	60.8	.93	72.6	52.3	.03	37.8	78.1	<.01
Getting my child's prescriptions filled	56.0	62.8	52.1	.31	56.3	55.8	.96	69.2	45.3	.01	26.0	84.8	<.01
Getting an appointment	60.9	61.9	60.3	.88	65.1	55.8	.32	66.7	56.3	.27	27.7	86.9	<.01
Getting early medical care	61.4	69.1	56.9	.25	68.3	52.9	.11	68.0	56.3	.19	37.8	79.4	<.01
Getting transportation	16.5	38.1	4.1	<.01	15.9	17.3	.82	27.5	7.8	<.01	8.4	73.3	<.01
Getting resources for my child	59.7	61.9	58.3	.72	63.5	54.9	.37	60.8	58.7	.84	43.3	79.2	<.01
Getting respite care for my child	23.0	31.7	18.1	.14	23.8	22.0	.84	25.5	20.9	.63	17.0	60.0	<.01
Having the same nurse to talk to	68.4	71.4	66.7	.63	71.4	64.7	.46	78.4	60.3	.06	37.8	90.5	<.01
Getting letters of medical necessity	66.9	76.2	61.6	.16	69.8	63.5	.48	76.5	59.4	.08	32.6	90.9	<.01
Setting goals for my child	51.8	57.1	48.6	.45	57.1	45.1	.21	58.8	46.0	.22	28.6	80.4	<.01
Understanding my child's medical condition	56.2	65.0	51.4	.19	64.5	46.0	.05	62.0	51.6	.32	22.7	77.8	<.01
My relationship with my child's doctor	58.3	71.4	50.7	.04	63.5	51.9	.21	70.6	48.4	.03	N/A	N/A	
Communicating with my child's doctor	60.9	69.1	56.2	.19	63.5	57.7	.52	76.5	48.4	<.01	N/A	N/A	
Getting referrals to doctors	60.5	69.1	55.6	.21	63.5	56.9	.46	72.0	51.6	.03	29.8	83.9	<.01
<i>N</i>	116§	43	73		64	52		51	65				

\* Positive responses were "much easier" and "somewhat easier" to the items listed.

† Nurse involvement assessed by asking, "How much has the PACC PNP been involved in the following parts of your child's care?" Answers were grouped into the following 2 categories: Yes = "very involved," No = "not involved, a little involved, somewhat involved."

‡ *P* value of  $\chi^2$  test with 1 degree of freedom. All *P* values were corrected for clustering on the practice and family levels.

§ Sample size for per item varied from 112 to 116 because of missing data.

|| Sample size varied per cell from 107 to 110.

ratio of the sample was 2:1. About 60% of the children were white. Every socioeconomic group was represented.

For the analyses throughout the article, we report on the 117 children for whom we have data at T1 and T2. There were a variety of reasons that families did not submit data at T2, including moving, changing pediatric practices, inability to find the time and/or overwhelming social circumstances, and patient death. One family refused to complete the survey because of overall dissatisfaction with their health care experience. As seen in Table 1, the 33 children for whom T2 data are not available do not differ from the total group on age, gender, or number of conditions. There are missing data on half of these families about their mothers' educational attainment, and for this characteristic, there is a statistically significant difference between the groups. The children who were no longer represented in the sample were more likely to be nonwhite (54.6%) than were those in the remaining samples (37.6%). More of them were rated as having "severe" conditions (57.6%) than were the children in the remaining group (44.4%). These racial and severity differences for those who remained and those who left the sample did not reach statistical significance.

Table 2 presents the results of the questionnaire specific to the PACC intervention. In most cases, the families reported that compared with before PACC, it was "much easier" or "somewhat easier" to obtain health and support services. Table 2 shows that families whose children had more severe problems were more likely to indicate improvement. In addition, there was a clear correlation between PACC PNP

involvement and the likelihood that the family would report that it was "much easier" or "somewhat easier" to obtain services. Families reported that, during the intervention, it was easier having the same nurse to talk to (68.4%), getting letters of medical necessity (66.9%), getting early medical care when the child is sick (61.4%), getting telephone calls returned (61.2%), getting appointments (60.9%), communicating with the child's doctor (60.9%), getting referrals to specialists (60.5%), getting resources for the child (59.7%), forming a relationship with the child's doctor (58.3%), understanding the child's medical condition (56.3%), getting prescriptions filled (56.0%), and setting goals for the child (51.8%). Note that these percentages were calculated out of the total number of families who answered each question. For all of these questions, the results are even more positive when families who rated the service "not applicable" are excluded. For most, the difference is small (3%–5% higher). "Getting respite" and "getting transportation" are the 2 exceptions to this, with 38% of families who needed these services noting an improvement (compared with 23% and 16% of the totals).

Table 3 presents responses on the type and quality of care received by the children. Baseline satisfaction with the PACC practices was very high. At T1, the families rated the care that they received from their PCP as 8.9 on a 10-point scale (with 10 being the best). This rating increased to 9.1 at T2, and the increase was not statistically significant. Compared with baseline, more families reported that their PCP gave them a written health care plan (30% at T1 and 47% at T2; *P* < .01). The pre- and postquestions

**TABLE 3.** Comparison of Primary Care Delivery Before (T1) and After (T2) PACC Intervention

	Primary Care Delivery													
	Total					% Positive Answers*								
	N	T1	T2	P†		N	T1	T2	P†		N	T1	T2	P†
How would you rate the care you have received from your child's PCP? Mean (1-10) ± SD	94	8.9 ± 1.3	9.1 ± 1.5	.21‡		80	8.9 ± 1.2	9.1 ± 1.5	.24‡		14	9.1 ± 1.4	9.2 ± 1.6	.67‡
Access to written health care plan														
Has your child's PCP ever given you a written health care plan?	97	29.9	47.4	<.01		83	20.5	45.8	<.01		14	85.7	57.1	.22
Involvement in decision making														
In the last 6 months, were any decisions made about your child's health care?	93	74.2	69.9	.52		79	72.2	69.6	.82		14	85.7	71.4	.50
Written information														
Has your child's PCP given you written information about your child's medical condition?	92	44.6	44.6	1.00		78	35.9	38.5	.85		14	92.9	78.6	.50
Communication														
Does your child's PCP speak your child's language?	95	94.7	97.9	.38		82	96.3	98.8	.50		13	84.6	92.3	1.00
Access to medical records														
Has your child's PCP ever offered to let you see your child's medical record?	93	32.3	30.1	.81		80	30.0	30.0	1.00		13	46.2	30.8	.63
Have you reviewed the information in your child's medical record?														
Getting basic services from your child's PCP in the last 6 months	89	47.2	34.8	.02		75	44.0	36.0	.18		14	64.3	28.6	.06
When child needed to see doctor for an illness or injury, how often did you see a doctor or other health professional as soon as you wanted?	86	96.5	89.5	.07		74	97.3	90.5	.13		12	91.7	83.3	1.00
When you wanted to get help/advice from a health professional by telephone, how often were you able to get that advice without a long wait, like within a day?	92	85.9	89.1	.63		80	87.5	90.0	.80		12	75.0	83.3	1.00
When you needed a new or refill prescription, how often were you able to get that without a long wait, like within a day?	83	95.2	91.6	.51		71	95.8	91.6	.51		12	91.7	91.7	§
How often were you able to get the special equipment that your child needs without taking a lot of time and energy?	47	46.8	48.9	1.00		39	46.2	48.7	1.00		8	50.0	50.0	1.00
How often were you able to get special medical supplies (eg, tubing, diapers, gauze pads) without taking a lot of time and energy?	46	63.0	71.7	.45		40	62.5	70.0	.61		6	66.7	83.3	1.00
Have you received enough reassurance and support from health professionals?	75	89.3	86.7	.77		62	12.9	14.5	1.00		13	100.0	92.3	§
When your child needed a referral to a specialist, how often were you able to get the referral?	73	87.7	89.0	1.00		60	90.0	88.3	1.00		13	76.9	92.3	.50
Support groups														
Has your child's PCP told you about support groups for parents?	96	48.9	53.1	.62		82	41.5	51.2	.22		14	92.9	64.3	.13

\* Positive answers refer to "yes" or "always/usually" to the items measuring primary care delivery.

† P values from McNemar test.

‡ Based on paired-sample t test.

§ No statistics computed because of empty cells.



The sample was derived from practice panels as they existed and was chosen because the PCPs wanted to improve the care for these particular children. As a result, there is a wide range of ages and diagnoses. By definition, CSHCN encompass a heterogeneous group regarding the types of problems and the natural histories of the disorders. The pre-post design allows for the children to act as their own controls, which is helpful with the protean nature of the conditions in the sample. There is, however, an aging effect. We attempted to control for this by stratifying by age in the analyses.

The study recruitment phase began in the fall of 1997. The baseline survey for this evaluation went into the field just as several evaluation tools (in particular the Consumer Assessment of Health Plans for CSHCN) were being pilot tested and validated.<sup>35</sup> This study benefited from having access (with permission) to some of the early versions of these tools, especially the New England SERVE adaptation<sup>36</sup> that had been used previously. However, because some of the questions were in the pilot phase, they are not all comparable to the now-validated questionnaires. This unfortunately precludes direct comparisons with some of the findings from other studies.

## DISCUSSION

We have demonstrated that the medical home for CSHCN (as recommended by the AAP) can be put into operation within community-based primary care practices through the modest addition of new resources. Each of the practices added 8 hours of a PNP's time specifically dedicated to working with a defined population of CSHCN. The PNPs and PCPs received regularly scheduled CME training and networking with subspecialists and resource providers. The practices used more systematic approaches to their CSHCN, including an IHP and family-centered office practice tip sheets.

We had hypothesized that fielding the PACC model would allow the children in the practices better access to needed health care services. When questioned directly about improvement during the intervention, the families indicated that there were improvements in getting appointments, referrals, telephone calls answered, prescriptions filled, transportation, and respite care. Communication with PCPs showed improvement, particularly for those families whose children had conditions that were considered severe. With high PNP involvement, more than three quarters of the families indicated a better understanding of their child's medical condition.

The IHP was introduced to facilitate communication. Although fewer than 30% of the families had an IHP before PACC, nearly 50% had received an IHP at T2. The families who were most likely to have received an IHP were those who reported that the PNP was very involved (78%) with their child's care. Among those who received the IHP, more than two thirds of the families indicated that the document helped with planning their child's goals, explaining their child's condition and medical issues, and planning for school. For those 38 families who used the

IHP when they needed to go to the emergency department, 80% reported that it improved their experience.

The children in these practices were hospitalized fewer times and their parents missed fewer days of work than before the institution of the program. Although these effects cannot be attributed with complete certainty to the intervention, these findings are completely in line with the intent of the project. The PNPs and PCPs in the PACC practices actively sought opportunities to improve access to care for the children in the practices. They were aware of how complicated it was for some of the families to come into the office or clinic for visits. For patients whose children were hard to transport, they made special efforts to carry out routine visits and sick visits in the home. They worked with subspecialists to coordinate specialty care assessments on the same day. The IHP was designed to cut down on unnecessary duplication of visits and tests by providing the most up-to-date information for all health care professionals.

There was no change for these children in the report of emergency department visits or missed days of school. The children in this sample were very medically involved with significant numbers of conditions that put them at risk for intercurrent illness. Moreover, whereas at T1 21.4% of the parents reported that their child's condition was "changing all the time for the better," 8.9% of the T1 responses were that the child's condition was "changing all the time and getting worse." The comparable responses for getting better and worse at T2 were 13.8% and 11%. At T1 and T2, almost three quarters of the parents reported that their child's condition was "stable" or "changed only once in a while." That the children had chronic conditions may be a partial explanation for the lack of PACC impact on emergency department visits and school absences.

We were most gratified to find that within PACC, the nonwhite and non-English-speaking families fared as well as the white and English-speaking families. The PACC physicians worked explicitly throughout the project to address the potential barriers to health care services that might lead to health care disparities.<sup>36</sup> The PACC practices were particularly attuned to cultural issues, and all had focused attention on improving the language proficiency of their staff members. The PACC newsletter was translated into Spanish so that information about parent resources was available to all families. The home visits gave the PACC PCPs insights into the families' living situations and needs for equipment, home modification, transportation, child care, and other social services.

## CONCLUSIONS

The PACC addressed a fundamental question: "How feasible is it to put a medical home for CSHCN into operation?" Our answer is that it is definitely feasible as long as certain conditions are met. Successfully fielding medical homes in this experiment required 1) committed primary care leadership; 2) the addition of financial resources; 3) a formal ongo-

ing relationship with an academic medical center for training, consultation, and hospitalization; 4) cultural and language expertise; and 5) family buy-in.

The smooth running of the PACC project owed a great deal to the leadership from the PCPs. These physicians were committed to the idea that CSHCN could be cared for in the community, and all had made a conscious decision that they wanted to improve their practices to accommodate children with complex problems. In the hands of these gifted and motivated clinicians, the project was nurtured and promoted. The clinicians volunteered special time out of their busy schedules to coordinate and review the progress of the project and to add in components such as the home visits and IHPs. They ensured that the suggestions of the local parent consultant were implemented and regularly attended CME and advisory committee meetings. In practices where the care of CSHCN was not as great a priority, it is possible that the experience would have been different.

Fully implementing the medical home for CSHCN required the addition of financial resources. Our estimate is that the PACC project cost roughly \$400 per child with severe special health care needs per year. This figure is derived from the cost of the PNP's salary plus the stipend for the LPC plus additional moneys for training and supplies. There are several potential sources for these funds. First, as health insurers and the health plans that they sponsor are reviewing the cost and quality of care for CSHCN, there may be opportunities for creating differential prepayments, capitation, or other arrangements based on risk-adjusted tiers of the primary care population. The data presented here add weight to the argument that enhanced primary care can have an impact on hospitalization rates and parental workdays lost and are consistent with other related studies.<sup>37</sup> These 2 outcomes are greatly desired by insurers and employers. Funding for medical home services might be garnered from state public health agencies such as Title V. In communities where physicians and hospitals have joined together to form physician-hospital organizations, these entities might sponsor the support to improve the overall level of care for CSHCN. Finally, community-based philanthropic organizations are a potential source for at least some components of the program.

The formal ongoing relationship with the academic medical center for training, subspecialty care, and hospitalization was a critically important element in the PACC program. The PACC physicians and PNPs reported on many occasions how valuable they found the training and networking provided by the program. Through the educational sessions, they learned specific new information about the care of CSHCN. In addition, they had a chance to meet with subspecialists, present challenging issues to them, and even arrange for timely consultations. Having the subspecialists as part of the PACC network improved communication. Electronic links between the PCPs and the local children's hospital allowed them to receive daily updates about the emergency department, hospital admissions, and subspecialty consul-

tation activities of their patients, thus strengthening the delivery system of the medical home.

The PACC program was expressly offered to a socioeconomically, culturally, and ethnically diverse group of families. Originally, similar outreach activities for each practice site were planned. Early in the project, it became clear that what worked in 1 clinic's close-knit, ethnically similar community would not work at all for the families of another PACC practice where the patients came from all over the greater metropolitan area.

A critical element in ensuring the successful operation of the medical home is family buy-in. From the time of the original needs assessment, families were involved in PACC as consultants. Parents helped write the informed consent document, and families participated in the formal and informal evaluation of the program. Several parents served on the project's advisory committee.

Although the findings of this study strongly suggest positive outcomes, it was a small-scale, noncontrolled demonstration project that needs replication. There is currently great national interest in CSHCN because their care is so important and such a significant cost item. It would seem to be time for a large-scale, well-funded, randomized, controlled trial using the types of interventions whose feasibility we have demonstrated here. Nationwide, the work of a number of groups makes this an excellent time for such a study. There is now a growing consensus around the definition of and criteria for the selection of samples to participate in such a study of CSHCN. Moreover, unlike the situation when the PACC project began, there are now excellent survey tools that have been field-tested, validated, and standardized that offer great opportunities for comparisons across populations or study groups.<sup>35</sup>

From experience with the PACC project, it is predicted that a larger scale study will corroborate the effectiveness of an enhanced care model. Qualitative debriefings with the 6 primary care practices at the conclusion of the externally funded study period documents a common sense validation of this assertion. Among the 6 practices, all have found ways to continue the enhanced coordination roles at least for the present. Five are continuing with the services of a PNP, and 1 has chosen to hire a social worker instead of a nurse.

It is feasible to field medical homes for CSHCN. The work ahead is to do this in the most effective and efficacious manner and to determine ways to ensure that the gains made can be sustained for the children and families and for the PCPs who care for them.

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## The Pediatric Alliance for Coordinated Care: Evaluation of a Medical Home Model

Judith S. Palfrey, Lisa A. Sofis, Emily J. Davidson, Jihong Liu, Linda Freeman and Michael L. Ganz

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