

# Care Coordination for CSHCN: Associations With Family-Provider Relations and Family/Child Outcomes

## abstract

**OBJECTIVE:** To examine the association between receiving adequate care coordination (CC) with family-provider relations and family/child outcomes.

**METHODS:** We analyzed data from the 2005–2006 National Survey of Children With Special Health Care Needs. Eligible subjects were the 88% of families asked about experience with CC, service use, and communication. Respondents also reported on demographic characteristics, health status, family-provider relations, and family/child outcomes. Weighted, multivariate logistic regression models were constructed to assess independent associations of adequate CC with outcomes.

**RESULTS:** Among families with children with special health care needs asked about CC, 68.2% reported receiving some type of CC help. Of these, 59.2% reported receiving adequate CC help, and 40.8% reported inadequate CC. Families that reported adequate compared with inadequate CC had increased odds of receiving family-centered care, experiencing partnerships with professionals, and satisfaction with services. They had decreased odds of having problems with referrals for specialty care, missing >6 school days because of illness (previous year), and visiting the emergency department more than twice in the previous 12 months ( $P < .001$ ). Those who reported adequate compared with inadequate CC had decreased odds of the following: more than \$500/y of out-of-pocket expenses, family financial burden, spending more than 4 hours/week coordinating care, and stopping/reducing work hours.

**CONCLUSIONS:** Parental report of adequate CC was associated with favorable family-provider relations and family/child outcomes. Additional efforts are needed to discern which aspects of CC are most beneficial and for which subgroups of children with special health care needs. *Pediatrics* 2009;124:S428–S434

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### KEY WORDS

care coordination, children with special health care needs, family-centered care, medical home, National Survey of Children With Special Health Care Needs

### ABBREVIATIONS

CSHCN—children with special health care needs  
MCHB—Maternal and Child Health Bureau  
CC—care coordination  
ED—emergency department  
OOP—out-of-pocket  
NS-CSHCN—National Survey of Children With Special Health Care Needs  
aOR—adjusted odds ratio  
CI—confidence interval

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Children with special health care needs (CSHCN) often require multiple services and providers to maintain and improve their functioning. Recent estimates suggested that ~13% to 18% of all children and youth have special health care needs in the United States.<sup>1,2</sup> The Maternal and Child Health Bureau (MCHB) defines CSHCN as those with a “chronic physical, developmental, behavioral, or emotional condition who require health and related services of a type or amount beyond that required by children generally.”<sup>3</sup>

The medical home model is the standard of health care delivery for CSHCN and their families.<sup>4,5</sup> The medical home concept is associated with improvements in health care quality and improved child/family functioning.<sup>6</sup> Core elements of the medical home concept include family-centered care, care coordination (CC), cultural competency, accessible care, and having a personal health care provider.<sup>4,7</sup>

The need for CC is related to medical complexity, use of multiple providers and services, and family-based social stressors.<sup>8</sup> In 1 study, effective CC fostered communication among health care providers, improved satisfaction, and decreased barriers to effective care.<sup>9</sup> These promising findings warrant further evaluation.

Family-centered care, a core element of the medical home,<sup>10</sup> “assures the health and well-being of children and families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship.”<sup>11</sup> As such, the tenants of family-centered care are included in the Healthy People 2010 objectives,<sup>12</sup> the President’s New Freedom Initiative,<sup>13</sup> and the MCHB core outcome measures.<sup>14</sup> However, limited literature has identified health system components associated with receiving family-centered care. Furthermore,

there has been a paucity of studies depicting relationships between CC and family-child outcomes such as family financial burden, time spent by parents coordinating care, parental employment, school absences, and emergency department (ED) visits.

We examined the association between CC and family-provider relations and family/child outcomes. Our hypothesis was that CSHCN and their families who receive adequate help with needed CC will experience positive associations with (1) family-provider relations defined as family-centered care, experiencing partnerships with professionals, and satisfaction with services and ease of access to needed referrals and (2) family/child outcomes defined as decreased out-of-pocket (OOP) expenses, less family financial burden, less time spent coordinating care, impact on parental/family unemployment, and fewer school absences and ED visits.

## METHODS

We analyzed data from the 2005–2006 National Survey of Children With Special Health Care Needs (NS-CSHCN). Background on NS-CSHCN methodology, sponsorship, and derivation of subjects is available.<sup>15,16</sup> Analyses were conducted on the Data Resource Center indicator data set for the NS-CSHCN. This data set merges NS-CSHCN public-use data files and provides numerous constructed variables of relevance for research applications using MCHB-approved coding conventions for the key variables used in this analysis. It was developed by using SPSS software (SPSS Inc, Chicago, IL), and an SAS (SAS Institute, Inc, Cary, NC) version was created by using Stat Transfer.<sup>17</sup>

All findings are based on weighted, population-based estimates, and because of the complex sampling design of the NS-CSHCN, SEs were adjusted

by using Stata (Stata Corp, College Station, TX). Stata was used for all analyses.<sup>18</sup>

Binary outcome variables were used, and  $\chi^2$  statistics tested the strength of associations between CC and the independent and dependent variables of interest. Logistic regression models were constructed to examine relations between CC, family-provider relations, and family/child outcomes while adjusting for potential confounders. Adjusted odds ratios (aORs) and 95% confidence intervals (CIs) are reported. Confounders included gender, age, race/ethnicity, insurance status, income level, family structure, education, and CSHCN screener qualifying categories (described below). Weighted, multivariate logistic regression for multicategorical outcome variables was explored, but given comparable findings, only logistic regression results that modeled binary outcomes are reported. Missing data (<3%) were excluded from final analyses.

The composite measure of CC was divided into 3 groups based on parental report of need for help with CC services. Inadequate CC was defined as (1) parent reported needing help coordinating child’s care, but help was not received, and/or (2) parent reported being “less than very satisfied” with needed communication between doctors and between doctors and school/programs. Adequate CC was defined as (1) parent reported receiving help coordinating child’s care, but he or she either did not need extra help or the extra help needed was received, and (2) parent reported being “very satisfied” with needed communication between doctors and between doctors and school/programs. Group 1 includes parents who reported that their CSHCN used 2 or more services in the previous 12 months but received inadequate CC. Group 2 included parents who reported that their CSHCN used 2

or more services in the previous 12 months and received adequate CC. Group 3 comprised 2 sets of parents who reported not needing CC: group 3a included parents who reported use of 2 or more services in the previous 12 months and no need for communication between doctors and between doctors and school/programs, and group 3b included parents who reported using fewer than 2 services in the previous 12 months and no need for communication between doctors and between doctors and school/programs.

Multiple child, family, and health system characteristics inform need and use of coordination services. Because sociodemographic factors (age, race, insurance status, income, education, and family structure) of children/families and complexities of CSHCN may influence CC services,<sup>19</sup> they were incorporated in adjusted models and analyses of CC experiences and outcomes.

The CSHCN screener was used in the NS-CSHCN to identify CSHCN on the basis of their experience of 5 common consequences of having an ongoing health condition. Children were classified into 4 mutually exclusive groups that suggested the intensity of service use or functional impact of their condition.<sup>20,21</sup> The CSHCN screener has been shown to reliably differentiate these subgroups of CSHCN according to health status and need complexity.<sup>20</sup> Therefore, this was an independent variable in adjusted models.

The outcomes in this study included (1) family-provider relations (eg, presence of family-centered care, experiencing partnerships with professionals and satisfaction with services, and ease of getting referrals) and (2) family/child outcomes (eg, OOP expenses, family financial burden, hours per week coordinating care, impact on parental employment, school absences,

and frequency of ED visits over the previous 12 months).

Family-provider relations include a family-centered care composite variable, experiencing partnerships with professionals and satisfaction with services, and ease of getting referrals. Responses to the family-centered care composite indicator were dichotomized (yes/no). This indicator includes whether the child had 1 or more doctor visits during the previous 12 months and responses of usually/always to all 5 items (doctors/health care providers spend enough time, listen well, are sensitive to values/customs, provide needed information, and make family feel like a partner) and, if needed, responses of “usually” or “always” to accessing interpreter services during the child’s health care visits. “Families experiencing partnerships with professionals and satisfied with services” is a composite variable assessing whether families usually or always feel like partners in their child’s care and are very satisfied with the services they receive (yes/no). “Ease of getting referrals” assessed CSHCN who needed referrals for specialty care/services in the previous 12 months and had problems getting one (yes/no).

Family/child outcomes include OOP expenses, family financial burden, hours per week coordinating care, impact on parental employment, school absences, and frequency of ED visits. OOP medical expenses included payment for all types of health-related needs such as medications, specialty foods, durable medical equipment, home modifications and therapies. This variable was dichotomized into \$500 or less and more than \$500 per year. Family financial burden was defined as sustaining financial problems caused by the child’s health condition. Hours per week coordinating care is the time ( $\leq 4$  or  $> 4$  hours) a caregiver spent

coordinating his or her child’s care. Impact on parental employment indicates families who cut hours or stopped working because of their child’s health needs (yes/no). Frequency of school absences was dichotomized as 6 or fewer vs more than 6 days/year. Finally, ED visits were dichotomized into fewer than 2 and 2 or more visits per year.

## RESULTS

Among families with CSHCN asked about CC, 68.2% reported receiving some type of CC help. Of these, 59.2% reported receiving adequate CC help, and 40.8% did not. Within each CC group, the largest percentage of children was accounted for by the older (12- to 17-year-old) CSHCN (Table 1). Boys and white/non-Hispanic children comprised a larger percentage of CSHCN than girls and nonwhite/Hispanic youth in each group, mirroring previous nationally representative analyses that profiled CSHCN.<sup>22</sup>

Those parents who reported receiving adequate CC (group 2) compared with inadequate CC (group 1) had lower percentages of having publicly insured and uninsured CSHCN. This same group qualified for special needs less frequently via functional status and service-need criteria compared with those with inadequate CC. Group 1 (inadequate CC) had the largest percentage of CSHCN who qualified for a special need on the basis of prescription and service needs. In addition, group 3a (no CC needed and  $\geq 2$  services used) had the largest percentage of CSHCN who qualified on the basis of prescription use alone (Table 1).

In adjusted models, parents who reported receiving adequate CC (group 2) compared with inadequate CC (group 1) had increased odds of receiving family-centered care (80% vs 43%; aOR: 5.03 [95% CI: 4.55–5.55]) and experiencing partnerships with pro-

**TABLE 1** CC and Child and Family Characteristics

	Group 1: Inadequate CC (Weighted <i>N</i> = 3 171 432), % (SE)	Group 2: Adequate CC (Weighted <i>N</i> = 4 592 731), % (SE)	Group 3a: No CC, No Help Needed, ≥2 Services Used (Weighted <i>N</i> = 1 817 611), % (SE)	Group 3b: No CC, No Help Needed, <2 Services Used (Weighted <i>N</i> = 402 888), % (SE)
<b>Child characteristic</b>				
Age, y <sup>a</sup>				
0–5	19 (0.59)	22 (0.56)	20 (0.81)	25 (0.36)
6–11	37 (0.73)	37 (0.61)	39 (0.98)	33 (0.41)
12–17	44 (0.76)	41 (0.40)	41 (0.94)	42 (0.42)
Gender				
Male	60 (0.76)	59 (0.62)	59 (0.21)	62 (0.42)
Female	40 (0.76)	41 (0.62)	41 (0.21)	38 (0.42)
Race/ethnicity <sup>a</sup>				
Hispanic	14 (0.59)	10 (0.44)	9 (0.63)	21 (1.98)
White/non-Hispanic	62 (0.77)	69 (0.63)	69 (0.96)	43 (2.11)
Black/non-Hispanic	17 (0.62)	15 (0.50)	15 (0.77)	30 (2.08)
Multiracial/non-Hispanic	4 (0.27)	4 (0.27)	4 (0.38)	3 (0.71)
Other non-Hispanic	3 (0.30)	2 (0.18)	3 (0.34)	3 (0.62)
Insurance status <sup>a</sup>				
Private	53 (0.77)	62 (0.63)	70 (0.91)	36 (2.04)
Public	31 (0.74)	27 (0.59)	20 (0.82)	39 (2.18)
Private and public	9 (0.43)	7 (0.33)	4 (0.41)	9 (1.46)
Other comprehensive	2 (0.21)	2 (0.19)	3 (0.28)	1 (0.40)
Uninsured	5 (0.29)	2 (0.17)	3 (0.29)	15 (1.55)
Qualified for special-need on the basis of: <sup>a</sup>				
Prescription-medication need	23 (0.67)	44 (0.63)	78 (0.82)	54 (2.17)
Functional status	34 (0.71)	19 (0.51)	6 (0.46)	15 (1.56)
Service needs	18 (0.61)	14 (0.45)	6 (0.47)	22 (1.70)
Prescription and service needs	25 (0.65)	23 (0.53)	11 (0.60)	9 (1.23)
Usual source of care <sup>a</sup>				
Doctors office	74 (0.66)	79 (0.54)	84 (0.68)	61 (2.13)
Clinic	20 (0.58)	16 (0.49)	11 (0.59)	23 (1.87)
No usual source, rely on ED	6 (0.40)	5 (0.29)	5 (0.39)	16 (1.51)
<b>Family characteristic</b>				
Income <sup>a</sup>				
0%–99% FPL	21 (0.67)	17 (0.53)	13 (2.33)	41 (0.37)
100%–199% FPL	25 (0.70)	21 (0.58)	18 (2.20)	30 (0.39)
200%–399% FPL	28 (0.70)	31 (0.61)	34 (1.55)	18 (0.40)
≥400% FPL	26 (0.68)	31 (0.59)	35 (1.40)	11 (0.40)
Family structure <sup>a</sup>				
2 biological/adopted parents	49 (0.78)	58 (0.65)	62 (0.97)	41 (2.24)
2-parent step-families	10 (0.52)	10 (0.39)	9 (0.52)	10 (1.28)
Mother only	35 (0.76)	28 (0.60)	24 (0.89)	40 (2.24)
Other family	6 (0.34)	4 (0.28)	5 (0.39)	9 (1.23)
Education <sup>b</sup>				
Less than high school	8 (0.45)	6 (0.34)	4 (0.48)	18 (1.80)
High school	22 (0.67)	23 (0.57)	22 (0.90)	38 (2.19)
Beyond high school	70 (0.73)	71 (0.61)	74 (0.95)	44 (2.14)

The SEs are reported as percentages.

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

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

professionals and satisfaction with services (76% vs 24%; aOR: 8.85 [95% CI: 7.97–9.81]) (Tables 2 and 3). These same families had decreased odds of having problems with needed referrals. There were protective associations of receiving adequate CC with family/child outcomes. Parents who reported

adequate CC (group 2) had decreased odds of having more than 2 ED visits and of missing more than 6 school days because of illness in the preceding year. In addition, group 1 compared with group 2 had decreased odds of having more than \$500 per year OOP expenses (32% vs 43%; aOR:

0.57 [95% CI: 0.50–0.61]), family financial burden (13% vs 33%; aOR: 0.38 [95% CI: 0.34–0.43]), spending more than 4 hours/week coordinating care (17% vs 28%; aOR: 0.66 [95% CI: 0.59–0.74]), and parents stopping working or cutting their work hours (20% vs 40%; aOR: 0.47 [95% CI: 0.42–0.52]) (Table 3).

**TABLE 2** Associations of CC With Family-Provider Relations and Family/Child Outcomes

	Group 1: Inadequate CC (Weighted <i>N</i> = 3 171 432), % (SE)	Group 2: Adequate CC (Weighted <i>N</i> = 4 592 731), % (SE)	Group 3a: No CC, No Help Needed, ≥2 Services Used (Weighted <i>N</i> = 1 817 611), % (SE)	Group 3b: No CC, No Help Needed, <2 Services Used (Weighted <i>N</i> = 402 888), % (SE)
Family-provider relations				
Family-centered care <sup>a</sup>				
Does not have family-centered care	57 (0.78)	20 (0.54)	27 (0.92)	52 (2.50)
Has family-centered care	43 (0.78)	80 (0.54)	73 (0.92)	48 (2.50)
Experience partnerships with professionals/ satisfaction with services <sup>a</sup>				
No	76 (0.66)	24 (0.58)	29 (0.94)	48 (2.22)
Yes	24 (0.66)	76 (0.58)	71 (0.94)	52 (2.22)
Ease of getting referrals <sup>a</sup>				
No problems getting referrals	66 (1.09)	91 (0.73)	92 (1.76)	68 (6.10)
Problems getting referrals	34 (1.09)	9 (0.73)	8 (1.76)	32 (6.10)
Child outcomes				
Missed school days <sup>a</sup>				
0–6 d missed	65 (0.79)	74 (0.62)	85 (0.79)	79 (2.02)
>6 d missed	35 (0.79)	26 (0.62)	15 (0.79)	21 (2.02)
ED visits <sup>a</sup>				
<2 ED visits per year	75 (0.67)	81 (0.52)	90 (0.64)	81 (0.81)
≥2 ED visits per year	25 (0.67)	19 (0.52)	10 (0.64)	19 (0.81)
Family outcomes				
OOP expenses <sup>a</sup>				
\$500 or less per year	57 (0.75)	68 (0.56)	76 (0.83)	84 (1.54)
More than \$500 per year	43 (0.75)	32 (0.56)	24 (0.83)	16 (1.54)
Family financial burden <sup>a</sup>				
No financial burden	67 (0.70)	87 (0.44)	94 (0.47)	83 (1.68)
Financial burden	33 (0.70)	13 (0.44)	6 (0.47)	17 (1.68)
Time coordinating care <sup>a</sup>				
≤4 h/wk	72 (0.68)	83 (0.51)	92 (0.53)	80 (1.86)
>4 h/wk	28 (0.68)	17 (0.51)	8 (0.53)	20 (1.86)
Impact on work <sup>a</sup>				
Employment not affected	60 (0.74)	80 (0.53)	93 (0.51)	85 (1.54)
Cut back on hours	40 (0.74)	20 (0.53)	7 (0.51)	15 (1.54)

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

Two groups (3a and 3b) did not receive CC and reported not needing it. These groups varied with respect to service use in the previous year (≥2 vs <2). Group 3a, relative to group 3b, included a higher percentage of children who were white, non-Hispanic, and privately insured, had doctors' offices as their usual source of care, had families with higher incomes, had 2 biological or adopted parents, had parents with more than a high school education, and had children who qualified for special needs on the basis of use of prescription medications only (Table 1). A larger percentage of those in group 3a relative to those in group 3b experienced family-centered care, partnerships with professionals/satisfaction with services, and ease of get-

ting referrals. Smaller percentages of children in group 3a missed more than 6 school days or had 2 or more ED visits. Families in group 3a also reported less financial burden, fewer hours coordinating care, and less impact on employment (Table 2).

## DISCUSSION

This study supports positive associations between families with CSHCN who reported adequate CC with family-provider relations and family/child outcomes. The increased need for CC services with increasing children's ages is likely explained by increasing diagnoses, complexity, need for multiple providers, and preparations for transition to adulthood in home and educational settings.

Our findings support previous work that demonstrated CC as an integral part of the medical home model.<sup>7</sup> Specifically, we found that CC is associated with receipt of family-centered care, experiencing partnerships with professionals and satisfaction with services, ease of getting referrals, less OOP expenses and family financial burden, fewer hours per week spent coordinating care, less impact on parental employment, and fewer school absences and ED visits. CC models in community and health care settings merit further investigation given the supportive findings from this study.<sup>23</sup>

The CC groups identified in these analyses represent unique experiences of families with CSHCN, including those

**TABLE 3** Adequate Help with CC, Family-Provider Relations, and Family Child Outcomes Among Families Receiving CC Services

Outcome	aOR (95% CI)
Receiving family-centered care <sup>a</sup>	5.03 (4.55–5.55)
Experiencing partnerships with professionals and satisfaction with services <sup>a</sup>	8.85 (7.97–9.81)
Problems getting referrals <sup>a</sup>	0.19 (0.15–0.23)
Missed school days (>6 vs ≤6 d) <sup>a</sup>	0.77 (0.69–0.85)
ED visits (≥2 vs <2 visits) <sup>a</sup>	0.79 (0.70–0.88)
OOP expenses (more than \$500 vs \$500 or less) <sup>a</sup>	0.57 (0.50–0.61)
Family financial burden (yes vs no) <sup>a</sup>	0.38 (0.34–0.43)
Time coordinating care (>4 vs ≤4 h/wk) <sup>a</sup>	0.66 (0.59–0.74)
Impact on work/cut back on hours <sup>a</sup>	0.47 (0.42–0.52)

Shown are the odds of respondents reporting that CSHCN received adequate help with CC services versus reporting inadequate help with CC services. Models were adjusted for: gender, age, race/ethnicity, insurance status, income level, family structure, education, and CSHCN screener qualifying categories.

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

who reported no need for CC. Families without help with CC that used fewer than 2 services (group 3b) include uninsured, lower-socioeconomic-status, and minority populations. They also reported less favorable experiences regarding family-centered care, satisfaction, getting referrals, ED use, and school absences. Compared with group 3a, group 3b experienced more financial burden, time spent coordinating care, and impact on employment. Further examination is needed to understand the experiences of this group including access, expectations, and links to services. Disenfranchised families may use fewer resources/services because of lack of access, knowledge, and insurance. Ultimately, this could inform their perception of need for services. Recent literature suggested that insurance favorably affects health care access and utilization and has a protective effect on family financial burden.<sup>24,25</sup>

In 1 study, a majority of CSHCN reported receiving family-centered care.

However, minority status, lack of insurance, poverty, and functional limitations were associated with decreased perception of family-professional partnerships.<sup>26</sup> In adjusted models that controlled for these same factors, we found that receiving adequate CC was associated with family-centered care, experiencing partnerships with professionals, and satisfaction with services. These results support integration of CC into the health care–delivery system (including medical home and community systems) in the effort to achieve optimal family-centered care for CSHCN and their families.

Our findings demonstrate an inverse relationship between receiving adequate CC and family financial burden and parents having to cut back or stop working because of their child's health. These findings may encourage employers' provision of benefit packages for families of CSHCN that include CC services and workplace support.<sup>27</sup> On the basis of our findings, doing so could foster a positive societal impact: retention of parents of CSHCN in the workforce. Recent estimates suggested that up to 40% of families with CSHCN experience financial burden, and this burden correlates with poor child health status.<sup>28</sup> Our findings imply a benefit of adequate CC with financial burden on families, perhaps mitigating negative consequences that financial hardship may have on CSHCN. CC is an essential element in the provision of the medical home. Studies have demonstrated that providing CC is not cost-prohibitive and does not necessarily need to be provided by a physician.<sup>29</sup> Our findings imply variability across access to CC and qualifying for special needs. Parents who reported inadequate CC comprised a larger group of children who qualified for a special need on the basis of prescription and service needs. Future work should continue examining different

delivery and financing models for CC, matching ranges of CC needs required by CSHCN and their many complex health condition and service needs. In addition, future work is needed to further define and assess the direct impact and quality of CC services on health care utilization and functional status, including ED utilization and participation in developmentally appropriate life activities. Policy reform to drive financial models to support CC as a critical component of a high-performing pediatric health care system will be necessary to ensure that all CSHCN experience optimal health outcomes.

There are several limitations in this study. First, this was a cross-sectional survey; thus, no causal inferences can be made. Only associations are noted. The direction of association needs to be discerned via longitudinal data analyses. It is possible, for example, that those with good family-provider relations may be more likely to experience CC because providers listen to and respond to their concerns. Second, it is difficult to measure the need for CC services among those respondents who qualified for the CC questions but did not report getting any help with CC. However, we included these groups in our descriptive analyses. Finally, these results represent caregiver/parental perceptions and might reflect recall and/or caregiver biases. The NS-CSHCN contains limited information on health system characteristics and community resources.

## CONCLUSIONS

CC is integral to the functioning of many CSHCN and their families. These findings support positive associations and potential benefits to quality of care, family-centered care, family/child functioning, and family financial burden. Future studies are warranted to delineate which aspects of CC are

most efficacious, prospective evaluations of CC, and which children (diagnoses and functional status) receive the most benefit from CC. Further discussion should ensue regarding policy

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