

# Evidence for Family-Centered Care for Children With Special Health Care Needs: A Systematic Review

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## ABSTRACT

**OBJECTIVE:** Family-centered care (FCC) has received widespread endorsement for use in care in the United States. In this study, we conducted a systematic review of evidence for FCC focusing specifically on family-provider partnership as the activity that constitutes FCC.

**METHODS:** We found and reviewed articles from the medical, nursing, psychology, and sociology literature spanning 1986 to 2010. We also reviewed articles obtained through related references and through recommendations from key informants. Four sets of terms were used to search, including FCC, child/adolescent, children with special health care needs (CSHCN, defined broadly or by condition), and a relevant outcome.

**RESULTS:** Twenty-four studies met the review criteria. Eight were cross-sectional studies from the National Survey of Children With Special Health Care Needs, and 7 were reports of randomized, controlled trials. Of the 24 articles reviewed, 13 examined populations of CSHCN or similar populations, 6

examined children with asthma, and the remaining studied children with other specific conditions. We found positive associations of FCC with improvements in efficient use of services, health status, satisfaction, access to care, communication, systems of care, family functioning, and family impact/cost. There was little available evidence, however, for some outcomes, including cost and transition.

**CONCLUSIONS:** The available evidence suggests that FCC is associated with improved outcomes for CSHCN. With positive findings for most of the studies reviewed here and the compelling arguments for FCC, we recommend the use of this approach by individuals and organizations.

**KEYWORDS:** children with special health care needs; family-centered care

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## WHAT'S NEW

In a review of the published literature, we found that family-centered care for children with special health care needs is associated with improved health and well-being, improved satisfaction, greater efficiency, improved access, better communication, better transition services, and other positive outcomes.

CHILDREN WITH SPECIAL health care needs (CSHCN) are those with “chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required of children generally.”<sup>1</sup> Although sometimes considered, we did not include the at-risk population in our study. An estimated 12.8% of the US child population, or over 9 million children, are CSHCN.<sup>2</sup>

Efforts to incorporate family-centered principles into care for CSHCN have been underway since 1987, when the Surgeon General called for “family-centered,

community-based, coordinated care for children with special health care needs and their families.” The Maternal and Child Health Bureau (MCHB) endorses family-centered care (FCC) as a part its integrated set of core objectives for CSHCN. These core objectives form the basis of the work of state Title V programs and are reflected in the Nation’s Healthy People 2010 Objectives.<sup>3</sup> The FCC objective states that “families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive.”<sup>3</sup> MCHB further delineates the principles of FCC, including the following: families and professionals working together; respect for the skills and expertise brought to the relationship, trust, and open and objective communication; joint decision making; and a willingness to negotiate.<sup>4</sup> On the basis of the partnership, MCHB lists activities that characterize FCC as follows: acknowledge the family as the constant in a child’s life, build on family strengths, support the child in participating, honor diversity, recognize the importance of community-based services, promote an

individual and developmental approach, encourage family-to-family/peer support, develop family-centered policies and practices, and celebrate successes.

FCC has been endorsed more broadly for all children and individuals. The American Academy of Pediatrics (AAP) recommends FCC care in various settings.<sup>5</sup> Other AAP policy statements support FCC as well; most importantly, FCC is viewed as a primary component of the medical home.<sup>6</sup> The Institute for Family-Centered Care, which also endorses FCC in various settings, lists the following as core concepts that should exist between families and professionals: dignity and respect, information sharing, participation, and collaboration.<sup>7</sup> The consideration of family-centered rather than patient-centered care is a hallmark of the pediatric medical home.<sup>8</sup>

Although many groups endorse FCC, no one has conducted a systematic review of the literature assessing whether providing FCC improves patient and family outcomes. We examined the evidence base for FCC to determine its relationship to key outcomes for children and families. Specifically, we sought to determine the extent to which family-provider partnership (FPP) is associated with improvements for a variety of outcomes. This effort is part of a larger project that examines the evidence base for each MCHB core objective and for an overall comprehensive, organized, accessible system of care for CSHCN.<sup>9</sup> Because this review was a part of an effort to assess systems of care for CSHCN by the US MCHB, we included only US-based evidence in this review.

## ORGANIZATION OF REVIEW

Definitions of FCC include a variety of specific activities. We used FCC-related statements by the MCHB<sup>3,4</sup> and AAP,<sup>5</sup> input of the project advisory committee (comprising CSHCN researchers, family members, and health care providers), and input from reviewers to identify the “family-provider partnership” as our functional definition of FCC for this review. This decision parallels the operationalization of FCC in the National Survey of Children with Special Health Care Needs (NSCSHCN). To be included, articles needed to mention FCC or FPP, and FCC activities needed to include FPP. Outcomes included care processes and satisfaction as well as more traditional outcomes, such as health status. We included the following: health (broadly defined), satisfaction, efficient use of health care resources, access to care, communication, system improvements, transition to adulthood, family functioning, financial impact, and cost.

We used 4 search engines to search medical, nursing, and social science literatures: Medline (medical), CINAHL (nursing and allied health), PSYCINFO (psychology), and SSCI (sociology). We searched these databases using different combinations of 4 terms. Each of these searches included FCC/FPP, child/adolescent, CSHCN (defined broadly or using a specific condition), and an outcome (Table 1). Specific conditions are listed in Table 1. Subsequent searches combined each set of terms in the searches with an “and.” In our search, we identified articles that examined FCC but did not examine FPP; these articles

were subsequently excluded. For example, an article where the FCC activity was having parents serve as advisors or care providers would not be included. We included only studies that used quantitative methods to evaluate an intervention to promote FCC or studies that examined associations between FCC and an outcome. We also limited our search to studies of US populations, studies with abstracts in the search engines, and studies that were published in English between January 1, 1986, and May 31, 2010.

Two authors independently reviewed titles and abstracts and, after discussion, retrieved potentially relevant articles in their entirety. Specifically, if both authors thought that an article should be included or excluded (in the set of articles to be fully reviewed), then that was the final decision. If the 2 authors disagreed, a third reviewer was included to help resolve the differences. Where there differences remained, we examined the full article. The 3 authors then screened the full articles for eligibility criteria and study relevance and reached a consensus about which articles to include. Given that our search strategy may have inadvertently missed relevant articles, we additionally included articles in our review if they were recommended by expert colleagues or identified through the citations of relevant articles. These articles needed to meet the same inclusion criteria as those identified through the search engines. We included articles that were of sufficiently high quality, above a score of 12 using the metric of Downs and Black.<sup>10</sup> One author completed the Downs and Black checklist for each article. Downs and Black created a checklist that provides an overall score for the study quality that is appropriate for assessing both randomized and nonrandomized studies.

## RESULTS

The initial searches yielded 4886 articles that met the search criteria and had abstracts, 2828 of which were based in the United States. From this list, 2 authors reviewed all titles and/or abstracts. They then identified 98 articles to review in full. We included 24 in this review. These articles met the search criteria and the quality score criterion. Seven of the articles were based on randomized, controlled trials (RCTs), 11 were based on cross-sectional associations with no intervention, and the rest examined interventions with controls or before-and-after comparisons. Two interventions resulted in more than one article. Eight articles were based on analyses of the NS-CSHCN and used similar measures of FCC with a variety of outcomes. Six articles were published before the year 2000. The articles identified CSHCN in different ways, with 13 articles looking at CSHCN, children with disabilities, and/or children with multiple chronic conditions; 6 articles examining populations of children with asthma; and 5 examining other specific chronic conditions. The most commonly found outcomes were health, mental health, and/or well-being of patients and family members ( $n = 11$ ), satisfaction ( $n = 7$ ), efficient use of resources ( $n = 7$ ), and access ( $n = 7$ ).

We discuss findings by outcomes. We then summarize all of the findings from the NS-CSHCN. In discussing

**Table 1.** General Search Terms**Child/Children**

- Child
- Children
- Adolescent

**Children With Special Health Care Needs (CSHCN)**

- Disabled children
- Disabled
- Developmental disabilities
- Chronic disease
- Chronic conditions
- Special needs
- Special health care needs
- Activities of daily living
- Activity limitation
- Specific conditions\*

**Family-Centered Care**

- Professional patient relations
- Family-centered care (family-centered nursing)
- Patient-centered care
- Nurse-patient relations
- Physician-patient relations
- Professional patient relations
- Patient participation
- Shared decision making
- Physician-patient communication
- Family- and youth-driven care
- Consumer-driven care
- Family advisor group
- Consumer advisor group
- Leadership
- Family leadership
- Consumer leadership

**Outcomes**

- Quality of health care health
- Health status, (health behavior, health knowledge attitude and practice)
- Family health
- Mental health
- Patient satisfaction
- Health policy
- Health services/utilization
- Accessibility
- Family financial burden
- Cost/expenditure empowerment uncertainty
- Organizational efficiency
- Health system improvement
- Delivery of health care
- Child is decision maker
- Decision making
- Quality of life
- Mental health
- Mental health services
- Health transition
- Behavior/behavior disorders, child/adolescent development, mortality
- Child welfare
- Maternal welfare
- Hospitalized, parent-child relationship
- Health insurance

\*Specific conditions include: attention-deficit and disruptive behavior disorders, attention-deficit disorder with hyperactivity, cerebral palsy, asthma, human immunodeficiency virus (HIV-1, HIV-2), acquired immunodeficiency syndrome (AIDS), epilepsy (subtypes myoclonic, partial, absence, frontal lobe, rolandic, temporal lobe), heart defects, congenital diabetes mellitus, hemophilia A, hemophilia B, spina bifida occulta, developmental disabilities, mental retardation, sickle-cell anemia, juvenile rheumatoid arthritis, cancer/neoplasms, Down syndrome, trisomy 21, cystic fibrosis, low birth weight, preterm birth, and transplantation.

the results, we give greater weight to RCTs and other intervention studies over purely associational studies. Within each of these groups, we prioritize the discussion of articles on the basis of broad populations of CSHCN over those based on specific chronic conditions. Table 2 summarizes characteristics of the selected studies.

**EVIDENCE BY ENDPOINT***HEALTH, MENTAL HEALTH, AND WELL-BEING*

Four RCTs examined the health status of the child/youth or parent. Three of these 4 articles found some health improvement of the intervention. Stein and Jessop investigated a program of comprehensive health care for inner-city children with chronic conditions that included a multidisciplinary team that helped involve families in management and decision making. Researchers found that the intervention group had better personal adjustment scale scores, a measure of psychological functioning after intervention with some differences in the findings depending on the time frame.<sup>11</sup> Other RCTs examined populations with specific conditions. A RCT conducted by Guendelman and colleagues used the Internet to facilitate family-focused nurse-family communication in families with children with asthma. This study found that among other outcomes, intervention families had significantly fewer peak flow readings in the yellow or red zone than the comparison group.<sup>12</sup> Among children with traumatic brain injury, a problem-solving and skill-building intervention was associated with a decline in internalizing symptoms compared to the control group, but no difference in total symptoms or attention problems.<sup>13</sup> In a group of children with attention-deficit/hyperactivity disorder (ADHD), Wolraich and colleagues assessed 1) a manual for diagnosis and treatment of ADHD for providers, and 2) a team (parent, teacher, and primary care provider) session on how to communicate about ADHD. This intervention showed no effect on behavioral symptoms.<sup>14</sup>

Other non-RCTs of CSHCN show similar associations. Several of these articles examined missed school days and found mixed results. In a before-and-after comparison of an intervention to integrate systems of care for CSHCN based on family-centered principles, Palfrey and colleagues found no significant change in the proportion of children who missed more than 20 days of school.<sup>15</sup> However, a similar study by Farmer and colleagues showed a reduction in missed school days.<sup>16</sup> Mangione-Smith and colleagues showed no difference in school days missed for a study of an intervention that included a learning collaborative to improve patient self management support.<sup>17</sup> In one NS-CSHCN study, a cross-sectional survey, FCC was associated with fewer missed school days.<sup>18</sup>

Mangione-Smith and colleagues showed higher quality-of-life scores and higher asthma-specific quality of life.<sup>17</sup> A family-centered, school-based behavioral intervention for children with inattentive and disruptive behavior problems also showed FCC activity was associated with improved child health status, with 3 of 21 symptom severity and function outcomes statistically significantly improved and 19 trending in the right direction.<sup>19</sup> In assessing

**Table 2.** Characteristics of Selected Studies

First Author, Year	Strength of Findings	Component of Family-Centered Care	Outcome Measured	Condition	Other Characteristics
Baruffi G, 2005	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (NS-CSHCN)</li> </ul>	<ul style="list-style-type: none"> <li>Systems of care</li> </ul>	Generic	449 CSHCN, representative of Hawaii NS-CSHCN sample
Blumberg, 2009	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (NS-CSHCN)</li> </ul>	<ul style="list-style-type: none"> <li>Systems of care</li> </ul>	Generic	79 589 CSHCN, nationally representative from 2001 and 2005–2006 NS-CSHCN
Clark NM, 1998	RCT	<ul style="list-style-type: none"> <li>Family-provider partnership</li> <li>Physician-patient communication</li> </ul>	<ul style="list-style-type: none"> <li>Efficient use of HCR</li> <li>Communication</li> </ul>	Asthma	74 physicians treating 637 assessed patients
Clark NM, 2000	RCT	<ul style="list-style-type: none"> <li>Family-provider partnership</li> <li>Physician-patient communication</li> </ul>	<ul style="list-style-type: none"> <li>Efficient use of HCR</li> <li>Communication</li> </ul>	Asthma	67 physicians seeing 527 patients
Denboba D, 2006	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (NS-CSHCN)</li> </ul>	<ul style="list-style-type: none"> <li>Satisfaction</li> <li>Access</li> <li>Health (missed school)</li> </ul>	Generic	37 316 CSHCN, nationally representative
Farmer JE, 2005	Intervention with before-and-after comparison	<ul style="list-style-type: none"> <li>Family-to-family peer support within a medical home intervention</li> </ul>	<ul style="list-style-type: none"> <li>Health</li> <li>Access</li> <li>Satisfaction</li> <li>Family functioning</li> </ul>	Generic	83 families with children with complex chronic health conditions consented with 51 completing full-year intervention
Frost M, 2010	Intervention with before-and-after comparison	<ul style="list-style-type: none"> <li>Family-provider partnership</li> <li>Family as staff</li> </ul>	<ul style="list-style-type: none"> <li>Systems of care</li> </ul>	Generic	39 parents of hospitalized infants and toddlers for pretest, 34 for posttest, 76 staff members for pretest, 51 for posttest
Gavin LA, 1999	Cross-sectional association	<ul style="list-style-type: none"> <li>Treatment alliance</li> </ul>	<ul style="list-style-type: none"> <li>Efficient use of services</li> <li>Family functioning</li> </ul>	Asthma	60 adolescents with severe chronic asthma
Guendelman S, 2002	RCT	<ul style="list-style-type: none"> <li>Physician-patient communication</li> <li>Asthma self-management and education program</li> </ul>	<ul style="list-style-type: none"> <li>Efficient use of HCR</li> <li>Health status</li> </ul>	Asthma	134 children with ED or hospital visits for asthma, primarily a Medicaid population, mean age 12 y, >70% African American
Jessop DJ, 1994	RCT	<ul style="list-style-type: none"> <li>Family-provider partnership</li> <li>Peer support</li> <li>Home care intervention</li> </ul>	<ul style="list-style-type: none"> <li>Access</li> <li>Communication</li> </ul>	Generic	219 children with chronic physical conditions
Mangione-Smith R, 2005	Intervention with control group	<ul style="list-style-type: none"> <li>Family-provider partnership</li> <li>Learning collaborative including patient self-management support</li> </ul>	<ul style="list-style-type: none"> <li>Efficient use of HCR</li> <li>Health status</li> <li>Satisfaction</li> <li>Family functioning</li> <li>Parent financial impact and cost</li> </ul>	Asthma	26 practices, 385 children with moderate to severe asthma
Ngui EM, 2006	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (NS-CSHCN)</li> </ul>	<ul style="list-style-type: none"> <li>Satisfaction</li> <li>Access</li> </ul>	Generic	36 238 CSHSCN, nationally representative
Owens JS, 2005	Intervention with before-and-after comparison	<ul style="list-style-type: none"> <li>Family-provider partnership</li> </ul>	<ul style="list-style-type: none"> <li>Health status</li> </ul>	Inattentive and disruptive behavior problems	42 children K–6th grade, 77% met criteria for ADHD
Palfrey JS, 2004	Intervention with before-and-after comparison	<ul style="list-style-type: none"> <li>Family-provider partnership</li> </ul>	<ul style="list-style-type: none"> <li>Efficient use of HCR</li> <li>Health status</li> <li>Satisfaction</li> <li>Family financial impact and cost</li> </ul>	Generic	117 CSHCN, 56% between 0–5 y, 38% nonwhite
Scal P, 2005	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (NCSHCN)</li> </ul>	<ul style="list-style-type: none"> <li>Transition</li> </ul>	Generic	4426 CSHCN age 14–18 y, nationally representative of CSHCN age 14–18 y

*(Continued)*

Table 2. Characteristics of Selected Studies (Continued)

First Author, Year	Strength of Findings	Component of Family-Centered Care	Outcome Measured	Condition	Other Characteristics
Smaildone A, 2005	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (NS-CSHCN)</li> </ul>	<ul style="list-style-type: none"> <li>Access</li> </ul>	Generic	748 CSHCN, representative of New York State
Stein REK, 1991	RCT	<ul style="list-style-type: none"> <li>Family-provider partnership</li> <li>Parent peer support</li> </ul>	<ul style="list-style-type: none"> <li>Health status</li> </ul>	Generic	Follow-up of 81% of original 178 families, 59% Hispanic, 33% African American, 8% other
Van Riper M, 1999	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership</li> </ul>	<ul style="list-style-type: none"> <li>Satisfaction</li> <li>Family functioning</li> <li>Health status</li> <li>Health status</li> </ul>	Down syndrome	89 children with Down syndrome, 95% white, 58% family income between \$25K and \$55K, average age 8 y
Wade SL, 2006	RCT	<ul style="list-style-type: none"> <li>Family-provider partnership (family-centered skill building)</li> </ul>	<ul style="list-style-type: none"> <li>Health status</li> </ul>	Traumatic brain injury	32 mothers with children aged 5–16 y, 65.6% male, 19% African American
Wang G, 2007	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (NS-CSHCN)</li> </ul>	<ul style="list-style-type: none"> <li>Access</li> </ul>	Generic	NS-CSHCN 2001, nationally representative of CSHCN
Weiland J, 2003	Intervention with before-and-after comparison	<ul style="list-style-type: none"> <li>Family-provider partnership (shared decision making)</li> </ul>	<ul style="list-style-type: none"> <li>Efficient use of HCR</li> </ul>	Cystic fibrosis	43 children with cystic fibrosis, 47% of intervention vs 40% of control group has insurance
Wissow L, 1998	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (patient-centered provider style)</li> </ul>	<ul style="list-style-type: none"> <li>Satisfaction</li> <li>Communication</li> </ul>	Asthma	104 children with asthma from ED, 60% male, average age 6.3 y, average 4 ED visits in past year
Wolraich M, 2005	RCT	<ul style="list-style-type: none"> <li>Family-provider partnership (seminar, one-on-one sessions)</li> </ul>	<ul style="list-style-type: none"> <li>Health status</li> </ul>	ADHD	249 children at risk for or with ADHD, 52% African American, 317 teachers
Young MC, 2005	Cross-sectional association	<ul style="list-style-type: none"> <li>Family-provider partnership (NS-CSHCN)</li> </ul>	<ul style="list-style-type: none"> <li>Access</li> </ul>	Generic	719 CSHCN representative of Texas

RCT = randomized controlled trial; CSHCN = children with special health care needs; NS-CSHCN = National Survey of Children With Special Health Care Needs; ED = emergency department; HCR = health care resources; ADHD = attention-deficit/hyperactivity disorder.

a team approach to cystic fibrosis treatment in the hospital, Weiland and colleagues found no difference in airway clearance.<sup>20</sup> An assessment of perceptions of family-provider relationships for children with Down syndrome found better overall parental psychological well-being but no differences in parental depression measures.<sup>21</sup>

#### SATISFACTION

Nonrandomized interventional studies show mixed association between FCC and satisfaction. The study of Palfrey and colleagues of CSHCN found no change after intervention in satisfaction with care.<sup>15</sup> The study of Mangione-Smith and colleagues, noted above, reported no difference in adolescent satisfaction.<sup>17</sup> A study of children with Down syndrome that looked at FPPs showed that having less maternal-provider discrepancy was associated with greater satisfaction.<sup>21</sup> In another study, children with patient-centered providers were more likely to be very satisfied with the physicians' job performance and to consider the physician to be informative. However, there was no difference in these parents' overall satisfaction with care.<sup>22</sup> FCC was, however, associated with greater parental reports of satisfaction with care in 2 separate 2001 NS-CSHCN analyses.<sup>18,23</sup>

#### MORE EFFICIENT USE OF HEALTH CARE RESOURCES

Several RCTs, all in populations with specific chronic conditions, showed associations between improved patient-provider partnership and more efficient use of services. In one asthma RCT by Clark and colleagues, researchers randomly assigned providers into a seminar that helped physicians partner with patients or to no intervention. Patients whose physicians were in the intervention group were more likely to be treated with inhaled anti-inflammatory medications (68% vs 56%  $P = .04$ ).<sup>24</sup> Although the study found no main effect on emergency visits or hospitalizations for the whole population, there were significant interactions with low income and number of baseline hospitalizations/emergency department visits. A second article using the same intervention study examined longer-term outcomes and found that the intervention was associated with fewer hospitalizations (−1.3 per year,  $P = .03$ ), but no reduction in overall emergency department use.<sup>25</sup> As in the first paper, there were interaction effects for vulnerable populations. An RCT conducted by Guendelman and colleagues used the Internet to facilitate family-focused nurse-family communication in families with children with asthma. This study found that, among other outcomes, intervention families were less likely to make urgent calls to their providers (odds ratio = 0.43, 95% confidence interval = 0.18–0.99,  $P = .05$ ).<sup>12</sup>

One nonrandomized study examined interventions that provided comprehensive coordinated care with family peer supports for CSHCN. The study of Palfrey and colleagues examined change in health care utilization before and after the intervention. Although they found no change in the percentage of children with emergency department visits, they did find a reduction in hospitalization.<sup>15</sup> Nonrandomized, condition-specific interventions

also show that more efficient use of services is associated with FCC. Specifically, research shows more efficient use of services is associated with improved care based on the Improving Chronic Illness Care Model<sup>17</sup> and better physician and patient partnerships,<sup>26</sup> but not with improved scheduling.<sup>20</sup>

### ACCESS

The relationship between FCC and access to care is consistently supported. A RCT that examined a comprehensive intervention also studied by Stein showed that among CSHCN not receiving services at baseline, access to care—in particular having a usual source of care—improved significantly more for the intervention group than for controls.<sup>27</sup> Additionally, several studies using the NSCSHCN generally showed an association of FCC with better access to care. Specifically, FCC was associated with receiving more genetic counseling,<sup>28</sup> having greater access to specialty care,<sup>18,29</sup> having fewer unmet child and family needs,<sup>18</sup> using services with greater ease,<sup>23</sup> and receiving less delayed and forgone care.<sup>30</sup>

### COMMUNICATION

FCC was consistently associated with better communication in the studies cited here. Jessop and Stein found improvements in family-provider communication associated with the comprehensive intervention, in particular improvements were seen in providers listening to concerns, especially for those without services at enrollment.<sup>27</sup> Clark and colleagues found that improved FPP was associated with improved communication on a variety of asthma-related communication measures.<sup>24,25</sup> In contrast, an intervention to improve communication among parents, teachers, and primary care providers for children with and at risk of ADHD showed few significant effects on communication, and those that were identified were short lived.<sup>14</sup> Patient-centered provider styles were associated with parents providing more medical information.<sup>22</sup>

### SYSTEMS IMPROVEMENTS

FCC was associated with systems improvements in 2 NS-CSHCN studies, and a third hospital-based study found mixed results. The hospital-based family-centered intervention of Frost and colleagues showed mixed results for systems improvements.<sup>31</sup> Two studies from the NSCSHCN showed associations with systems improvement. The first, a study of Hawaiian families showed associations of FCC with having an easy-to-use community-based care system (odds ratio = 4.7, 95% confidence interval = 2.0–11.0).<sup>32</sup> The second, by Blumberg and Carle, found similar findings using the whole 2005–2006 NS-CSHCN sample and showed that FCC was associated with the latent construct of the well-being of the health care environment.<sup>33</sup>

### IMPROVED TRANSITION TO ADULTHOOD

Families who reported that they received FCC also reported higher scores on a health care transition scale.<sup>34</sup>

### FAMILY FUNCTIONING

Two of the 3 studies that examined family functioning found associations with FCC and family functioning. The assessment of Mangione-Smith and colleagues of a family-centered intervention around improving chronic care for children with asthma showed no differences in family functioning.<sup>17</sup> In a separate study of children with asthma, Gavin and colleagues showed associations of treatment alliance with family functioning.<sup>26</sup> Van Riper found an association between mothers reporting fewer discrepancies between their family's relationship with their health care provider and higher levels of individual and family functioning ( $r = .22, P \leq .05$ ).<sup>21</sup>

### FAMILY FINANCIAL IMPACT AND COST

Only 2 studies examined family financial impact and cost, and their findings differ. The medical home intervention of Palfrey and colleagues showed statistically significant differences in parents' missed workdays ( $P = .02$ ), with greater differences found for children with more severe conditions.<sup>15</sup> The Improving Chronic Illness Care Model intervention reported no differences in parental work loss.<sup>17</sup>

### SUMMARY OF THE NATIONAL SURVEY FINDINGS

Because of the prominence of the NS-CSHCN in studies of FCC, we summarize the findings of these studies here. The 2001 NS-CSHCN showed associations of FPP and several health outcomes. Partnership in care was associated with less missed school, fewer unmet needs, and greater satisfaction;<sup>18</sup> better transition services among adolescents;<sup>34</sup> and improved satisfaction;<sup>23</sup> the use of genetic counseling;<sup>28</sup> and the well-being of the health care environment.<sup>33</sup> Analyses of individual states additionally show associations between FPP and the likelihood of reporting ease of use of community-based care,<sup>32</sup> delayed and forgone care,<sup>30</sup> and less need for a specialist and fewer problems with specialist referrals.<sup>29</sup>

## DISCUSSION

This review found evidence that FCC is associated with improved outcomes in several domains. We found these associations among different populations of CSHCN, operationalizations of FCC, and outcomes. We did not find evidence that FCC was associated with poorer outcomes. For most studies, there was at least one association of FCC with a positive outcome. Most studies measured several outcomes, and some studies had mixed findings, with only a few having only nonsignificant or negative findings. The relationships were documented both in RCTs and in cross-sectional studies. Analogous evidence from a review of patient-focused educational interventions found positive evidence for health literacy, clinical decision-making, self-care, and patient safety.<sup>35</sup> A Cochrane review of consumer involvement found moderate-quality evidence favoring involving consumers in materials development, though in other areas, evidence was lacking.<sup>36</sup> A review of evidence for family-based services in children's mental health showed

improvements in quality of care outcomes though a need for more research.<sup>37</sup>

In our review, we found that the evidence in certain areas dominates. Over a third of the articles examined populations of CSHCN, children with disabilities, and/or groups of children with several chronic conditions rather than specific single conditions. Among children with specific chronic conditions, most of the studies were of children with asthma. Similarly, when looking at the evidence by endpoint, the health domain stands out because these outcomes were included in nearly half the articles. Other areas (such as transition and family financial impact) had very little evidence.

Several studies examined minority populations or populations at higher risk. Several studies examined populations with high proportions of African American, Latino, and/or minority children.<sup>11,12,14,15,16,17,24,25,27</sup> One study examined populations with a high proportion of children insured by Medicaid.<sup>12</sup> Several studies examined interactions of risk factor (such as poverty and low baseline service use) and intervention and generally found that children and parents at higher baseline risk experienced stronger intervention effects than children and parents at low baseline risk.<sup>11,15,24,25,27</sup>

This review has several limitations. We only examined US studies and studies published in English. The heterogeneity of study outcomes did not allow us to conduct a meta-analysis. Although there were many RCTs, other studies lacked control subjects or were purely the findings of cross-sectional surveys. Publication bias likely favors studies that demonstrate an association with FCC, though it is useful to note that not all studies found positive associations with relevant outcomes. The literature has many gaps.

The review indicates several areas of needed research. First, it would help to have studies that better isolate the value of family-centeredness rather than considering family-centered efforts in the context of a broader intervention. Several of the studies did not isolate the effect of the family-centeredness, but rather looked at the overall impact of the intervention; thus, any effect of the intervention may or may not reflect the degree of family-centeredness. Second, it is necessary to more clearly define and operationalize FCC and FPP. This will help future researchers build the field systematically. Nevertheless, the research recommended above along with the research presented here will also help providers and practices target their FCC implementation efforts.

Consensus on what exactly FCC entails and operationalizing the FCC will help future research activities build a body of evidence related to FCC. We chose FPP as our definition of FCC. This, however, captures only part of what is generally considered FCC. It would be helpful if a definition of FCC would include several dimensions of FCC in a way that studies could either fully implement and measure FCC, or examine specific aspects of FCC. The Family Voices Family-Centered Care Self-Assessment tool<sup>38</sup> and the self-assessment tools designed by the Institute for Family-Centered Care<sup>39</sup> could be good bases for assessing FCC efforts and operationalizing a definition of FCC.

The relatively strong evidence for FPP should be of interest to practitioners. This is shown in our review and in broader reviews for other populations. Providers may consider making changes in their practices to improve communication and partnership with children and their families. High-quality patient-provider encounters with a focus on the patient and family perspective, needs, expertise, and priorities is a central part of the description of FCC put forth by various organizations.<sup>3,5,7</sup> Similarly, providers should consider whether there is a need for additional staff to improve the partnership and communication with families. This may be particularly important to consider for vulnerable families. This review provides evidence of reasonable strength and quality, some from RCTs, that FCC and its components can improve outcomes for CSHCN and their families. We believe that this evidence supports the endorsement and further study of FCC.

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**Appendix.** Findings From the Literature Review of Family Centered Care

First Author, Year, Type	Population Characteristics	Sample	Interventions/Study Focus	Findings
Baruffi G, 2005, Cross-sectional assoc.	Part of the Hawaii NSCSHCN Sample. Representative of Hawaii. No race/ethnicity data was shown.	449 CSHCN	They measured FCC from the NSCSHCN's measure of parent provider partnership.	Partnering in the care of their child is associated with reporting that community-based service systems are organized so that families can use them easily, OR = 4.7 (CI 2.0 to 11.0).
Blumberg SJ, 2009, Cross-sectional assoc.	NSCSHCN. Nationally representative. No race/ethnicity data was shown.	79,589 CSHCN	Latent-variable association, how different indicators, including family-centered care (with FPP as necessary component) contribute to or affect the 'Well-being of the health care environment.'	Better levels of the 'well-being of the health care environment' were indicated by the receipt of family-centered care.
Clark NM, 1998, RCT	MDs were 60% male, 59% <49 years old, 57% were in individual practices, 54% spoke English only. Patients 70% boys, 59% between 2 and 7 years old, 20% have incomes < 20K a year, 30% non white.	83 MDs responded and met criteria, of those 74 agreed to participate, (1276 letters initially sent). Children enrolled included those age 1-12 with asthma. 637 families responded.	An interactive seminar based on theory of self regulation guiding MDs to examine ways to develop a partnership with their patients.	Intervention MDs reported more treatment with appropriate mediations (e.g. with inhaled anti-inflammatory meds 68% vs. 56% p = .04), more communication (e.g. wrote down how to adjust dose of meds when symptoms change), and spent less time with new patients (23 vs. 27 min.). Parent perceptions of intervention MDs included more reassurance by MD (4.63 vs. 4.42 p = .006) and other outcomes. Changes reported on health services use including fewer nonemergency MD visits (1.24 vs. 2.25 p = .005), follow-up MD visits (.94 treatment vs. 1.61 control p = .005) but no effect on ED or hospitalization use as a whole. Low income children in treatment group had a reduction in ED use. The higher the number of baseline hospitalizations the greater the intervention effect was on reducing hospitalizations and the same is true of ED visits.

Clark NM, 2000, RCT	MDs were 60% male, 59% <49 years old, 57% individual practices, 54% spoke English only. Patients 70% boys, 59% between 2 and 7 years old. 20% have family incomes <20K a year, 30% non-White.	67 physicians at long term evaluation (1276 letters sent to MDs to recruit). Final sample of children seen by these MDs is 527.	An interactive seminar based on theory of self regulation guiding MDs to examine ways to develop a partnership with their patients.	Communication and patient education strategies taught in the intervention were used more extensively by treatment group MDs. (For example, MDs wrote down how to adjust dose or timing of meds related to child's symptoms (OR 5.7 p = .05). Parents of patients in intervention group reported MD paid close attention (adjusted mean 4.54 vs. 4.41 p < .04), were commended by the MD for asthma management, physician asked open-ended questions, physician asked about specific fears/concerns with medicine, physician gives me a good idea of the short-term treatment plan, physician makes it easy for us to follow instructions for medications, but there was no difference in physician spending enough time with family. Healthcare use shows that intervention families had fewer hospitalizations (with those with higher baseline hospitalizations having a greater program effect) but no overall reduction in ED use but there was an intervention effect for those with high baseline ED use. No main effects for office visits scheduled or unscheduled but there were interaction effects.
Denboba D, 2006, Cross-sectional assoc.	Nationally representative.	37,316 CSHCN	They measured FCC from the 2001 NSCSHCN's measure of parent provider partnership.	Family provider partnership is associated with less missed school, less unmet need for specialty care (OR for never/sometimes feeling like a partner vs. usually/always 3.75 CI 3.23 to 4.30), greater satisfaction, fewer unmet needs, and fewer family unmet needs.

(Continued)

**Appendix.** Findings From the Literature Review of Family Centered Care (*Continued*)

First Author, Year, Type	Population Characteristics	Sample	Interventions/Study Focus	Findings
Farmer JE, 2005, Int. pre- post comp.	Sample of children with complex chronic health conditions. 33% were of racial and ethnic minority. Mean age 7.4 years, 57% male, 83% of mothers had a HS diploma.	175 referred by physicians in 3 university affiliated clinics. 83 consented and completed baseline research measures. 51 remained in the study for the full year intervention.	Family to family peer support provided as a part of the medical home model with individualized advice given, a care team, care coordination, home visits, and a written health plan.	Improved access to mental health services (29% to 45% got mental health services T1 and T2 respectively); no changes in number of children who received primary, preventive, specialty, inpatient, emergency, or dental services. Were decreases in the number of primary and specialty cared visits. Report of hospitalizations and in-home nursing stayed the same. Satisfaction with care coordination improved but there was a decline in satisfaction with primary care and no change in satisfaction with other health and related services. Family functioning improved on several measures, e.g. the total number of needs (-1.83 difference $p = .0013$ ) and child functioning did not change but missed school days were reduced.
Frost M, 2010, Intv. w/pre-post comp.	No demographic data identified	39 parents of hospitalized infants and toddlers for pretest, 34 for posttest, 76 staff members for pretest, 51 for posttest	Pretest assessing concerns of parents with children in the hospital unit as well as staff concerns. Intervention of FCC educational program, environmental changes to the unit based on parent/staff suggestions, and unit policy changes to increase family centered environment. Posttest to compare responses.	No statistically significant changes in parent pre-post comparison though some may be clinically significant- parents noted improvement in staff interactions, educational resources, respect for decisions and others. Staff reported statistically significant improvements in inclusion of fathers, and unit improvements as well as clinically significant improvements in recognizing parents as primary decision makers. In addition to the Pre-post test comparisons, Press Ganey Scores showed improvements in all key areas of the project including respect for parent knowledge, teamwork and inclusion in decision making. These improvements were seen both in the post-test scores and the late follow-up.

Gavin LA, 1999, Cross-sectional assoc.	Mean age 14, 75% White 13% African-American, 10% Hispanic, 50% female, mostly middle class, median length of stay 28 days.	60 adolescents with severe chronic asthma, 70% response rate.	Goal alliance is the measure of FCC	Adherence with asthma medications was related to the physician's goal alliance and physical defeat alliance ( $r = .28$ $p < .05$ $r = .34$ $p < .01$ ) Follow-up adherence also related to physicians' goal alliance, physician defeat alliance. Better MD ratings of goal alliance and treatment defeating scales were associated with less urgent office visits in the year post hospitalization but not related to ED visits or hospitalizations. Family functioning related to physician goal alliance and physician defeating alliance in multiple regressions. In similar models, physician goal alliance related to the parent functioning on the behavior control dimension and physician defeating alliance related the quality of the family interaction.
Guendelman S, 2002,RCT	Primarily a Medicaid population. Mean age was 12, just over 90% of sample has public insurance and over 70% was African-American.	134 children with ED or hospital visits for asthma (out of 136 screened eligible)	Asthma self-management and education program, "the Health Buddy", an internet query device a nurse uses to communicate with the family and provide information to health providers. Comparison intervention was a standard asthma diary.	Post intervention significantly fewer children in the Health Buddy program had peak flow readings in the yellow or red zone during the 14 days before the follow-up visit compared to the control (OR = .43 CI .23-.82 $p = .01$ ). The same is true for limitations in activity (OR = .52 CI .29-.94 $p \leq .03$ ). The only health services measure that differed was urgent calls (OR = .43 CI .18-.99 $p .05$ ). ED and hospitalization results not statistically significant.
Jessop DJ, 1994, RCT	Children ages birth through 11. 60% Hispanic, 27% African-American; 40% of parents are married; 45% of children live with both parents; 55% have some public assistance income.	219 children with chronic physical conditions - 178 with complete data.	Home care program - multidisciplinary team that delivers comprehensive services including case management. Team members monitor condition, deliver direct care, ongoing primary care, specialized care in conjunction with specialist, coordinate services, patient education and advocacy. Team involves family in management and decision-making.	For those with out services at baseline, service use increased for both groups but they increased more for the intervention group. Significant results found for listens to concerns and for those with services there were significant results for coordination with other agencies. Other aspects of the results are not statistically significant.

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**Appendix. Findings From the Literature Review of Family Centered Care (Continued)**

First Author, Year, Type	Population Characteristics	Sample	Interventions/Study Focus	Findings
Mangione-Smith R, 2005, Int. w/ control group	Mean age 8.9 intervention 10.5 control, race/ethnicity 19% and 43% non-Hispanic White, 30% and 23% non-Hispanic African-American, 29% and 22% Hispanic, 22% and 12% other.	26 practices involved in the ICI intervention 9 agreed to be evaluated. With 4 of the 9 providing comparison sites. 385 children with moderate to severe asthma	A learning collaborative to improve pediatric asthma care using the Improving Chronic Illness Care (ICI) model. ICI model includes organizational/leadership, patient self-management support, delivery system design, provider decision support, clinical information systems, and links to community services.	For 6 of 8 quality indicators and the overall process of care score the scores in the intervention group improved substantially while the control sites showed little or no improvement (overall score difference of difference was 13 $p < .0001$ ). Process of care: children in intervention sites are more likely to monitor their peak flow (70% vs. 43% $p < .001$ ) and have a written action plan (41 vs. 22% $p < .001$ ) compared to control sites. Intervention sites had higher PedsQL 4.0 general QOL, higher asthma quality of life treatment problems, and asthma specific QOL re symptoms scale No difference found on family functioning, adolescent satisfaction, school days, or work loss.
Ngui EM, 2006, Cross-sectional assoc.	Nationally representative of CSHCN	36,238 CSHCN	They measured FCC from the 2001 NSCSHCN's measure of parent provider partnership.	Predictors of dissatisfaction include: sometimes or never having each component compared to always or usually predicted dissatisfaction, specifically, inadequate time spent with provider (OR = 1.72 CI 1.20–2.45), provider listening skills, provider gives enough information to the family, sensitive to values and customs, and provider helps family feel like partners in child's care. For models predicting problems with ease of using health care FCC predictors were similar to above.
Owens JS, 2005, Int. w/ pre-post comp.	77% met criteria for ADHD of whom 19 met criteria for ODD or CD.	42 children in kindergarten through sixth grade with inattentive and disruptive behavior problems.	A school-based mental health program that provides an evidence-based treatment package using daily report card which was used in school and encouraged at home. They also had a behavioral parenting series.	For 19 of the 21 parent rated symptom severity and functioning variables there was a trend toward improvements with only 3 statistically significant differences between groups. For teacher rated variables, 7 variables differed between treatment and control. Grades for the treatment group stayed the same while the control group's grades declined ( $p < .05$ ).

Palfrey JS, 2004, Int w/ pre-post comp.	About 56% were age 0–5. 38% non-White	117 CSHCN with severe issues who had data available at 2 year evaluation. (222 invited, 150 met criteria and agreed to participate).	Integrated system of care for CSHCN based on principles of family-centered care and the medical home. Family-centered aspects include: each child had an individual health plan, families served as advisors to the care team, a family newsletter was created.	Families reported that during intervention it was much easier or somewhat easier to obtain health and support services. Families that had more severe problems were more likely to indicate improvement. There was a non-significant increase in satisfaction; more families had a written care plan after the intervention. No difference in the percentages of children with missed school days, or ED visits but there were significant difference in parents' missed work days and hospitalizations. (The more severe group had greater changes and other interactions were significant.)
Scal P, 2005, Cross-sectional assoc.	Nationally representative of CSHCN age 14–18.	4426 CSHCN age 14–18	They measured FCC from the 2001 NSCSHCN's measure of parent provider partnership.	Higher quality of parent-provider partnership was associated with significantly higher scores on the transition scale (coefficient .0831 $p < .001$ ) and quality of the parent-provider interaction was one of the strongest predictors in multivariate analyses.
Smaldone A, 2005, Cross-sectional assoc.	Representative of CSHCN in NY state.	748 CSHCN	They measured FCC from the 2001 NSCSHCN's measure of parent provider partnership.	Adjusted multivariate results show that FCC (e.g. provider spends enough time OR = 1.9 for usually, 2.9 for sometimes, 7.3 for never vs. always $p < .001$ ) predicting delayed/foregone care.
Stein REK, 1991, RCT	All children enrolled in the original study who were 5 or older at enrollment. 59% Hispanic 33% African-American 8% other. 56 of mothers had less than HS graduation.	Follow-up sample - 81% of original 178 families.	Home care program - multidisciplinary team that delivers comprehensive services including case management. Team members monitor condition, deliver direct care, provide ongoing primary care, specialized care in conjunction with specialist, coordinate services, patient education and advocacy. Team involves family in management and decision-making.	Long term follow up findings - Significant difference in adjustment (as measured by the PARS II) with better changes in adjustment in the experimental group (mean scores - home care 74 vs. standard care 67; $p = .009$ ). Higher levels of adjustment on the withdrawal, anxiety/depression, productivity, and hostility subscales with no difference in peer relationships or dependency.

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**Appendix. Findings From the Literature Review of Family Centered Care (Continued)**

First Author, Year, Type	Population Characteristics	Sample	Interventions/Study Focus	Findings
Van Riper M, 1999, cross-sectional assoc.	95% White, 58% family income between 25K and 55K, mean maternal education 15 years, average age 8 years old.	89 children with down syndrome of 130 invited to participate	They assessed family provider relationships.	Significant correlations between beliefs about family provider relationship and satisfaction .43 ( $- \leq .01$ ) and family provider relationship and belief-desire discrepancy -.56 ( $p \leq .01$ ). Mothers who wanted and believed they had family centered relationships reported better psychological well-being and family functioning. No correlations with depression.
Wade SL, 2006, RCT	Mean age 10.8 years, 8.8 months since injury, 65.6% male, 19% African American, 53% of mothers had at least a high school education.	32 mothers of children age 5–16 with moderate to severe TBI	A family-centered, problem solving/skill building intervention including 6 months of 7 biweekly core sessions on problem solving/skill building, 4 individualized sessions.	Intervention group had larger decline in internalizing symptoms 5.81 decline in intervention vs. 2.07 in control ( $p = .05$ ), anxiety/depression decreased (3.8 in the intervention group and .06 in the control group $p = .05$ ), no difference in total symptoms or attention problems based on the CBCL. No difference on BSI global severity and anxiety and depression subscales.
Wang G, 2007, Cross-sectional assoc.	Nationally representative of CSHCN	NSCSHCN 2001	They looked at the association between access to genetic counseling for CSHCN and their families and having a medical home	CSHCN with a medical home are 2.70 times more likely to receive genetic counseling than CSHCN without medical homes (95% CI: 1.58, 4.61; $p \leq .001$ ). Family centered care was the only element, out of four, comprising medical home that was significantly associated with receiving genetic counseling.
Weiland J, 2003, pre-post comp. of interv.	Mean age about 17, 47% of intervention vs. 40% of control group has insurance.	43 children with CF for clinical outcomes	Team to address concerns of patients with CF at a hospital especially telling teens what would happen to them and working out negotiable parts of the schedule together on a day to day basis.	Found no difference in airway clearance, or the proportion of days patients received all airway clearance treatments as ordered. No difference in physical therapy treatments given as ordered or the proportion who got at least 75% of treatments.
Wissow L, 1998, Cross-sectional assoc.	60% male, mean age 6.3 years, average of 4 ED asthma visits in past year.	104 children with asthma recruited in the ED. Children had to live in census tracts with 20% or more households below poverty and between 4–9 years old.	They looked at patient-centered provider style in the ED.	Parents gave more medical and psychosocial information to parent/patient centered providers. Overall parent satisfaction was not related to a child having a parent/child centered provider, but parents in visits with a child/patient-centered provider were more likely to be “very satisfied” with the MDs job, to consider the MD to be more informative.

Wolraich M, 2005, RCT	52% were African-American.	1536 children with or at risk of ADHD were eligible with final sample of 249 also 317 of 975 teachers participated by completing behavior rating scales (VADTRS) on all students in their classrooms.	1) A manual and seminar on how to diagnose and treat ADHD for PCPs. 2) Treatment group students had a parent, teacher, and or PCP attend a single one on one session with a trained representative about communication about ADHD (based on model of academic detailing).	Workshop approach did not have enough participants to estimate it. The PCP intervention associated with a significant increase in PCP school communication ( $p = .04$ ) but over time the difference declined to non significance. Effectiveness of intervention with parents and teachers was not significant. Of 20 analyses 1 met Bonferonni corrected significance ( $p < .0025$ ) the intervention with PCP leads to an increase in parental communication with other physicians followed by subsequent decline. Basically there were no effects on behavioral symptoms (1 of 32 a number that could be due to chance alone).
Young MC, 2005, Cross-sectional assoc.	The sample is representative of Texas.	719 CSHCN	They measured FCC from the NSCSHCN's measure of parent provider partnership.	Respondents who reported that MDs were sometimes sensitive to family values/customs were three times more likely to report that they needed a specialist and nine times more likely to experience problems in obtaining a referral to a specialist compared to those whose MDs were always sensitive. Respondents who never or sometimes obtained enough information about medical problems were more likely to face problems obtaining referrals than those who always did. But respondents who reported that MDs never spent enough time with them were significantly less likely to have problems obtaining a referral to a specialist than those with MDs who always spent enough time (this last result was opposite than expected but it was small).

FCC = Family-centered care; RCT = randomized controlled trial; Intv. = intervention study; Assoc. = associational study; TBI = traumatic brain injury; HS = high school; ED = emergency department; HH = household; Comp. = Comparison; CYSHCN = children and youth with special health care needs; NSCYSHCN = national survey of CYSHCN; BW = birth weight; ADHD = attention deficit activity disorder; EI = early intervention, VLBW = very low birth weight; NICU = neonatal intensive care unit; ODD = oppositional defiant disorder, g = grams.