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A Review of the Literature Pertaining to Family-Centered Care for Children with Special Health Care Needs

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Introduction

The health care system in the United States is in the process of rapid transformation, and the idea that each patient should have a patient- or family-centered medical home is gaining broad acceptance. Well prior to the enactment of the Affordable Care Act (ACA), which provides incentives and other mechanisms to promote delivery systems that emphasize medical homes and patient-centered care, the American Academy of Pediatrics (AAP) recommended a medical home for children with chronic diseases or disabling conditions.[1] In 1992, the AAP adopted a policy statement recommending medical homes for *all* children, defined as medical care that is "accessible, continuous, comprehensive, family-centered, coordinated and compassionate."[2] In 2002 the definition was modified as care that is "delivered or directed by well-trained physicians who provide primary care and help to manage and facilitate essentially all aspects of pediatric care. The physician should know the child and family and should be able to develop a partnership of mutual responsibility and trust with them."[3]

In the interval between those policy statements the federal Maternal and Child Health Bureau provided grant support to the AAP for a project subsequently known as the Medical Home Program for Children with Special Needs. In part due to the influence of the Bureau, as well as through the organized efforts of families with children with special health care needs (CSHCN), the centrality of families not only in the care of these children but also in the medical decision-making about their care became appreciated.

For CSHCN, ideal health services are necessarily grounded in "family-centered care" (FCC), which includes the planning, organization and delivery of health care that involves a partnership between families, patients and health care providers.

Family-Centered Care Core Principles

"Family-centered care" is a framework for delivery of services that has influenced policies, programs, facility design and staffing, clinical practice and professional education.[4] Rooted in the consumer movement of the 1960s, the concept was formally endorsed by the Surgeon General in 1987,[5] is reflected in the Nation's Healthy People 2010 Objectives, and is incorporated into core objectives for CSHCN by the federal Maternal and Child Health Bureau (MCHB).[6] Though the specific components have evolved over time, the concept of family-centered care is rooted in the belief that the family has the greatest influence over an individual's health and well-being, and that because of this influence families must be supported in their roles as caregivers. The generally accepted principles that guide FCC are as follows:

1. In family-centered care, people are treated with dignity and respect;
2. In family-centered care, health care providers communicate and share information with patients and families that is affirming and useful;
3. In family-centered care, individuals and families build on their strengths by participating in experiences that enhance feelings of control and independence;

4. In family-centered care, collaboration among patient, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.[7]

Medical Homes and Family-Centered Care for CSHCN

The Maternal and Child Health Bureau uses six critical indicators to measure the quality of a system of care for CSHCN. These include concepts related to both the medical home and family-centered care:

1. Families of children and youth with special health care needs partner in decision-making at all levels and are satisfied with the services they receive;
2. Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home;
3. Families of CSHCN have adequate private and/or public insurance to pay for the services they need;
4. Children are screened early and continuously for special health care needs;
5. Community-based services for children and youth with special health care needs are organized so families can use them easily;
6. Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.[8]

The concepts of a medical home and family-centered care are complementary and mutually supportive; both are considered the standards of care for all children, regardless of health status.[9,10] However, because of the complexities that families with CSHCN face in coordinating and navigating services, as well as in participating in shared decision-making, the benefits of family-centered care are especially important for CSHCN. In addition to the elemental differences between these two concepts, a medical home can be an individual provider or a place where children go regularly for care, while family-centered approaches are to be applied more broadly to the entire system of care.

Literature Review

According to estimates from national, population-based surveys, approximately 15 to 20 percent of children have special health care needs.[11,12] Defined as "those [children] who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally,"[13] CSHCN experience at least one type of ongoing health condition that results in a need for non-routine health and related services.[14] FCC is a method of planning, designing, organizing and delivering health and related services to ensure that CSCHN and their families obtain needed services that reflect the principles outlined above.

The purpose of this literature review is to provide an overview of findings from selected research related to family-centered care for CSHCN. According to the Maternal and Child Health Bureau, in operational terms, FCC "not only meet[s] the physical emotional, developmental, and social needs of children, but also support[s] the family's relationship with the child's health care providers and recognize[s] the family's customs and values."[15] Given the value of FCC, it is of interest to know what has been learned about the problems families of CSHCN face in having these needs met, and what the impact is of family-centered care that incorporates these elements.

An excellent review of the literature on this subject by Kuhitau et al was published in 2010.[16] This review looked specifically at the family-provider relationship and its impact on child and family outcomes. In this present review, we build on that analysis with updated references related to family-provider relationships, and we explore two other concepts associated with FCC: care coordination and linguistic and cultural competency. Literature published since 2008 was emphasized so as to not be redundant with other literature reviews, particularly related to family-provider partnerships. However, in some cases, older articles and reports are referenced.

Presented below are brief summaries of the findings. The table in Appendix A presents these same studies and many more organized into five sub-tables:

- Articles/Reports on Access, Unmet Need and Satisfaction for CSHCN;
- Articles/Reports on Outcomes of Family-Centered Care and Medical Homes for CSHCN;
- Articles/Reports on Family-Provider Partnerships for CSHCN;
- Articles/Reports on Care Coordination for CSHCN;
- Articles/Reports on Linguistic and Racial/Ethnic Barriers and Cultural Competence and Children with Special Health Care Needs and their Families

Findings

Health care in the United States is considered among the best in the world—if individuals have access to the care that is appropriate for their needs. The US system of health care, however, is highly fragmented and delivery is non-standardized. Responsibility for navigating between insurers, health care providers and institutions falls largely, if not exclusively, to patients and families. While daunting under most circumstances, this responsibility presents a more significant burden and barrier to care for families with children with special health care needs. Lack of communication among providers, limited access to pediatric subspecialists, inconsistent eligibility criteria for special services, and lack of quality standards all contribute to tremendous strain on families, adverse health outcomes for children, and increased costs both for families and for the health care system. For low income families, those who are non-English speakers or are of limited education the repercussions are particularly acute. Family-centered care is intended to address these systems-level issues associated with the organization and financing of health care in this country. This review highlights findings from studies that examine three components of FCC: family-provider partnerships, care coordination and cultural competence, as well as barriers to FCC among ethnic/racial minorities and non-English speaking families.

Family-Provider Partnerships

The central role of family-provider partnerships is derived from understanding the role of families in affecting children's health, as well as the rights of families to share in decision-making. This partnership is intended to improve communication between the two partners; contribute to greater understanding by the family about the child's condition and treatment options; and improve the provider's knowledge of the family's circumstances, needs and preferences. All of these can lead to a better experience for families, higher quality care, greater satisfaction on both sides and better outcomes for the child.

The family-provider relationship is a well-studied component of FCC. Kuhitau et al (2010)[17] systematically reviewed the literature on the family-provider component of FCC and its impact on child and family outcomes; they found that family-centered care for CSHCN is associated with improved health and well-being, improved satisfaction, greater efficiency, improved access, better communications, better transportation and other positive outcomes.

Denoba et al (2006)[18] examined variations in reported perceptions of the family-provider partnerships as well as in the perceived benefits associated with these partnerships and the downsides of their absence. Among their chief findings was that perceived partnerships varied greatly across race, ethnicity, income, and severity of condition. Latino families were 71% more likely than non-Hispanic whites to report not feeling a sense of partnership. The lowest income families were twice as likely to lack a sense of partnership as families at the highest measured income level. Families with CSHCN whose conditions were classified as severe were significantly less likely to report feeling like a partner in care. Not surprisingly, lack of a perceived partnership was associated with negative outcomes; parents and caregivers who reported "never or sometimes feeling like a partner" were approximately 10 times more likely to be dissatisfied with services, four times more likely not to get needed specialty services, and two to three times more likely to have unmet child and family needs.

Knapp et al (2010) also found the presence of a family-provider partnership to be associated with various benefits (and adverse effects when not present). Their analysis found an association between perceived partnerships and adequate insurance coverage, early and continual screenings, and organized health care. Like Denoba et al, Knapp et al found wide disparities in perceived partnership by race and ethnicity, as well as income and insurance status. Latino or African American respondents, and those who were from low-income families or who lacked insurance, were significantly less likely to report a perceived family-provider partnership compared to parents not reflecting these characteristics. Parents/caregivers of children with functional limitations were also less likely to report a perceived partnership. As with the earlier study, this study found a relationship between family-provider partnerships and some process outcomes; the presence of a partnership was associated with 20% fewer emergency department visits and 9 % fewer school days missed.[19]

Kenney et al 2011 found similar results. The presence of a partnership (combined with satisfaction with care) was associated with fewer school absences, higher rates of necessary referrals, and reduced rates of unmet child and family health needs. Their model found that the odds of going without needed care or referrals were reduced two- to threefold when families were partners in care.[20]

Coordinated Care

Coordinated care is an important component of family-centered care for CSHCN. In the National Survey of CSHCN (NS-CSHCN), the Maternal and Child Health Bureau defined the achievement of coordinated care as when: 1) families receive help with care coordination; 2) families are "very satisfied" with communication among PCP and other health care providers; and 3) when interactions are needed, families are "very satisfied" with how their doctors communicate with school, day care or other programs. According to the 2009-10 NS CSHCN, approximately 58% of CSHCN did not receive care that met this MCHB standard.[21]

Turchi et al 2009 used the 2005 NS-CSHCN to determine association between coordinated care and various outcomes.[22] They found that receiving coordinated care was associated with more satisfying care for families experiencing partnership, decreased odds of problems with referrals, and a lower likelihood of having to reduce work hours to care for their children. Other concrete benefits associated with coordinated care included decreased family financial burden (lower out-of pocket expenses), fewer missed school days, and significantly decreased odds of visiting the emergency department more than two times in the previous year. Parental report of adequate care coordination was associated with favorable family-provider relations and family/child outcomes.

Farmer and her colleagues (2005)[23] evaluated a demonstration project to assess the feasibility and applicability of comprehensive, coordinated care in rural America. The program was implemented in three rural clinics in Missouri with a sample of 51 children with 28 distinct primary diagnoses. Most families were of lower socioeconomic status and ethnic/racial minorities were overrepresented. The program intervention involved the establishment of a care team including the primary care physician, the child and family, a nurse practitioner and a paid parent consultant.

"The intervention focused on the provision of care coordination, information about resources and services, emotional support and encouragement, and empowerment for families to advocate for their children," all of which are elements of family-centered care (pg. 650). The nurse practitioner played a central role in this model, working with the families and assisting them with care coordination, in addition to consulting with all three practices. One of the notable changes involved families' access to mental health services, increasing from 29% to 45% of children who received services. There was also a significant improvement in satisfaction with health services, as well as decreased primary care and specialty care visits. Mothers reported a reduction in total family needs (such as social support, financial/material assistance) as well as a decrease in family strain and significant improvement in school attendance. While child functional status did not change in the one-year period, 95% of the participants reported that they found the intervention to be helpful. Improvements were more significant for mothers of children with lower functional status, who reported a greater decrease in unmet needs.

The extent to which care coordination is available, in general, and to families with CSCHN specifically, is somewhat of a debate,[24] as is how to measure it. There is, however, a solid and growing body of knowledge about what constitutes care coordination and how it should be operationalized. Antonelli and colleagues (2009) produced a framework for care coordination within pediatric care, including CSHCN.[25] This framework includes a definition of care coordination, outlines its principle characteristics, competencies and functions and offers a detailed process for its delivery. Another recently published analysis of care coordination programs across the US offers important program and policy recommendations based on lessons learned from these models.[26] This report identifies the key building blocks of a care coordination policy/program, describes how states have designed these elements, and presents some lessons from these programs. Thus, there are opportunities for significant growth in this arena for both implementation and study.

Racial/Ethnic and Linguistic Barriers and Culturally Competent Care

Children with Special Health Care Needs are a diverse population; the 2009/10 NS CSHCN found that 17.5% of CSHCN identified as African American and another 11.2% identified as Latino, with 8.2% of those identifying as a Spanish language household. Despite the importance of family-centered care in mitigating the challenges families with CSHCN face, major disparities in access to such care exist. Coker et al (2010) found Latino and African American children had lower odds of receiving FCC, with Latino children having the lowest odds, being half as likely as White children to receive family-centered care.[27] These disparities persisted even after adjusting for child health, socioeconomic, geographic and access variables. Ngui and Flores (2006) also found inequities in obtaining FCC among Latino and African American parents; these parents were significantly more likely than their White counterparts to report inadequate family-centered care, as well as dissatisfaction with care.[28]

Language barriers can be serious impediments to gaining access to quality, family-centered care as they can hinder communication between the family and provider, as well as complicate disease management by the family. Approximately 13.1% of families with CSHCN do not use English as the primary language in their household.[29] Yu and Singh conducted a secondary analysis of the 2005 NS-CSHCN to study the associations between primary household language and health care access. In bivariate analyses, primary language was associated with striking differences in the prevalence of family-centered care, access to a personal doctor/nurse, and insurance coverage. Respondents with a non-English primary language (NEPL), were more likely to spend more than 10 hours coordinating or providing care, stop employment, lack insurance, not receive adequate care coordination, and experience family financial problems. In a multivariate model controlling for age, gender, race/ethnicity, poverty status, region of residence, insurance status, and condition severity, NEPL children were twice as likely to lack family-centered care.[30] This finding provides additional evidence that language can serve as a formidable barrier to the receipt of quality, family-centered care for CSHCN.

When evaluating access to FCC, Montes and Halterman (2011)[31] compared access to health care for different conditions, contrasting children with autism spectrum disorders (ASD) to the rest of the CSHCN population. They found that fewer parents of children with ASD reported receiving family-centered care. Within this subset, African American parents of children with ASD were much less likely to report important FCC measures such as the provider spending adequate time with their child, demonstrating cultural sensitivity, and including them in a partnership. The authors posit that their findings "suggest that the presence of ASD compounds white-black racial differences in the provision of family-centered care" (pg. 302).

While the measures used to determine whether families receive FCC vary, one aspect of care that contributes to establishing family-centeredness is cultural competence. In fact, culturally competent care is one of the components of family-centered care as defined by the MCHB. Nearly all definitions of cultural competence are derived from the work of Cross et al (1989) who describe cultural competence as "a set of congruent behaviors, attitudes, and policies that come together in a system, agency or among professionals that enable that system, agency or these professions to work effectively in cross-cultural situations."[32] The importance of cultural competence within FCC is underscored by Kerfeld et al (2011) who found that parents who perceived their provider to be culturally competent were less likely to report delayed or forgone care and were less likely to be dissatisfied with their care in general.[33]

Telfair et al in 2009 analyzed responses from a survey of state Maternal and Child Health directors to evaluate implementation of culturally (and linguistically) competent policies, structures and practices by state Title V programs.[34] Respondents were asked to report on whether their program had implemented organizational change processes and systems and services activities recommended by the National Center on Cultural Competence specifically for organizations serving children with special needs. More than half of respondents indicated that efforts had been made to implement at least some of the recommended processes and policies, and three-quarters had incorporated the concept of cultural and linguistic competence into their mission, vision, and values statements. In other areas, the states had further to go, however, particularly in terms of self-assessment. Moreover, the authors noted that almost all changes enacted were implemented "as needed" rather than as purposeful, systematic change, reflecting organizational and budgetary restrictions.

Conclusions

Numerous studies demonstrate important benefits of family-centered care for Children with Special Health Care Needs, including fewer unmet health care needs and increased satisfaction with care. Family-centered care also increases quality of life by reducing family burden and has been associated with fewer school days missed. While all families can benefit from FCC, access to it varies widely by race, ethnicity, socioeconomic status, age, condition severity, and condition type. Moreover, even among the general population of CSCHN an insufficient proportion receive FCC. Great strides are needed to integrate FCC into current and emerging delivery systems.

The volume of research on improving care for CSHCN is increasing and is likely to continue to grow as principles of FCC in general and for CSHCN specifically are applied with support from the Affordable Care Act. Innovations in service delivery abound, as documented by organizations such as the Institute for Patient- and Family- Centered Care (http://www.ipfcc.org/), the Center for Medical Home Improvement (http://www.medicalhomeimprovement.org/), the Lucile Packard Foundation for Children's Health (http:lpfch-cschn.org/) and others. These current and future demonstrations provide important opportunities to further examine the application of FCC in different systems and with different populations, building upon the current literature from secondary analyses of the NS-CSHCN and on models intended to meet the MCHB goals for family-centered care.

In the midst of the current movement toward transformation of health care delivery, the application and testing of FCC for CSHCN provides a unique opportunity to achieve what FCC can offer for all populations, such as improved access to care and care experiences, reduced costs and better health outcomes. FCC has the potential to produce these results—and more—for CSCHN and their families. In order to reach this potential, greater attention and more resources are needed from federal, state and local policy makers, as well as public and private health system leadership, to develop and implement policies and practices that promote FCC and support families' access to it.

References

1. American Academy of Pediatrics, Council on Pediatric Practice. Pediatric Records and a "medical home." In: Standards of Child Care. Evanston, IL: American Academy of Pediatrics 1967:77-79
2. American Academy of Pediatrics, Task Force on the Definition of the medical home. The medical home. *Pediatrics*. 1992;90:774
3. Medical Home Initiatives for Children with Special Needs Project Advisory Committee (2002). The medical home. *Pediatrics.* 110(1):184-186.
4. Johnson BH (2000). Family-centered care: four decades of progress. *Families, Systems & Health*. 18(2):137-156.
5. Ibid
6. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Core outcomes: Key measures of performance. The National Survey of Children with Special Health Care Needs chartbook 2005-2006:44-51. Available at: http://mchb.hrsa.gov/cshcn05/MI/cokmp.pdf
7. Johnson (2000). *Op Cit.*
8. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Core outcomes: Key measures of performance. The National Survey of Children with Special Health Care Needs chartbook 2005-2006:44-51. Available at: http://mchb.hrsa.gov/cshcn05/MI/cokmp.pdf
9. Conway J, Johnson B, Edgman-Levitan S, Schluecter J, Ford D, Sodomka P, Simmons L (2006). Partnering with patients and families to design a patient- and family-centered health care system. *Institute for Family-Centered Care and Institute for Healthcare Improvement*. June 2006.
10. Medical Home Initiatives for Children with Special Needs Project Advisory Committee (2002). *Op Cit.*
11. Bethell CD, Read D, Blumberg SJ, Newacheck PW (2008). What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *Maternal and Child Health Journal.* 12(1):1-14.
12. Child & Adolescent Health Measurement Initiative (2012). Who are Children with Special Health Care Needs? Retrieved from http://www.childhealthdata.org/docs/nschdocs/whoarecshcn_revised_07b-pdf.pdf.
13. McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B (1998). A new definition of children with special health care needs. *Pediatrics*. 102:137-140.
14. Bethell CD, Read D, Stein R, Blumberg S, Wells N, Newacheck P (2002). Identifying children with special health care needs: development and evaluation of a short screening tool. *Ambulatory Pediatrics*. 2002;2(1):38-48.

15. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, (2004). The national survey of children with special healthcare needs chartbook 2001. Rockville: U.S. Department of Health and Human Services, 2004.
16. Kuhlthau KA, Bloom S, Van Cleave J, MD. Knapp AA, Romm D, Klatka K, Homer CJ, Newacheck PW, Perrin JM (2010). Evidence for Family-Centered Care for Children With Special Health Care Needs: A Systematic Review. *Academic Pediatrics*. 11:136-143.
17. Kuhlthau KA, Bloom S, Van Cleave J, MD. Knapp AA, Romm D, Klatka K, Homer CJ, Newacheck PW, Perrin JM (2010). Evidence for Family-Centered Care for Children With Special Health Care Needs: A Systematic Review. *Academic Pediatrics*. 11:136-143.
18. Denboba D, McPherson MG, Kenney MK, Strickland B, Newacheck PW (2006). Achieving family and provider partnerships for children with special health care needs. *Pediatrics.* 118(4):1607-1615.
19. Knapp CA, Madden VL, Marcu MI (2010). Factors that affect parent perceptions of provider-family partnerships for children with special health care needs. *Maternal and Child Health Journal*. 14:742-750.
20. Kenney MK, Denboba D, Strickland B, Newacheck PW (2011). Assessing family-provider partnerships and satisfaction with care among US children with special health care needs. *American Pediatrics.* 11(2):144-151.
21. NS CSHCN 2009/10. Available at: http://www.childhealthdata.org/browse/snapshots/cshcn-profiles?rpt=9&geo=1
22. Turchi RM, Berhane Z, Bethell C, Pomponio A, Antonelli R, Minkovits CS (2009). Care coordination for CSHCN: associations with family-provider relations and family/child outcomes. *Pediatrics.* 124(4):S428-S434.
23. Farmer JE, Clark MJ, Sherman A, Marien WE, Selva TJ (2005). Comprehensive primary care for children with special health care needs in rural areas. *Pediatrics.* 116(3):649-656.
24. Silow-Carroll S, Ehrenpreis B, Rosenstein S (2014). Care coordination for California's children and youth with special health care needs: building blocks from other states. Lucile Packard Foundation for Children's Health: Palo Alto, CA.
25. Antonelli RC, McAllister JW, Popp J (2009). Making care coordination a critical component of the pediatric health system: a multidisciplinary framework. *The Commonwealth Fund*: New York.
26. Silow-Carroll S, Ehrenpreis B, Rosenstein S (2014). Care coordination for California's children and youth with special health care needs: building blocks from other states. Lucile Packard Foundation for Children's Health: Palo Alto, CA.
27. Coker TR, Rodriguez MA, Flores G (2010). Family-centered care for US children with special health care needs: who gets it and why? *Pediatrics*. 125(6):1159-67.
28. Ngui EM, Flores G (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: the roles of race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics*. 117(4):1184-96.

29. NS CSHCN 2009-10.
30. Yu SM and Singh GK (2011). Household language use and health care access, unmet need, and family impact among CSHCN. *Pediatrics*. 124 (Supplement 4): S414-S419.
31. Montes G, Halterman JS (2011). White-black disparities in family-centered care among children with autism in the United States: evidence from the NS-CSHCN 2005-2006. *Academic Pediatrics*. 11(4):97-304.
32. As cited in http://www.nccccurricula.info/culturalcompetence.html
33. Kerfeld CI, Hoffman JM, Clol MA, Kartin D (2011). Delayed or forgone care and dissatisfaction with care for children with special health care needs: The role of perceived cultural competency of health care providers. *Maternal and Child Health Journal.* 15:487-496.
34. Telfair J, Bronheim SM, Harrison S (2009). Implementation of culturally and linguistically competent policies by state title V children with special health care needs programs. *Maternal and Child Health Journal.* 13:677-686.

Appendix A: Tables of Literature Findings Related to Components of Family-Centered Care for Children with Special Health Care Needs

Table 1: Articles/Reports on Access, Unmet Need and Satisfaction for Children with Special Health Care Needs

Author(s)	Title	Year Published	Data Source(s)	Findings
Davidoff AJ.	Insurance for Children with Special Health Care Needs: patterns of coverage and burden on families to provide adequate insurance	2004	The 2000 & 2001 NHIS for children	The purpose of this study was to update national estimates of insurance coverage of CSHCN to reflect better the current economic and policy environment and to examine the burden on families and adequacy of coverage. Compared with other children, CSHCN had higher rates of public insurance (29.8% vs 18.5%), lower rates of private insurance (62.5% vs 69.1%, and a smaller percentage without insurance (8.1% vs 11.5%). More than 13% of low-income CSHCN were uninsured. Most (78.1%) families of CSHCN contributed to private insurance premiums. Family premium contributions for employer-sponsored insurance plans averaged $2058, or 4.4% of income; premiums for private non-group insurance were higher and consumed a larger percentage of income (6.6%). For children with insurance, rates of unmet need for specific services were relatively low, suggesting that insurance coverage was adequate. However, almost 20% of low income CSHCN experiences some form of unmet need, and out-of-pocket spending was significantly higher for families with CSHCN compared to those without CSHCN.

Author(s)	Title	Year Published	Data Source(s)	Findings
McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck PW, Perrin JM, Shonkoff JP, Strickland B.	A new definition of Children With Special Health Care Needs	1998	NA	The explosive growth of managed care and changing public responsibilities, especially in state programs for children with special health care needs, accentuates the importance of a clear definition of children with special health care needs. Working as a broad-based consensus panel, the authors considered several ways of defining children with special health care needs, including lists of diagnoses and measures of functional status, but concurred on a definition based on increased service use or need. They also clarified the importance of including at-risk populations along with those already demonstrating special health care needs.
Newacheck PW, Kim SE.	National profile of health care utilization and expenditures for Children With Special Health Care Needs	2013	2000 Medical Expenditure Panel Survey (MEPS)	The purpose of this study was to provide the first nationally representative data on total health care expenses, out-of-pocket expenses and information on the extent to which out-of-pocket expenses are financially burdensome for families with CSHCN. Families with CSHCN experience much higher expenditures than those with children without special needs. Insurance plays an important protective role for families of CSHCN, but it still provides incomplete protection. Health policy changes that would extend the breadth and depth of insurance coverage are needed to ensure that all families of CSHCN are protected against burdensome expenses.

Author(s)	**Title**	**Year Published**	**Data Source(s)**	**Findings**
Tang MH, Hill KS, Boudreau AA, Yucel RM, Perrin JM, Kuhlthau KA.	Medicaid managed care and the unmet need for mental health care among children with special health care needs		2000-2002 National Survey of Children With Special Health Care Needs (NS-CSHCN)	The purpose of this study was to determine the association between Medicaid managed care pediatric behavioral health programs and unmet need for mental health care among CSHCN. In multivariable models, among CSHCN with only Medicaid, living in states with Medicaid managed care (odds ratio [OR] = 1.81; 95 percent confidence interval: 1.04-3.15) or care-out programs (OR = 1.93; 1.01-3.69) were associated with greater reported unmet mental health care need compared with states with FFS programs. Among CSHCN with emotional problems on Medicaid, the association between managed care and unmet need was stronger (OR = 2.48; 1.38-4.45). State Medicaid pediatric behavioral health managed care programs were associated with greater reported unmet mental health care need than FFS programs among CSHCN insured by Medicaid, particularly for those with emotional problems.

Author(s)	Title	Year Published	Data Source(s)	Findings
Yu SM, Singh GK.	Household language use and health care access, unmet need, and family impact among CSHCN	2009	2005-2006 National Survey of Children With Special Health Care Needs (NS-CSHCN)	The authors examined the association of household language use and access to care among CHSCN. Nearly 14% of all US children live in non-English primary language (NEPL) households. NEPL CSHCN were significantly more likely to be Hispanic or other non-white races, be poor, have less educated parents, reside in metropolitan areas and larger households, and were likely to be on cash assistance from welfare. Logistic regression showed that NEPL CSHCN were twice as likely to lack access to a medical home, a usual source of care, and family-centered care. They were 4 times as likely to lack health insurance, and their family members were also more likely to lack adequate insurance. Family members of NEPL children were almost twice as likely to have to stop employment as a result of their child's condition. Although limited by program eligibility contingent on immigrant status and state policies, increased referrals to programs such as State Children's Health Insurance Program and Medicaid can improve access, while utilization can be improved by the availability of interpreters, community health workers, linguistically concordant providers, and outreach education efforts of NEPL parents.

Table 2: Articles/Reports on Outcomes of Family-Centered Care and Medical Homes for Children with Special Health Care Needs

Author(s)	Title	Year Published	Data Source(s)	Findings
Conway J, Johnson B, Edgman-Levitan S, Schluecter J, Ford D, Sodomka P, Simmons.	Partnering with patients and families to design a patient- and family-centered health care system	2006	NA	This report provides background information to facilitate the development of an action plan to ensure that sustained, meaningful partnerships with patients and families are in place in all settings in which CSHCN are treated, learn and live.
Johnson BH.	Family-centered care: four decades of progress	2000	NA	Family-centered care is a framework for the delivery of health care that is creating change in health care policies, programs, facility design, day-to-day practices of individual practitioners, and professional education. This paper traces the history of family-centered care over the past 35 years and presents the conceptual basis for family-centered care. It includes an overview of the origin, activities, and future directions of the Institute of Family-Centered Care, a non-profit organization founded in 1992 to advance the understanding and practice of family-centered care.

Author(s)	Title	Year Published	Data Source(s)	Findings
Kuo DZ, Bird M, Tilford JM.	Association of family-centered care with health care outcomes for Children with Special Health Care Needs	2010	2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN)	The purpose of this study was to examine the association between family-centered care (FCC) with specific health care service outcomes for CSHCN. Receipt of family-centered care was reported by 65.6% of respondents. Predisposing characteristics associated with family-centered care included younger age, female gender, white ethnicity, residence in Midwest, and higher parent education level. Enabling characteristics associated with family-centered care included private insurance, higher income, English as primary household language, having a usual source of care, and having a usual source of preventive care. Children with fewer functional limitations were more likely to have family-centered care. The results are similar to those reported by the MCHB. Of respondents, 91% reported their child had one of the 16 medical conditions specifically addressed by the survey. Parents reporting FCC were less likely to report that their child had ADD, autism, Down syndrome, mental retardation, emotional problem, blood problem, muscular dystrophy, seizure disorder, migraine/headache and joint problem. Large absolute differences were seen with ADD, mental retardation, emotional problem and migraine/ headache.
Kuo DZ, Frick D, Minkovitz CS.	Association of family-centered care with improved anticipatory guidance delivery and reduced unmet needs in child health care	2011	2004 Medical Expenditure Panel Survey (MEPS)	This study sought to examine the association of family-centered care with the quality of pediatric primary care. Only a subset of the study population (22.1%) were CSHCN. FCC was positively associated with anticipatory guidance for all children but no relation was found for CSHCN in stratified analyses (OR-1.01; 5% CI .75, 1.37). FCC was associated with reduced unmet needs (OR =.38; 95% CI .31,.46) with consistent findings for both non-CSHCN and CSHCN subgroups. That the association between FCC and anticipatory guidance did not persist for CSHCN suggests the need for enhanced understanding of the appropriate anticipatory guidance for this population.

Author(s)	Title	Year Published	Data Source(s)	Findings
Medical Home Initiatives for Children with Special Health Care Needs Project Advisory Committee.	The medical home	2002	NA	The American Academy of Pediatrics proposed a definition of the medical home in a 1992 policy statement. Efforts to establish medical homes for all children have encountered many challenges, including the existence of multiple interpretations of the "medical home" concept and the lack of adequate reimbursement for services provided by physicians caring for children in a medical home. This policy statement contains and expanded and more comprehensive interpretation of the concept and an operational definition of the medical home.
McAllister JW, Cooley WC, Van Cleave J, Boudreau AA, Kublthau K.	Medical home transformation in pediatric primary care—what drives change?	2013	Medical Home Index applied to 12 primary care practices	The aim of this study was to characterize essential factors in the medical home transformation of high performing pediatric primary care practices. At 6 to 7 years after learning collaborative participation, 4 essential medical home attributes emerged as drivers of transformation: (1) a culture of quality improvement, (2) family-centered care with parents as improvement partners, (3) team-based care, and (4) care coordination. These high-performing practices developed a comprehensive, family-centered, planned care process including flexible access options, population approaches, and shared care plans. Eleven practices evolved to employ care coordinators. Family satisfaction appeared to stem from better access, care safety, and having a strong relation with their health care team. Physician and staff satisfaction was high even while leadership activities strained personal time. In sum, participation in a medical home learning collaborative stimulated, but did not complete, medical home changes in 12 pediatric practices. Medical home transformation required continuous development, ongoing quality improvement, family partnership skills, an attitude of teamwork, and strong care coordination functions.

Table 3: Articles/Reports on Family-Provider Partnerships for Children with Special Health Care Needs

Author(s)	Title	Year Published	Data Source(s)	Findings
Denoba D, McPherson MG, Kenney MK, Strickland B, Newacheck PW.	Achieving family and provider partnerships for children with special health care needs	2006	2001 National Survey of Children With Special Health Care Needs (NS-CSHCN)	Among children with special health care needs, 85.5% of families reported usually or always feeling like a partner in their child's care. However, living in poverty, minority racial and ethnic status, absence of health insurance, and depressed functional ability placed children with special health care needs and their families at elevated risk of being without a sense of partnership. The authors found that the sense of partnership was associated with improved outcomes across a number of important health care measures, including missed school days, access to specialty care, satisfaction with care, and unmet needs for child and family services. Results of the survey demonstrated that whereas most families of children with special health care needs feel they are partners in the care of their child, further work is needed, particularly for poor, uninsured, and minority children, as well as those with functional limitations. The survey results also demonstrate the importance of partnership; children whose care met the partnership core outcome experienced improved access to care and well-being.
Kenney MK, Denboba D, Strickland B, Newacheck PW.	Assessing family-provider partnerships and satisfaction with care among US children with special health care needs	2011	2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN)	The authors' purpose was to examine demographic, health, and other associations with the perception of family-provider partnership and satisfaction with care; determine the associations between these perceptions and other child/family outcomes; and evaluate differences in the perception of partnership and satisfaction between the families of CSHCN and those with other children. The proportion of CSHCN attaining the core outcome—satisfaction—was 57.4% and was lower for households with no insurance, minority ethnic status, non-English speakers, nontraditional family structure, lower income, and lower functioning CSHCN. Lower rates of satisfaction and partnership were associated with poorer child and family outcomes.

Author(s)	Title	Year Published	Data Source(s)	Findings
Knapp CA, Madden VL, Marcu MI.	Factors that affect parent perceptions of provider-family partnerships for children with special health care needs	2010	2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN)	The purpose of this study was to identify factors associated with family-provider partnership and determine the association between partnership and other outcome measures for CSHCN. Children who were White non-Hispanic, younger than 12, reside in households with incomes above 400% of the FPL and have a usual source of care were associated with family-provider partnership. Family-provider partnership was associated with 20% fewer emergency department visits and 9% fewer school days missed in addition to: adequate insurance, early and continual screening, organized health care services, and transition preparedness.
O'Sullivan M.	It takes a family: an analysis of family participation in policy making for public programs serving children with special health care needs in California	2014	various	This report reviewed information regarding family participation requirements and support offered in a select range of government entities serving CSHCN, including health care, disability, education, child welfare and social justice agencies; examines approaches to maximizing the value of family participation; and makes recommendations, including that California state law should institutionalize family participation on government entities that serve CSHCN to ensure that the point of view of families is well represented in decision-making.

Author(s)	**Title**	**Year Published**	**Data Source(s)**	**Findings**
Stille CJ, Fischer SH, La Pelle N, Dworetzky B, Mazor KM, Cooley C.	Parent partnerships in communication and decision-making about subspecialty referrals for children with special needs	2013	Focus groups of parents of CSHCN and clinicians	The purpose of this study was to describe factors that influence parent-clinician partnerships in information exchange and shared decision-making when CSHCN are referred to subspecialists. Nineteen parents and 23 clinicians participated. Parents discussed partnerships more easily than clinicians did, though clinicians offered more ideas as session progressed. Parents and clinicians agreed on the importance of 3-way communication and valued primary care involvement in all stages of referral and consultation. Shared decision-making was seen by all as important; clinicians cited difficulties inherent in decision-making when options are unclear, while parents cited insufficient information as a barrier to understanding. Use of a brief referral care plan with parent coaching was embraced by all parents and most clinicians. Clinicians cited time pressures and interference with work flow as potential barriers to its use.

Table 4: Articles/Reports on Care Coordination for Children with Special Health Care Needs and their Families

Author(s)	Title	Year Published	Data Source(s)	Findings
Antonelli RC, McAllister JW, Popp J.	Making care coordination a critical component of the pediatric health system: a multi-disciplinary framework	2009	Literature review, key informant interviews and convened an expert panel	The purpose of this report was to present a framework for care coordination in a high performing pediatric health care system. The framework includes a definition of care coordination, outlines its principle characteristics, competencies and functions, and sets forth a detailed process for its delivery. It also describes a model to implement care coordination across all health care settings and related disciplines.
Farmer JE, Clark MJ, Sherman A, Marien WE, Selva TJ.	Comprehensive primary care for Children With Special Health Care Needs in rural areas	2005	Subsample of program participants	The purpose of this study was to evaluate the feasibility and impact of a medical home demonstration project in a rural part of the country. Parents reported significant increases in satisfaction with care coordination and access to mental health services after the intervention. They also noted decreases in family needs, caregiver strain, parents missed work days, children's school absences, and utilization of ambulatory services. Satisfaction with primary care declined slightly but remained in the "very good" range. Families of children with more complex conditions were more likely to report a decrease in needs after intervention, but other factors, such as geographic location or socioeconomic status, were not related to key outcome variables.

Author(s)	Title	Year Published	Data Source(s)	Findings
Turchi RM, Berhane Z, Bethell C, Pomponio A, Antonelli R, Minkovitz CS.	Care coordination for CSHCN: Associatioans with family-provider relations and family/child outcomes	2009	2005-2006 National Survey of Children With Special Health Care Needs (NS-CSHCN)	The purpose of this paper was to examine the association between receiving adequate care coordination (CC) with family-provider relations and family/child outcomes. Among families with children with special health care needs asked about CC, 67.2% 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 2 hours/week coordinating care, and stopped/reducing work hours.

Table 5: Articles/Reports on Linguistic and Racial/Ethnic Barriers and Cultural Competence and Children with Special Health Care Needs and their Families

Author(s)	Title	Year Published	Data Source(s)	Findings
Coker TR, Rodriguez MA, Flores G.	Family-centered care for US Children with Special health Care Needs: who gets It and why?	2010	2005-2006 National Survey of CSHCN	The purpose of this study was to examine racial/ethnic and language disparities in family-centered care and in FCC components for CSHCN. A total of 66% of CSHCN with health visit in the past year received FCC. In adjusted analyses, lower odds of FCC were found for Latino, African American and other children, compared with white children, and for children in households with a non-English primary language, compared with those households with English as a primary language. These disparities persisted after adjustment for child health, socioeconomic and access factors. Of these factors, only condition severity was significantly associated with the racial/ethnic disparities; none was significantly associated with the racial/ethnic disparities. Disparities were found for Latino and African-American children and children in households with a non-English primary language for the FCC components of time spent with the provider and sensitivity to the family's values and customs.
Cooper LA, Roter DL, Garson KA, Beach MC, Sabin JA, Greenwald AG, Inui TS.	The associations of clinicians' implicit attitudes about race with medical visit communication and patient ratings of interpersonal care	2012	Survey of clinicians and patients	The authors examined the associations of clinicians' implicit attitudes about race with visit communication and patient ratings of care. Among Black patients, general race bias was associated with more clinician verbal dominance, lower patient positive affect and poorer ratings of interpersonal care. Race and compliance stereotyping was associated with longer visits, slower speech, less patient centeredness, and poorer ratings of interpersonal care. Among White patients, bias was associated with more verbal dominance and better ratings of interpersonal care. Race and compliance stereotyping was associated with less verbal dominance, shorter visits, faster speech, more patient centeredness, higher clinician positive affect, and lower ratings of some aspects of interpersonal care.

Author(s)	Title	Year Published	Data Source(s)	Findings
Hamilton LJ, Lerner CF, Presson AP, Klitzner TS.	Effects of a medical home program for Children with Special Health Care Needs on parental perceptions of care in an ethnically diverse patient population	2012	The Medical Home Family Index administered to 22 parents	The purpose of this study was to determine the effect of an intensive care coordination program on parental satisfaction and to compare any differences between English and Spanish speaking parents. No statistically significant differences were noted in individual questions between English and Spanish speakers. However, a trend towards more positive responses by Spanish speakers was found in questions regarding physician-patient communication (p=0.054) and family-centeredness (p=0.053). The researchers conclude that a primary care model focused on providing intensive care coordination produces positive parental perceptions of the organization and delivery of primary care services in a medically complex population of CSHCN. Specifically, utilizing the AAP's approach to the medical home model, emphasizing family-centered and culturally competent care, can produce higher satisfaction scores in Spanish speaking parents when compared to English speaking parents.

Author(s)	Title	Year Published	Data Source(s)	Findings
Kerfeld CI, Hoffman JM, Clol MA, Kartin D.	Delayed or forgone care and dissatisfaction with care for children with special health care needs: The role of perceived cultural competency of health care providers	2011	2005 National Survey of Children with Special Health Care Needs (NS-CSHCN)	The purpose of this study was to better understand if reported delayed/forgone care and dissatisfaction with care for CSHCN are associated with parent's perceptions of health care providers' cultural competency. Perception of cultural competency was defined by questions related to time spent with child, respect for family values, listening to the family, sense of partnership, and information provided. The study found that delayed/forgone care and dissatisfaction with care in fact were associated with perceived health care provider cultural competency. Parents whose children were older, whose children's condition affected their ability to do things, whose interviews were not conducted in English, or were from certain racial and ethnic groups reported more delayed or forgone care and were more dissatisfied with their children's health care. While delayed/forgone care and dissatisfaction with care were associated with perceived cultural competency of health care providers, this did not appear to differ consistently by racial or ethnic group. The authors recommend further research using more refined instruments and longitudinal designs to assess the effects of health care providers' cultural competency and other cultural factors on the delayed/forgone care for CSHCN and on the dissatisfaction with care of parents with CSHCN.
Johnson RL, Roter D, Powe NR, Cooper LA.	Patient race/ethnicity and quality of patient-physician communication during medical visits	2004	Two cohort studies of physicians and patients	This study was designed to examine the association between patient race/ethnicity and patient-physician communication during medical visits. Physicians were 23% more verbally dominant, and engaged in 33% less patient-centered communication with African American patients than with White patients. Both African American patients and their physicians exhibited lower levels of positive affect than White patients and their physicians.

Author(s)	Title	Year Published	Data Source(s)	Findings
Montes G, Halterman JS.	White-Black disparities in family-centered care among children with autism in the United States: evidence from the NS-CSHCN 2005-2006	2011	2005-2006 National Survey of Children with Special Health Care Needs (NS-CSHCN)	This study compared the reported receipt of family-centered care between parents of White and African American children with autism spectrum disorders (ASD) in the US and examined the associations of race and ASD on different aspects of family-centered care. Among CSHCN but no ASD, more white parents than Black parents reported receiving family-centered care. Further, fewer parents of both White children and African American children with ASD reported receiving family-centered care compared with those with a child who had special needs other than ASD. Among parents with a child with ASD, being Black was associated with lower reporting of family-centered care for 3 of 5 items. In multivariate analyses, African American parents with a child with ASD had 2 to 5 times greater odds of not reporting family-centered care on each item compared with White parents without ASD.

Author(s)	Title	Year Published	Data Source(s)	Findings
Ngui EM, Flores G.	Satisfaction with care and ease of using health care services among parents of Children with Special Health Care Needs: the roles of race/ethnicity, insurance, language, and adequacy of family-centered care	2006	2000-2002 National Survey of Children With Special Health Care Needs (NS-CSHCN)	The authors sought to examine whether racial/ethnic disparities exist in parental reports of satisfaction with care and ease of using health care services among CSHCN. The prevalence of reported dissatisfaction with care and problems with ease of using services among parents of CSHCN were 7% and 25% respectively. African American and Latino parents were significantly more likely than white parents to be dissatisfied with care (13% and 16% vs 7%) and to report problems with ease of service use (35% and 34% vs 23%). Latino/White disparities in satisfaction with care and ease of using services disappeared only after multivariate adjustments for parental interview language. African American/White disparities in satisfaction with care disappeared after adjustments for adequacy of family-centered care measures, but disparities in ease of using services persisted. The severity of the child's condition, lack of insurance, parental interview in Spanish, and inadequate family-centered care were associated significantly with dissatisfaction with care and problems with ease of using health care services.
Telfair J, Bronheim SM, Harrison S.	Implementation of culturally and linguistically competent policies by state Title V children with special health care needs programs	2009	Survey of state Title V CSHCN directors	This study was intended to identify actual actions, steps and processes of CSHCN programs to develop, implement, sustain and assess culturally and linguistically competent policies, structures and practices. Findings indicated that almost all respondents are implementing some actions to provide culturally and linguistically competent services including adapting service practices, addressing workforce diversity, providing language access, engaging communities and including requirements in contracts. These individual actions were less often supported by processes such as self-assessment and creating an ongoing structure to systematically address cultural and linguistic competence. Programs are challenged by state agency organization and budget restrictions.

Bibliography

Antonelli RC, McAllister JW, Popp J (2009). Making care coordination a critical component of the pediatric health system: a multidisciplinary framework. *The Commonwealth Fund*: New York.

Chernoff RG, Ireys HT, Devet KA, Kim YJ (2002). A randomized, controlled trial of a community-based support program for families of children with chronic illness: pediatric outcomes. *Archives of Pediatrics and Adolescent Medicine*. 156(6):533-9.

Coker TR, Rodriguez MA, Flores G (2010). Family-centered care for US children with special health care needs: who gets it and why? *Pediatrics*. 125(6):1159-67.

Cooper LA, Roter DL, Garson KA, Beach MC, Sabin JA, Greenwald AG, Inui TS (2012). The associations of clinicians' implicit attitudes about race with medical visit communication and patient ratings of interpersonal care. *American Journal of Public Health*. 102(5):979-987.

Conway J, Johnson B, Edgman-Levitan S, Schluecter J, Ford D, Sodomka P, Simmons L (2006). Partnering with patients and families to design a patient- and family-centered health care system. *Institute for Family-Centered Care and Institute for Healthcare Improvement*. June 2006.

Davidoff AJ (2004). Insurance for Children With Special Health Care Needs: Patterns of Coverage and Burden on Families to Provide Adequate Insurance. *Pediatrics*. 114:394-403.

Denboba D, McPherson MG, Kenney MK, Strickland B, Newacheck PW (2006). Achieving family and provider partnerships for children with special health care needs. *Pediatrics*. 118(4):1607-1615.

Farmer JE, Clark MJ, Sherman A, Marian WE, Selva TJ (2005). Comprehensive primary care for children with special health care needs in rural areas. *Pediatrics* 116(3):649-656.

Hamilton LJ, Lerner, CF, Presson A P & Klitzner TS (2013). Effects of a medical home program for Children with Special Health Care Needs on parental perceptions of care in an ethnically diverse patient population. *Maternal and Child Health Journal*. 17:463-469.

Institute for Patient- and Family-Centered Care. See: http://www.ipfcc.org/about/index.html

Johnson BH (2000). Family-centered care: four decades of progress. *Families, Systems & Health*. 18(2):137-156.

Johnson RL, Roter D, Powe NR, Cooper LA (2004). Patient race/ethnicity and quality of patient-physician communication during medical visits. *American Journal of Public Health*. 94(12):2084-2090.

Kenney MK, Denboba D, Strickland B, Newacheck PW (2011). Assessing family-provider partnerships and satisfaction with care among US children with special health care needs. *Academic Pediatrics*. 11(2):144-151.

Kerfeld CI, Hoffman JM, Clol MA, Kartin D (2011). Delayed or forgone care and dissatisfaction with care for children with special health care needs: The role of perceived cultural competency of health care providers. *Maternal and Child Health Journal*. 15:487-496.

Knapp CA, Madden VL, Marcu MI (2010). Factors that affect parent perceptions of provider-family partnerships for children with special health care needs. *Maternal and Child Health Journal*. 14:742-750.

Kuhlthau KA, Bloom S, Van Cleave J, MD. Knapp AA, Romm D, Klatka K, Homer CJ, Newacheck PW, Perrin JM (2010). Evidence for Family-Centered Care for Children With Special Health Care Needs: A Systematic Review. *Academic Pediatrics*. 11:136-143.

Kuo DZ, Bird TM, Tilford JM (2011). Associations of family-centered care with health care outcomes for children with special health care needs. *Maternal and Child Health Journal*. 15(6):794-805.

Kuo DZ, Frick KD, Minkovitz CS (2011). Association of family-centered care with improved anticipatory guidance delivery and reduced unmet needs in child health care. *Maternal and Child Health Journal*. Nov 2011; 15(8):1228-37.

McAllister JW, Presler E, Cooley WC. (2007). Practice-based care coordination: a medical home essential. *Pediatrics*. 120:723-33.

McAllister JW, Cooley WC, Van Cleave J, Boudreau AA, Kublthau K (2013). Medical Home Transformation in Pediatric Primary Care—What Drives Change? *Annals of Family Medicine*. 11:590-598.

McPherson M, Arango P, Fox H, Lauver C, McManus M, Newacheck P, Perrin J, Shonkoff J, Strickland B (1998). A new definition of children with special health care needs. *Pediatrics*. 102(1):137-140.

Medical Home Initiatives for Children with Special Needs Project Advisory Committee (2002). The medical home. *Pediatrics*. 110(1):184-186.

Montes G, Halterman JS (2011). White-black disparities in family-centered care among children with autism in the United States: evidence from the NS-CSHCN 2005-2006. *Academic Pediatrics*. 11(4):297-304.

Newacheck PW, Kim SE (2013). National Profile of Health Care Utilization and Expenditures for Children With Special Health Care Needs. *Archives of Pediatric Adolescent Medicine*. 1:59(10):10-17.

Ngui EM, Flores G (2006). Satisfaction with care and ease of using health care services among parents of children with special health care needs: the roles of race/ethnicity, insurance, language, and adequacy of family-centered care. *Pediatrics*. 117(4):1184-96.

Okumura MJ, Van Cleave J, Gnanasekaran S, Houtrow A (2009). Understanding factors associated with work loss for families caring for CSHCN. *Pediatrics*. 124 (Supplement 4): S392-S398.

O'Sullivan M (2014). It takes a family: an analysis of family participation in policy making for public programs serving children with special health care needs in California. Lucile Packard Foundation for Children's Health: Palo Alto, CA.

Silow-Carroll S, Ehrenpreis B, Rosenstein S (2014). Care coordination for California's children and youth with special health care needs: building blocks from other states. Lucile Packard Foundation for Children's Health: Palo Alto, CA.

Stille CJ, Fischer SH, La Pelle N, Dworetzky B, Mazor KM, Cooley C (2013). Parent partnerships in communication and decision making about subspecialty referrals for children with special needs. *Academic Pediatrics*. 13(2):122-132.

Tang MH, Hill KS, Boudreau AA, Yucel RM, Perrin JM, Kuhlthau KA (2008). Medicaid managed care and the unmet need for mental health care among children with special health care needs. *Health Research and Educational Trust*. 43(3):882-900.

Telfair J, Bronheim SM, Harrison S (2009). Implementation of culturally and linguistically competent policies by state Title V children with special health care needs programs. *Maternal and Child Health Journal*. 13:677-686.

Turchi RM, Berhane Z, Bethell C, Pomponio A, Antonelli R, Minkovits CS (2009). Care coordination for CSHCN: associations with family-provider relations and family/child outcomes. *Pediatrics*. 124(4):S428-S434.

U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, (2004). The national survey of children with special healthcare needs chartbook 2001. Rockville: U.S. Department of Health and Human Services, 2004. Found at: http://childhealthdata.org/action/chartbooks

Yu SM and Singh GK (2011). Household language use and health care access, unmet need, and family impact among CSHCN. *Pediatrics*. 124 (Supplement 4): S414-S419.