

ABSTRACT

Title of Dissertation: FAMILY-CENTERED PEDIATRIC CARE:
PREDICTORS OF ACCESS AND
ASSOCIATIONS WITH CHILD WELL-
BEING

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Despite widespread recognition that family-centered care (FCC) is a critical component of quality pediatric health care, not all children receive FCC. This study builds on previous work by: (1) examining the extent to which socioeconomic resources are associated with the receipt of FCC after implementation of the Affordable Care Act, (2) exploring whether healthcare workforce shortages interfere with the delivery of FCC, and (3) extending previous research on the role of FCC in child well-being by measuring well-being across multiple domains and including children without special health care needs. Using data from the 2016 National Survey of Children's Health (n=50,212), this study found a graded relationship between the odds of receiving FCC and multiple indicators of family-level socioeconomic resources, indicating that socioeconomic resources, beyond health insurance, are important factors in accessing quality pediatric health care. Healthcare workforce shortages may also play a role in the availability of FCC. Results from this

study found consistent and significant associations between FCC and positive child well-being among healthy and typically developing children, and these associations were found across all domains of development. Findings indicated that FCC is particularly beneficial for young children (0-5 years), and children in households with low to moderate socioeconomic resources, making it a potentially meaningful tool to help reduce health disparities for children from households with more limited socioeconomic resources. Future research, and policies and practices aimed at increasing the delivery of FCC should include and emphasize the experiences of Hispanic families and families with limited socioeconomic resources.

FAMILY-CENTERED PEDIATRIC CARE: PREDICTORS OF ACCESS AND
ASSOCIATIONS WITH CHILD WELL-BEING

by

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Dedication

To women who struggle and learn how to be mothers every day, in hopes that we will be supported.

To my children, William, Emma, Samuel, and Grace—my greatest teachers. I love you.

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This work would not have been possible without the careful guidance and encouragement of intentional teachers, supportive friends, and loving family. Thank you to the faculty of the Department of Family Science for giving me this opportunity. Thank you to my fellow doctoral students for your friendship. I learned so much from your experiences and passions. I appreciate your patience with my never-ending questions in class. Thank you to my dissertation committee for your positive and critical feedback, patience, and push to think deeper and speak clearer. I would especially like to thank my advisor, Dr. Amy Lewin, for your seemingly endless positivity and encouragement. I could not ask for a better mentor! Thank you for motivating me when I needed words of encouragement, helping me focus on what is most important, and opening my eyes to new ways of thinking. I admire so much about your kind approach to life. I will forever be grateful for the opportunity to learn from you. I am also deeply grateful for my giant wonderful family. I would like to thank my mom for being the positive voice in my mind—always reframing things for the better. Thank you to my dad for teaching me to never give up. You both are the source of my grit and perseverance. Thank you to my siblings, especially my sisters, for being my role models and life supports. Most importantly, thank you to my husband, Geno, for loving and supporting all five of us. Thank you for making life an adventure, troubleshooting the tough stuff, making me feel important, and reminding me to sleep.

Table of Contents

Dedication.....	ii
Acknowledgements	iii
Table of Contents	iv
List of Tables.....	v
List of Figures.....	vi
List of Abbreviations.....	vii
Chapter 1: Statement of the Problem.....	1
<i>Purpose of the Study</i>	10
Chapter 2: Literature Review	12
<i>History of Pediatric Care</i>	12
<i>Family-Centered Care Emerges</i>	15
<i>Strengthening Families Framework</i>	24
<i>Access to Family Centered Care</i>	28
<i>Research Questions</i>	33
Chapter 3: Methods	35
<i>Description of the Data</i>	35
<i>Study Design</i>	38
<i>Analysis</i>	57
Chapter 4: Results.....	59
<i>Research Question 1</i>	59
<i>Research Question 2</i>	62
<i>Research Question 3</i>	64
<i>Research Question 4</i>	74
Chapter 5: Discussion.....	83
<i>Research question 1</i>	83
<i>Research question 2</i>	86
<i>Research Question 3</i>	89
<i>Research Question 4</i>	93
<i>Limitations</i>	98
<i>Future Research</i>	99
<i>Policy and Practice Implications</i>	102
<i>Conclusion</i>	106
Bibliography.....	108

List of Tables

Table 1: Bivariate relationships between FCC, child health, family characteristics, and socioeconomic factors	p 60
Table 2: Odds Ratios (95%CI) and Adjusted Odds Ratios (95%CI) for FCC socioeconomic indicators	p 61
Table 3: Odds Ratios (95%CI) and Adjusted Odds Ratios (95%CI) for FCC combined socioeconomic indicators	p 62
Table 4: Bivariate relationship between FCC and Tier 1 primary care workforce shortages in the U.S. in 2016	p 63
Table 5: Odds Ratios (95%CI) for FCC socioeconomic indicators, workforce shortages, and state fixed effects	p 64
Table 6: Bivariate relationships between FCC and child well-being among children 0-5 years	p 66
Table 7: Standardized regression coefficients for PHYSICAL HEALTH (0-5 years) regressed on covariates and FCC	p 67
Table 8: Standardized regression coefficients for PSYCHOSOCIAL HEALTH (0-5 years) regressed on covariates and FCC	p 68
Table 9: Standardized regression coefficients for COGNITIVE HEALTH (3-5 years) regressed on covariates and FCC	p 68
Table 10: Bivariate relationships between FCC and child well-being among children 6-17 years	p 70
Table 11: Standardized regression coefficients for PHYSICAL HEALTH (6-9 years) regressed on covariates and FCC	p 71
Table 12: Standardized regression coefficients for PHYSICAL HEALTH (10-17 years) regressed on covariates and FCC	p 72
Table 13: Standardized regression coefficients for PSYCHOSOCIAL HEALTH (6-17 years) regressed on covariates and FCC	p 73
Table 14: Standardized regression coefficients for COGNITIVE HEALTH (6-17 years) regressed on covariates and FCC	p 73

List of Figures

Figure 1: Conceptual Model, Predictors of Family-Centered Care	p 38
Figure 2: Conceptual Model, Associations with Child Well-Being	p 39
Figure 3: Percent of children receiving family-centered care by state	p 63
Figure 4: Average score for indicators of well-being for children 0-5 years by receipt of FCC	p 65
Figure 5: Average score for physical, psychosocial, and cognitive health of children 0-5 years by receipt of FCC	p 66
Figure 6: Average score for indicators of well-being for children 6-17 years by receipt of FCC	p 69
Figure 7: Average score for physical, psychosocial, and cognitive health of children 6-17 years by receipt of FCC	p 71
Figure 8: Interaction between FCC and SES on PHYSICAL health of children 0-5 years, unadjusted model	p 76
Figure 9: Interaction between FCC and SES on PHYSICAL health of children 0-5 years, adjusted model	p 76
Figure 10: Interaction between FCC and SES on PHYSICAL health of children 6-9 years, unadjusted model	p 77
Figure 11: Interaction between FCC and SES on PHYSICAL health of children 6-9 years, adjusted model	p 77
Figure 12: Interaction between FCC and SES on PHYSICAL health of children 10-17 years, unadjusted model	p 77
Figure 13: Interaction between FCC and SES on PHYSICAL health of children 10-17 years, adjusted model	p 77
Figure 14: Interaction between FCC and SES on PSYCHOSOCIAL of children 0-5 years, unadjusted model	p 79
Figure 15: Interaction between FCC and SES on PSYCHOSOCIAL health of children 0-5 years, adjusted model	p 79
Figure 16: Interaction between FCC and SES on PSYCHOSOCIAL health of children 6-17 years, unadjusted model	p 80
Figure 17: Interaction between FCC and SES on PSYCHOSOCIAL health of children 6-17 years, adjusted model	p 80
Figure 18: Interaction between FCC and SES on CONGITIVE health of children 0-5 years, unadjusted model	p 82
Figure 19: Interaction between FCC and SES on CONGITIVE health of children 0-5 years, adjusted model	p 82
Figure 20: Interaction between FCC and SES on CONGITIVE health of children 6-17 years, unadjusted model	p 82
Figure 21: Interaction between FCC and SES on CONGITIVE health of children 6-17 years, adjusted model	p 82

List of Abbreviations

AAP	American Academy of Pediatrics
ACA	Affordable Care Act
CAHMI	Child and Adolescent Health Measurement Initiative
FPL	Federal Poverty Line
HPSA	Health Professional Shortage Area
HRSA	Health Resources and Services Administration
FCC	family-centered care, also known as patient-and-family-centered care
MCHB	Maternal and Child Health Bureau
NSCH	National Survey of Children Health
NHSC	National Health Service Corps
PDT	Parent Development Theory
SES	socioeconomic resources

Chapter 1: Statement of the Problem

Maximizing a child's potential goes beyond minimizing adverse experiences to promoting opportunities and practices that facilitate flourishing (Lippman, Moore, & McIntosh, 2011). Flourishing is more than not wanting children to use drugs, commit crimes, drop out of school, or become teen parents (Moore & Lippman, 2005). It is more than the absence of disease. Flourishing is "a state in which an individual feels positive emotion toward life and is functioning well psychologically and socially" (Keyes, 2003). It is a key aspect of resilience that enables individuals to positively adapt to the many different challenges of life (Kandasamy, Hirai, Ghandour, & Kogan, 2018; Harper Browne, 2014). Flourishing is one of many positive indicators of child well-being that shifts our focus from reducing negative developmental processes to also identifying and supporting policies and practices that promote positive development (Guzman, Lippman, Moore, & O'Hare, 2003; Moore, Murphey, & Brandy, 2012; Lippman, Moore, & McIntosh, 2011).

The bioecological perspective on human development describes the pathways to well-being as reciprocal interactions between children, their families, and the broader social contexts in which they are situated (Bronfenbrenner & Morris, 2007). The theory posits that human development is shaped by the frequency and nature of the interactions between individuals and their social ecosystems over time (Bronfenbrenner & Morris, 2007), and has guided or influenced research in many different fields including neuroscience, developmental psychology, epidemiology, sociology, and economics (Harper Browne, 2014). Research findings from these

multiple disciplines have increased our understanding of environments and processes that contribute to child well-being.

Optimal child and adolescent development is inextricably linked with the capacity of families and communities to meet children's physical, social, emotional, and cognitive needs and enhance their abilities (Harper Browne, 2014; Schmit, Matthews, & Golden, 2014). The family is a child's primary source of support (American Academy of Pediatrics, 2012). Beyond providing the basic necessities of life, the consistency and quality of family relationships shape the development of the brain—providing the foundation for reasoning, memory, emotional expression, self-regulation, and executive functioning (Shah, Sobotka, Chen, & Msall, 2015; Harper Browne, 2014; Center for the Developing Child at Harvard University, 2009). Consistent, responsive, and stimulating parent-child interactions shape the development of neurobiological pathways that increase a child's capacity to live a productive, healthy and happy life (Perry & Hambrick, 2008). Conversely, neglectful, chaotic, and harsh interactions create an oversensitive, over utilized and dysfunctional stress response system that increases maladaptive feelings, thoughts, and behaviors (Perry & Hambrick, 2008).

The communities in which children live and grow also shape development. Communities directly influence child and adolescent well-being by providing safe infrastructure, access to resources, and opportunities for social interactions (Goldfeld et al, 2015). Safe infrastructure prevents children's exposure to environmental toxins, such as lead poisoning, which is associated with shortened attention spans and lower intelligence (Hanna-Attisha, Lachance, Sadler& Schnepf, 2016; Jusko et al., 2008;

Surkan et al., 2007). Sidewalks, parks, and playground equipment provide opportunities for children to safely engage in physical activities, which decrease childhood obesity (Dunton, Kaplan, Wolch, Jerrett, & Reynolds, 2009) and build gross motor skills (Fjortoft, 2004). Neighborhoods that offer organized extracurricular activities enable youth to practice social skills and express talents, which improve self-esteem and abilities to overcome adversity (Eccles, Barber, Stone, & Hunt, 2003; Barber, Eccles & Stone, 2001; Scales, Benson, Leffert, & Blyth, 2000).

Communities also indirectly influence child development through social expectations of parenting behaviors, and by providing networks of informal and formal support for parents. Communities can enhance parents' psychological well-being by providing opportunities for them to socialize or by offering resources that provide emotional, financial, or educational support (Harper Browne, 2014; Ceballo & McLoyd, 2002; Unger & Wadersman, 1985). Parents need supportive social networks to buffer the daily challenges of parenting. They need someone or somewhere to turn to help solve problems, find encouragement and hope, and assure their positive parenting efforts (Harper Browne, 2014). Parents with higher levels of social support report better psychological well-being (Huang, Costeines, Kaufman, & Ayala, 2014; Tran & McInnis-Dittrich, 2000; Campbell & Lee, 1992; Unger & Wadersman, 1985), and respond more sensitively to their children (Crnic, Greenberg, Robinson, & Ragozin, 1984).

Socioeconomic factors (e.g., income, parent education, geographic location) influence family and community level resources that are available to promote

flourishing in children and adolescents. Socioeconomic factors and geographic location influence if and where parents seek information to learn about parenting (Radey & Randolph, 2009), and parenting styles (Kohn, Scotch, & Glick, 1977; McLoyd, 1998). Parents with more education seek more information from every resource (e.g., family, friends, online sources, child's teacher) to learn about parenting (Radey & Randolph, 2009), and are more likely to encourage independent thinking and questioning; whereas parents with less education often emphasize obedience over questioning (Kohn, Scotch, & Glick, 1977; McLoyd, 1990). Parents under the age of 30 years (Radey & Randolph, 2009) and parents living in rural communities with limited access to in-person resources (Hall & Irving, 2009) are more likely than older parents or parents living in urban areas to seek information from online sources. Additionally, parents with fewer socioeconomic resources often work multiple and/or less flexible jobs, have to commute further, and deal with more frequent housing problems which leaves them less time, energy, and money to interact with their children (Chen & Miller, 2013), or participate in non-essential community activities. Unpredictable schedules and stressful economic conditions increase the likelihood of more inconsistent and harsh parent-child interactions, which contribute to long-term physical and mental health problems in children (Conger & Donnellan, 2007; Conger & Elder, 1994; El-Sheik & Harger, 2001).

Families with few socioeconomic resources are more likely to live in low-socioeconomic neighborhoods where they are more likely to witness violence (Buka, Stichick, Birdthistle, & Earls, 2001), making them more likely to believe that other people cannot be trusted (Sampson, Raudenbush, & Earls, 1997; Xue, Leventhal,

Brooks-Gunn, & Earls, 2005), and less likely to spend time outside their home (Carver, Timperio, & Crawford, 2008). Fear and isolation from living in unsafe neighborhoods contribute to more cynicism about other people, and more hostility and pessimism (Hagan, McCarthy, Herda, & Chandrasekher, 2018; Kirk, & Matsuda, 2011; Barefoot et al., 1998; Kawachi, Kennedy, Lochner, & Prothrow-Stith, 1997). These negative beliefs are likely to be reinforced when individuals experience discrimination as they engage with their community. Families receiving government provided assistance to meet basic needs (e.g., health care, housing, food) report experiences of economic-based discrimination when accessing or utilizing services (Han, Call, Pintor, Alarcon-Espinoza, & Simon, 2015; Weech-Maldonado, Hall, Bryant, Jenkins, Elliott, 2012; Allen, Wright, Harding, & Broffman, 2014), and racial minority adults are more likely than White adults to experience unfair treatment while interacting with others “at school”, “getting a job”, “at work”, “getting housing”, “getting medical care”, “on the street or in a public setting”, or “from the police or in the courts” (Krieger, & Sidney, 1996). Experiencing discrimination is associated with more parental depression, which is associated with poorer parenting practices, and more problematic social and emotional development in children (Anderson et al., 2015).

Efforts to strengthen the capacity of parents to practice positive parenting have sought to engage professionals who provide essential services (e.g., childcare, health care) to parents and children, especially services that reach families with few socioeconomic resources (Harper Browne, 2014; Langford, 2011). Pediatric primary care may be one institution that can address some of the limitations experienced by

less resourced families because it is among the most accessed services by parents—it is near universal and non-stigmatized. Sick visits are common during the first few years of life, while vulnerable immune systems build their defenses (Tang, 2010). Children from low socioeconomic families are more likely to experience health problems requiring medical attention, including injury, asthma, ear infections, and chronic conditions such as diabetes (Roubinov, Hagan, Boyce, Alder, & Bush, 2018; Evans & Marcynyszyn, 2004; Evans, 2003). In addition to sick visits, the American Academy of Pediatrics (AAP) recommends 10 well-child visits in the first two years of life (AAP, 2015), during which children receive immunizations required for enrollment in childcare or school. Beyond the frequency of visits, health care providers are viewed as authorities on child health and development by most parents (AAP, 2003; 2012).

The AAP has embraced the influential role pediatricians have in promoting the health of children by building parents' knowledge and encouraging positive parenting practices (Bauer, Childers, Curtin, 2016). Pediatricians recognize that families are essential allies to ensure the safety and well-being of children and adolescents (AAP, 2003; 2012) who are dependent on knowledge and skills beyond their own capabilities. Pediatricians use well-child visits to offer anticipatory guidance to help parents respond well to developmental changes, and strategies to ensure safe and stimulating environments (AAP, 2012). Clinicians also rely on parents to share specific health and development information about their child and help select treatment options most appropriate given family and community resources and barriers to care (Arango, 2011). Similarly, parents rely on pediatricians' expertise to provide specific health and development information, guidance, and

reassurance (Radecki, Olson, Frintner, Tanner & Stein, 2009). The success of this mutually beneficial relationship depends on the quality of communication and trust between pediatricians and families (AAP, 2012). For health care to be a trusted and utilized source of support for parents, physicians need to be accessible, sensitive and responsive to the needs of each family. Some parents readily provide appropriate information and ask the right questions to support the health and development of their child, while others are unsure or uncomfortable asking questions or providing information and need the pediatrician to initiate or facilitate discussions (Radecki, Olson, Frintner, Tanner, & Stein, 2009).

There is a growing movement within the field of pediatric primary care to establish family-centered medical homes, a culturally sensitive, relationship-based, and holistic model of care in which the needs of the whole family are addressed collaboratively between a family and their medical providers (Peikes et al., 2012). Practicing family-centered care (FCC) is central to the success of medical homes (Arango, 2011). FCC is the delivery of health care in a way that promotes high quality partnerships with families. The AAP, Academy of Family Physicians, the Institute of Medicine, and the Maternal and Child Health Bureau (MCHB) all encourage primary care physicians to practice FCC (Arango, 2011; AAP, 2012). The MCHB defines FCC as care in which the provider always or usually (1) spends enough time with the child, (2) listens carefully to the family, (3) shows sensitivity to family values and customs, (4) provides specific information the family needs concerning the child, and (5) helps the family feel like a partner in the child's care (CAHMI, 2016). Families who receive FCC report more satisfaction with the care

their children received, and use the health care system with more ease, than families who do not receive FCC (Ngui & Flores, 2006). Families who receive FCC are also more likely to perceive their health provider as a person or place they can turn to receive the help they need to support their child's health and development (Van Riper, 2001).

Studies of the impact of FCC on child well-being primarily focus on outcomes among specific pediatric subpopulations (e.g., children with special health care needs, children with asthma, or attention and behavior disorders). Stein and Jessop (1991) found better psychological functioning among inner-city children with chronic conditions after receiving FCC. Among groups of children with asthma, FCC was associated with better management of medications and symptoms (Guendelman, Meade, Benson, Chen, & Samuels, 2002), and higher quality-of-life scores (Mangione-Smith et al., 2005). Receipt of FCC at a school-based clinic was associated with reduced symptom severity (i.e., aggression, inattention) among children with inattention and disruptive behavior disorders (Owens et al., 2005). FCC was also associated with fewer missed days of school and unmet medical needs (Denboba, McPherson, Kenney, Stricklan, & Newacheck, 2006), better physical health, and more flourishing children (Russell, Beckmeyer, & Su-Russell, 2018) among a nationally representative sample of children with special health care needs. While FCC was associated with more preventative medical visits among the general pediatric population in the United States in 2011-2012 (Strickland, Jones, Ghandour, Kogan, & Newacheck, 2011), there are no studies exploring the potential impact FCC

has on positive child and youth development among children without special health care needs.

Despite widespread recognition that FCC is a key component of quality pediatric health care, disparities exist in accessing FCC. Studies highlight racial/ethnic (Bleser, Young, & Miranda, 2017; Guerrero, Chen, Inkelas, Rodriguez, & Ortega, 2010), socioeconomic (Thompson et al., 2009; Guerrero et al., 2010), and geographic (Singh, Strickland, Ghandour, & Van Dyck, 2009; Guerrero et al., 2010) disparities in receiving FCC. Guerrero and colleagues (2010) found that Black and White children were equally likely to receive FCC after adjusting for socioeconomic factors. However, after controlling for socioeconomic factors, Latino children were less likely than White children to spend enough time with their doctor, and less likely to receive adequate explanations (Guerrero et al., 2010). A more recent study by Bleser et al. (2017) found that racial and ethnic differences in receiving FCC were no longer significant after adjusting for insurance type, family income, parental age, geographic region, parental nativity, and child health status; only insurance type and family income predicted receipt of FCC.

Previous studies that examined receipt of FCC among nationally representative samples used data gathered prior to the implementation of the Affordable Care Act (ACA), which expanded health insurance coverage to 20 million Americans (Obama, 2016). While expanding insurance coverage is an important factor in accessing care, insurance alone does not guarantee access or quality health care for children. Several studies highlight insurance-based barriers to care and insurance-based discrimination when receiving care (Bindman & Coffman, 2014;

Sommers, Paradise, & Miller, 2011; Allen, Call, Beebe, McAlpine, & Johnson, 2017; Han, Call, Pintor, Alarcon-Espinoza, & Simon, 2015; Weech-Maldonado et al., 2012). Many clinics do not accept Medicaid patients (Bindman & Coffman, 2014; Sommers et al., 2011), and individuals who are able to access health care with Medicaid have reported unfair or inferior treatment because of their insurance type (Han et al., 2015; Weech-Maldonado et al., 2012; Allen et al., 2017).

Allen et al. (2017) found that experiencing discrimination (i.e. unfair treatment due to gender, ability to pay, being enrolled in public insurance, or race) was the strongest predictor of not receiving preventative care, and note that studies with contradictory findings (Hausmann, Jeong, Bost, Ibrahim, 2008; Trivedi & Ayanian, 2006) looked specifically at the influence of racial/ethnic discrimination on health care utilization. However, including measures of socioeconomic discrimination may more accurately capture payment-driven discrimination experiences in the fee-for-service health care setting (Allen et al., 2017).

Purpose of the Study

The primary aims of this study are: (1) to identify post-ACA disparities in receipt of FCC based on socioeconomic resources, and (2) to explore the potential association between receipt of FCC and child well-being, across family socioeconomic groups and children's developmental stages. An exploration of nationally representative data after the implementation of the ACA is needed to understand current socioeconomic disparities in access and quality of health care for children. Understanding current variations in access to care, and the relationship

between the quality of care and child well-being, will inform practice and policy efforts to further enhance the effectiveness of pediatric primary care to move beyond treating physical illness and to more comprehensively promote the well-being of children and adolescents.

A secondary aim of this proposed study is to explore the potential adverse influence of primary care workforce shortages on access to FCC. Multiple researchers suggested that future research should identify and address system-level barriers to implementation of FCC (Allen et al., 2017; Guerrero et al., 2010) by exploring state-level variations in delivery or receipt (Bleser et al., 2017). Primary care workforce shortages increase wait times and reduce the amount of time physicians spend with each patient (Kirch, Henderson, & Dill, 2012). Health insurance expansion, the aging population, and an increase in the prevalence of chronic diseases all increase the demand for primary care services (Pettersen et al., 2012). It is projected that by 2025 the United States will need an additional 52,000 primary care physicians to meet the demand (Pettersen et al., 2012) with rural and low-income populations experiencing the majority of health workforce shortages (Pettersen et al., 2012; Kirch & Vernon, 2009). State-level differences in physician recruitment and retention capabilities influence workforce shortages in each state, which may contribute to state-level differences in physician capacity to provide the more time-intensive FCC.

Chapter 2: Literature Review

History of Pediatric Care

Today the importance of family-centered care (FCC) is widely acknowledged as a critical component of quality health care for children. However, the idea that parent involvement is a critical component of quality health care for children was not always recognized. In the early 1900's, in the absence of antibiotics, hospitalized children were routinely separated from their parents as a precaution against the spread of infectious diseases (Jolley & Shields, 2009). At the time, hospital stays could last for as long as 2 years or more to manage chronic illnesses such as tuberculosis (Prugh, Staub, Sands, Kirschbaum, & Lenihan, 1953). Oftentimes parents were not allowed to see their children at all, or could only visit their child for a half hour per week (Robertson, 1970). These hospitalizations were often traumatizing for children. One nurse described an experience from her training, "And so this toddler that by now was distraught, sobbing, I went to pick him up. Because he was just, he was just left on the cot to break his heart and sob, so I went to pick him up and just as I did, he was like a little monkey, his arms around me, and [laugh] I can still see him today, his little fingers. I'm going to get upset again [crying] [pause] It was awful [crying] [pause]. The good children's nurse came and put a harness on him and fastened him down [emphasis]. [pause] And [he] sob, sob, sob. It was awful. I think, one of the worst things, he was just left to get on with it [pause]" (Jolley & Shields, 2009).

In the 1940's psychoanalysts began to explore the long-term psychological effects of separating children from parents during early childhood (Bowlby, 1944; Spitz, 1945). One influential theorist was John Bowlby. Between 1936 and 1939, Bowlby interviewed 44 juvenile delinquents referred to his clinic for stealing and their parents, and 44 youth who were not delinquents and their parents, to learn about their experiences of maternal separation during the first five years of life (Bowlby, 1944). He found that more than half of the youth with delinquent behavior were separated from their mother during early childhood (Bowlby, 1944). Many of the separations were due to prolonged hospitalizations (Bowlby, 1944). Bowlby described a boy named Derek who, at the age of 18 months, caught diphtheria and was hospitalized for nine months. His parents did not visit him during his hospitalization. "In hospital he was said to have been adored by everyone, but he returned home 'a little stranger'. He refused all food and called his mother 'nurse'. She described how 'it seemed like looking after someone else's baby.' At six Derek was prone to spells of unreasonable temper and destructiveness and was usually happiest playing alone. His mother described him as 'hardboiled' and commented that he was quite unmoved by either affection or punishment. He truanted from school and pilfered indiscriminately from children's pockets, the teacher's desk, from shops and from his mother" (Bowlby, 1944). In contrast, only two of the youth without delinquent behavior experienced a separation from their mother (Bowlby, 1944). Bowlby concluded that maternal separation during early childhood may cause permanent emotional damage, making some children unable to form meaningful attachments, feel concern for others, or to feel guilt (Bowlby, 1944). While critics

have highlighted the methodological errors of Bowlby's work (Rutter, 1979), additional research by Bowlby and others support his theory that separating children from parents during early childhood, especially when receiving health care in unfamiliar settings (Rinkoff & Corter, 1980), has lasting negative psychological effects (Bowlby, Ainsworth, Boston, & Rosenbluth, 1956; Bowlby, 1952; Spitz, 1945; 1948; Levy, 1945; Harlow & Zimmerman, 1958; Bifulco, Harris, & Brown, 1992).

Bowlby's colleague, James Robertson, made a film to demonstrate the effects of hospital separation of children from their parents and showed it to children's hospitals, parents, schools, and at town halls in the U.S., Australia and Europe (Bowlby & Robertson, 1952; Jolley & Shields, 2009). The film followed the experience of a two-year old girl in the hospital for eight days for surgery with only short visits from her parents (Bowlby & Robertson, 1952). At first the girl protested and told everyone around her that she wanted her mommy and threw tantrums when her mother left, but after a few days she detached from those around her, including her mother (Bowlby & Robertson, 1952). Bowlby and Robertson described that it is particularly concerning when a child loses hope and withdraws from those around them. Reflecting on the film, Bowlby stated, "It may be asked why bother to make and show a film of something so commonplace? The reason is that we believe that fretting should no longer be looked upon as an unavoidable inconvenience but as something of serious importance" (Bowlby & Robertson, 1952). He urged, "Enough is already known for us to be certain that some children receive very grave damage and many others are emotionally disturbed in less serious ways. This is particularly important for the medical profession since medical treatment in hospitals, sanatoria,

and convalescent homes represents one of the most common causes of separation” (Bowlby & Robertson, 1952; Bowlby, 1954). The film was well-received by the general public that was already concerned about the psychological trauma of the hundreds of thousands of European children separated from their parents during World War II (Jolley & Shields, 2009). Many citizen groups formed in the United States and across Europe to advocate for “child friendly” hospitals, giving parents more access to their children during hospitalizations (Jolley & Shields, 2009).

Family-Centered Care Emerges

Medicine was slow to change. Some health professionals liked having parents stay with their children (Shields & Nixon, 1998), but others felt parents undermined the relationship between medical providers and children (Aubuchon, 1958; Shields & Nixon, 1998). Still, as consumers demanded change and visiting hours expanded to 24 hours, the medical community gradually began to acknowledge parents as an important part of delivering health care to children (Robertson, 1970; Jolley & Shields, 2009). Advances in medicine created a new population of children with significant medical needs who wouldn't have survived prior to the newly developed technology (Wells, 2011). Physicians working with these children recognized the critical influence families played in caring for them, expanding the idea of how physicians could partner with families (Wells, 2011). The basic concept of family-centered care, that health care for children should be delivered in collaboration with families (Bamm & Rosenbaum, 2008), developed naturally from interactions between families and providers (Jolley & Shields, 2009). The concept was promoted by family advocates (Kuo et al., 2012; Jolley & Shields, 2009) and readily incorporated into

health care agencies' vision statements (Frost, Gance-Cleveland, Kersten, & Irby, 2010). FCC was further endorsed by a landmark report from the Institute of Medicine in 2001, "Crossing the Quality Chasm: A New Health System for the 21st Century," which prioritized patient- and family-centered care as a core component of quality health care (IOM, 2001). By 2003, many well-respected organizations (e.g., IOM, AAP, National Institute for Children's Healthcare Quality (NICHQ), and American Hospital Association) had policy statements or agendas emphasizing FCC as the standard of health care for all children (AAP, 2003; AAP, 2012; Kuo et al., 2012).

Several organizations including, Family Voices, the MCHB, the AAP, and the Institute for Patient- and Family-Centered Care developed definitions of FCC to provide guidance on practices that contribute to high quality family-provider relationships. Kuo and colleagues (2012) compared the principles of FCC developed by each organization and described substantial agreement among the groups. Common principles include: (1) open, unbiased, objective information sharing, (2) respect for diversity and honoring family cultural and linguistic preferences in care, (3) collaboration in making decisions that best meet the needs, strengths, values and abilities of the entire patient-family-provider team, (4) negotiation of medical plans, and (5) incorporation of families across all levels of care including in the development of policies (Kuo et al., 2012). Despite widespread acceptance and agreement, these aspirational principles were operationalized in many different ways.

In hospitals, a variety of models have been implemented to engage parents in the delivery of care for children, including the care-by-parent model, partnership-in-care model, and negotiated care model. The care-by-parent model, first implemented

in Kentucky in 1966, shifted the responsibility of care to parents by requiring them to share a room and provide unskilled nursing care for their sick child (Shields & Nixon, 1998). The partnership-in-care model aimed to share the responsibility between medical providers and parents through implementation of two key principles: (1) nursing care for a child can be given by the child or parents with support and education from the nurse, and (2) family or parental care can be given by the nurse if the family is absent (Casey, 1995; Jolley & Shields, 2009). The negotiated care model is a similar model in which providers write a care plan based on how much of the care parents want to be responsible for, and how much they want to leave to medical professionals (Shields & Nixon, 1998).

Today almost half of pediatric physicians working in hospitals practice family-centered rounds (FRC) in which physicians meet with each patient and their family at the bedside to make decisions about care (Sisterhen, Blaszak, Woods, & Smith, 2007). FCR is considered standard hospital practice (AAP, 2003), and an important part of medical education where students learn to communicate with families (Sisterhen, Blaszak, Woods, & Smith, 2007; Aronson, Yau, Helfaer, & Morrison, 2009; Gonzalo, Masters, Simons, & Chuang, 2009). Hospitals also regularly solicit feedback from families about their hospital stay experiences and, to ensure that families have input into practice and policy decisions, have incorporated families into formal advisory boards, family-peer support groups, and the delivery of presentations to medical staff (Kuo et al., 2012; Frost et al., 2010; Wells, 2011).

Family-centered care is now considered the standard of care for children in outpatient settings as well (AAP, 2012). In the mid-1980s, the MCHB held national

conferences on children with special health care needs to learn from families what it is like to care for a sick child at home (Kuo et al., 2012). Families underscored the importance of “partnerships, trust, respect, and joint decision-making” with all their child’s health providers regardless of the setting (Johnson, 2000). In 1987, the United States Surgeon General called for “family-centered, community-based care for children with special health care needs and their families.” In 1992, FCC was incorporated into the medical home model for community-based services, defined by the AAP as pediatric primary care that is “accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective” (AAP, 1992). FCC has been promoted by the MCHB for children with special health care needs specifically (Hadland & Long, 2014). In 2002, the American Academy of Pediatrics published a policy statement promoting the medical home model for all children.

Conceptualizing the medical home model involves considering many different components, including: (1) the provision of preventative care, (2) the assurance of ambulatory and inpatient care from infancy through adolescence, (3) continuity of care from infancy through adolescence, (4) appropriate use of subspecialty consultation and referrals, (5) interaction with school and community agencies, and (6) a central record and database that contains all pertinent medical information (Palfrey et al., 2004). These components consider the financial, long-term and complex coordination needs between families and multiple health providers/agencies. The FCC aspect of the medical home model goes one step further and considers the quality of communication between providers and families, and is central to the success of the medical home model in attaining desired child and family outcomes

(Arango, 2011). The American Academy of Pediatrics has repeatedly emphasized the central role that FCC plays in the quality of pediatric health care, and calls on pediatricians to increase family involvement in decision making and life-long planning (AAP, 2002; AAP, 2012).

FCC extends to all health professionals working with children, and has been operationalized in many different ways in the outpatient setting. FCC interventions focus on different aspects of the family-provider relationship. In recognition of the ways that relationships change as children age and assume more responsibility, the AAP updated the term “family-centered care” to “patient- and family-centered care” (AAP, 2012), though the MCHB continues to use the term “family-centered care.” Gallo and colleagues (2016) describe five distinct categories of patient- and family-centered care (PFCC) activities: (1) education from the provider to the patient and/or family, (2) information sharing from the family to the provider, (3) social-emotional support, (4) adapting care to match the family background, and/or (5) shared decision-making. Most interventions included activities from multiple categories, but the strategy almost universally (94% of 64 studies) used is education from the provider to the patient and/or family (Gallo, Hill, Hoagwood, & Olin, 2016). Gallo et al., (2016) described that multi-component interventions that attempt to personalize care to the family (i.e., adapting to match family background, or providing social-emotional support) were more effective than single-component interventions that only focus on one-sided information sharing in increasing family satisfaction or knowledge, and in improving parent-care behaviors or child health status.

Beyond studies evaluating the impact of specific FCC interventions on specific subgroups of families, efforts have been made to evaluate the accessibility and impact of FCC on all children in the United States. The MCHB is the government agency responsible for “assuring the continued improvement in the health, safety, and well-being of all America’s women, infants, children, adolescents, and their families” (Blumberg et al., 2005) To carry out their mission, the MCHB convened a National Expert Panel comprised of MCHB program directors, representatives of family organizations, child health services researchers, and survey design experts to develop the National Survey of Children with Special Health Care Needs, which was later merged with the National Survey of Children’s Health (Blumberg et al., 2005), to gather data from a nationally and state representative sample of parents and caregivers on children’s physical and mental health, access to quality health care, and the child’s family, neighborhood, school, and social context (Blumberg et al., 2005).

NSCH topic and statistical experts created survey questions to capture experiences that characterize pediatric family-centered health care regardless of the specific FCC intervention. Each question was pretested to validate respondents’ understanding of the questions (CAMI, 2016). The measure for FCC is made up of five experience-of-care questions including, “Does your provider: (1) spend enough time with your child, (2) listen carefully to you, (3) sensitive to your family values/customs, (4) give needed information, and (5) make you feel like a partner in your child’s care (CAHMI, 2016). In 2007, the question, “Does your provider get a non-family member to interpret conversations,” was added for families who do not

primarily speak English in the home, but the question was dropped from the survey in 2011 due to small sample sizes in each state (CAHMI, 2016).

The NSCH also includes measures of child well-being. The survey gathered extensive data on each child's physical, social, emotional, and behavioral health and the contexts in which they are situated (Blumberg et al., 2005). This micro-data allows researchers to assess the influence of family and community circumstances on each individual child rather than assuming a child's community equates his or her well-being (Moore, Murphey, & Bandy, 2012). Moore, Murphey, and Bandy (2012) used the 2007 NSCH data to develop a comprehensive index of child development. They described that "children are whole individuals, who need to develop in terms of their physical, psychological, and social health, not just their educational test scores," and identified positive and negative indicators of development for children ages 6-17 years categorized in four different domains: physical health, psychological health, social health, and educational achievement and cognitive development (Moore, Murphey, & Bandy, 2012). One subsequent update to the NSCH was the addition of an indicator of child resilience and thriving, called flourishing. Flourishing questions were included in the NSCH for the first time in the 2011-2012 (CAHMI, 2013). The questions were developed by a Technical Expert Panel comprised of experts in the fields of survey methodology, children's health, community organizations, and family leaders (CAHMI, 2013). The panel reviewed positive health indicators and public comments and created two developmentally appropriate sets of questions for children 0-5 years and 6-17 years (CAHMI, 2013). For children 0-5 years, four flourishing questions were asked to capture curiosity and discovery about learning, resilience,

attachment with parent, and content with life. For children 6-17 years, three flourishing questions were asked to capture curiosity and discovery about learning, resilience, and self-regulation (CAHMI, 2013).

Research using data from NSCH finds a positive association between FCC and desired child and family outcomes among children with special health care needs. Studies have either used each individual component of FCC to measure FCC (Denboba et al., 2006; Guerrero et al., 2010; Bleser, Young, & Miranda, 2017) and/or a composite measure of all components of FCC (Bleser et al., 2017; Russell, Beckmeyer, & Su-Russell, 2018; Guerrero et al., 2010) to explore factors associated with child and family outcomes. Denboba et al (2006) studied the influence of the “provider makes me feel like a partner” component of FCC on missed school days, access to specialty care, satisfaction with care, and unmet needs for child services for children with special health care needs. Children whose parents reported that they did not feel like a partner were approximately 4 times more likely not to receive specialty services and between 2 and 3 times more likely to have unmet needs after controlling for race/ethnicity, age, gender, poverty status, and insurance coverage (Denboba et al, 2006).

Russell et al. (2018) computed a composite score for FCC, by averaging scores across the five different components, to explore the influence of FCC on positive developmental outcomes (i.e., flourishing, participation in extracurricular activities, and excellent physical health) among children with special health care needs from families of different structures. FCC was positively associated with flourishing and excellent physical health for children with special health care needs in

married biological families, married stepfamilies, and divorced/separated single mothers, but not associated in cohabitating biological, cohabitating stepfamilies, or never married single-mother families (Russell et al., 2018). FCC was only associated with participation in extracurricular activities in married biological parent families (Russell et al., 2018). Russell and colleagues (2018) speculate that marriage may be the primary mechanism used by health providers to engage families in the care of children. Providers may not give the same attention to unmarried families because they may be perceived as less committed or invested in the child's care, or because of federal policies (e.g., Health Insurance and Accountability Act) that limit sharing medical information outside of legal ties (Russell et al., 2018).

Although research on the impact of FCC is predominantly explored among CSHCN populations, there are reasons to believe FCC can also benefit children without special health care needs. While no nationally representative studies exploring the association between FCC and child outcomes among children without special health care needs have been published to date, Hadland and Long (2014) reviewed literature to explore the potential benefit of medical homes on primary care services, health care utilization, and child well-being among healthy children. Healthy children in a medical home were more likely to receive preventative medical care (Strickland, Jones, Ghandour, Kogan, & Newacheck, 2011; Gadamski, Jenkins, & Nichols, 1998), anticipatory guidance (Romaine & Bell, 2010), developmental screening (Guerrero, Rodriguez, & Flores, 2011), and to have a higher health-related quality of life (Stevens, Vane, & Cousineau, 2011; Hadland & Long, 2014). Additional research is needed to determine whether receipt of FCC specifically is

associated with the well-being of healthy children in a nationally representative sample.

Strengthening Families Framework

There are many mechanisms by which FCC can benefit children without special health care needs. The Center for the Study of Social Policy's *Strengthening Families Framework* offers a theoretical explanation for the ways in which FCC might enable well-being in healthy children. The framework was developed by reviewing studies on child well-being across multiple disciplines that were derived from ecological and relational theories of development (Harper Browne, 2014). It uses a two-generation approach, which focuses on increasing the capacity of parents or caregivers to promote the healthy development children (Harper Browne, 2014). This strategy is supported by numerous studies that find a strong and persistent association between child well-being and parent mental health and/or parenting behaviors (Coyle, Roggman, & Newland, 2002; Stark, & Chazan-Cohen, 2012; Center for the Developing Child at Harvard, 2009) and is especially helpful to children from families with limited socioeconomic resources (Harper Browne, 2014). The Framework outlines five specific factors that promote child well-being in families: (1) parental resilience, (2) social connections, (3) knowledge of parenting and child development, (4) concrete support in times of need, and (5) social and emotional competence of children (Harper Browne, 2014). FCC is a mechanism through which pediatricians can provide each of these different aspects of family strengthening.

Parental resilience is defined as “the process of managing stress and functioning well in a particular context when faced with adversity” (Harper Browne, 2014). Harper Browne (2014) describes that parental resilience develops as parents receive support from relationships or environments when they face challenging life events. Parent Development Theory (PDT) posits that parenting is primarily learned and parents are capable of changing their behaviors based on what they learn to be important to do as parents (Mowder, 2005). Pediatric health care providers can be supportive in helping parents cope with the stress of caring for a sick child, and providing parents with an understanding of how to respond well to developmental changes to ensure safe and stimulating environments (AAP, 2012). A core component of FCC is for the pediatrician to provide that support and education, which can bolster parental resilience in the face of challenges.

The social connections factor emphasizes that all parents need someone who cares about them, who they can turn to for trusted advice to help solve problems, or from whom they can receive encouragement that they are doing the right things to promote their child’s healthy development (Harper Browne, 2014). Harper Browne (2014) describes that social institutions can provide social support by providing emotional sustenance, access to information and material resources, practice building skills, and social monitoring. Pediatricians are often considered experts on child well-being, and as such, are keepers and distributors of critical health and development information and resources (i.e., medications). Pediatricians who practice FCC provide these forms of social support through caring partnership and anticipatory guidance. They also refer families to specialists who can offer additional support.

The knowledge of parenting and child development factor refers to the fact that all parents can benefit from increasing their knowledge of child development at every developmental stage (Harper Browne, 2014). Parent Development Theory describes that parents use their knowledge and experiences to do what they believe is best for children, and that parents' behaviors change and adapt when they are given new information (Mowder, 2005). Pediatricians offer age-specific anticipatory guidance to increase parents' understanding of child development. Developmental information provided by pediatricians needs to be linguistically and culturally appropriate in order to be perceived as relevant and useful (Harper Browne, 2014). Parents with limited education and limited knowledge of child development, or little time or resources to access information from another source, may benefit most from developmental information provided by pediatricians who they visit in times of need. Parents who differ culturally or linguistically from health providers may be less likely to perceive the information provided as accessible, relevant, or useful. Pediatricians who practice FCC work to ensure that parents understand and are able to make use of the information given to them.

Concrete support in times of need refers to the tangible help that parents need sometimes, to ensure they and their children receive the basic necessities as well as health, mental health, social, legal, educational, or employment services (Harper Browne, 2014). Pediatric health providers offer expert education about healthy food and behaviors, and age-specific information about safe and stimulating environments. Pediatricians who practice FCC may also connect families to other needed services. Families need treatment options and recommendations that are feasible given their

life circumstances. Pediatricians who practice FCC engage families in the decision-making process to ensure a clear understanding of the barriers families face in providing care for their children. The back-and-forth open communication that characterizes FCC increases the likelihood that the pediatric support provided to families will match the families' specific needs.

Finally, social and emotional competence is the primary developmental goal of early childhood because it underlies all other developmental domains—physical growth, language development, and cognitive skills (Harper Browne, 2014). Children in unsafe, under-stimulating, and unresponsive environments are at greater risk of limited language and cognitive skills, difficulties interacting with peers, insecure attachments, developmental delays, behavioral and mental health problems, and chronic health conditions later in life (Boyd, Barnett, Leong, Bodrova, & Gomby, 2005; Stark & Chazan-Cohen, 2012; Felitti et al., 1998). Children living in poverty are at increased risk of experiencing unsafe (Eamon, 2002), under-stimulating (Fernald, Marchman, & Weisleder, 2012), and inconsistent environments (Repetti, Taylor, & Seeman, 2002; Kalil, 2009). Increasingly, pediatricians who practice FCC provide information about building positive parent-child relationships, screening for social and emotional developmental delays, and assessing parental health and well-being to connect families to additional supportive resources (Bauer, Childers, & Curtin, 2016; AAP, 2012).

The bioecological perspective on human development describes that children are shaped by the frequency and nature of the interactions between the child and individuals in his or her ecosystem (Bronfenbrenner & Morris, 2007). Parents or

primary caregivers have the most frequent interaction with their children. Children who receive responsive care from their parents develop positive social and coping skills, which enable them to develop cognitive skills necessary to be productive, healthy and happy (Perry & Hambrick, 2008). Pediatricians can help build parents' capacity to interact positively with their children. Health providers that provide FCC are trusted experts who parents can turn to in times of need, and from whom they can learn how to interact in ways that promote optimal physical, social and emotional, and cognitive development.

Access to Family Centered Care

While there is empirical evidence linking FCC with improved child and family outcomes for children with special health care needs, and the theoretical argument outlined above suggests that it might also improve outcomes for healthy children, it is not universally accessible to all families. Studies have consistently found that White children are more likely than children from minority groups to receive FCC (Ngui & Flores, 2006; Guerrero et al., 2010; Decamp, Choi, & Davis, 2011; Zickafoose & Davis, 2013). However, after adjusting for socioeconomic factors, racial disparities in receiving all or some components of FCC are no longer significant (Guerrero et al., 2010; Bleser et al., 2017). Guerrero and colleagues (2010) found that the differences between Black and White children in receiving FCC were no longer significant after adjusting for socioeconomic factors. The most persistent racial disparity in receiving all components of FCC after adjusting for socioeconomic factors is between Hispanic children and White children (Guerrero et al., 2010).

Hispanic children are less likely than White children to receive all components of FCC (AOR: 0.76, 95%CI 0.59-0.93; Guerrero et al, 2010). However, Bleser and colleagues (2017) describe conflicting results when assessing each individual component of FCC with race and ethnicity. Parents of Hispanic children were more likely than parents of White children to report that the child's doctor showed respect, but less likely to report that the doctor spent enough time with them (Bleser et al., 2017).

Socioeconomic disparities in accessing FCC are especially prevalent. Families consistently identified as most vulnerable to not receiving FCC are families with public insurance and families with incomes below 200% the federal poverty line (FPL) (Guerrero et al., 2010; Bleser et al., 2017). Allen et al. (2017) hypothesize that lower payments for medical services from public insurance compared to private insurance may drive discriminatory practices in the United States' fee-for-service health care settings. When evaluating each individual component of FCC, Bleser et al. (2017) found that families with incomes below 200% were less likely to report that providers listened carefully to them, explained things in an easily understandable way, or spend enough time with them. The education difference between providers and families living below 200% FPL may make explaining complex health conditions difficult (Bleser et al., 2017). Guerrero and colleagues (2010) found that mothers with an education above high school were more likely to receive all components of FCC than mothers with a high school degree and mothers with no high school degree (Guerrero et al., 2010). Children whose mothers have no high school degree were the least likely to report that doctors spent enough time with them (Guerrero et al., 2010).

Providers may spend less time with these families because the families ask fewer questions. Families with less education may be unsure of the right questions to ask, or less comfortable asking (Radecki et al., 2009).

There are also geographic disparities in receiving FCC. Guerrero and colleagues (2010) found that families living in the Northeast region of the United States are significantly more likely to receive FCC than families in the Western part of the United States. In a study to identify factors associated with having a medical home, Bethell and colleagues (2001) found a 30-point range across states in the proportion of publicly insured children who have a medical home (39%-62.6%, $p < .05$). Multiple researchers highlight the need to address system-level barriers to the implementation of FCC (Allen et al., 2017; Guerrero et al., 2010) by exploring state-level differences in the delivery or receipt of FCC (Bleser et al., 2017). Guerrero et al (2010) explain, "addressing adequacy of time and information requires not only action by physicians but also support from the health system. Primary care clinicians often feel rushed and do not always have complete control over time spent with patients." It is important to identify and address state-level policies and practices that influence the amount of time providers' spend with each patient.

State-level differences in physician recruitment and retention capabilities contribute to workforce shortages in each state, which may contribute to state-level differences in physician capacity to provide the more time-intensive FCC. Primary care workforce shortages increase wait times and reduce the amount of time physicians spend with each patient (Kirch, Henderson, & Dill, 2012). Health insurance expansion, the aging population, and an increase in the prevalence of

chronic diseases all increase the demand for primary care services (Petterson et al., 2012). It is projected that by 2025 the United States will need an additional 52,000 primary care physicians to meet the demand (Petterson et al., 2012) with rural and low-income populations experiencing the majority of health workforce shortages (Petterson et al., 2012; Kirch & Vernon, 2009).

Health professional shortage area (HPSA) designations are federal designations designed to identify and prioritize areas and populations in the United States that are in need of additional workforce support. HPSA designations are for specific geographic areas, populations, or facilities that lack or have limited access to primary health care professionals (HRSA, n.d.a). These designations were developed in the late 1970s in response to the national primary healthcare workforce crisis that emerged in the 1950s and 60s as rural physicians retired or moved to urban areas, and an increasing number of physicians chose to specialize over providing more comprehensive primary care services (Public Law No. 94-484, 1976; Lohr, Vanselow, & Detmer, 1996). There were increasingly too few primary care providers to meet the basic health needs of a growing, aging population afflicted with more chronic disease in the United States, especially among rural and poor populations (Lohr et al., 1996).

HPSA designations are evaluated and formally approved by State Primary Care Offices (PCO) and the United States' Health Resource and Services Administration (HRSA). Existing HPSAs are automatically reevaluated every three years, but anyone can request a formal evaluation for a HPSA designation at any time. Often a local health care organization or provider, experiencing the pressure of

increasing demand for services, will contact the state PCO and request a formal designation or rescore. To receive a formal designation, at a minimum the specific area or population has to have population-to-provider ratio above the standard HPSA ratio, which is 3,500 people to 1 provider or 3,000 people to 1 provider in areas with high needs for medical HPSAs (Health Resources and Services, n.d.b). Then each HPSA is categorized as a Tier 1 HPSA or a Tier 2 HPSA based on population health needs, provider density, and the population-to-provider ratio. Tier 2 designations represent areas with more workforce needs.

National Health Service Corps (NHSC) loan repayment and scholarship programs are examples of programing that helps direct providers to underserved areas. Many physicians are now exiting medical school with unprecedented amounts of student loan debt (Jolly, 2005), making loan repayment the number one physician recruitment incentive (Walker et al., 2011). NHSC provides scholarships and loan repayment to health providers in exchange for delivering services in underserved areas. Health providers delivering services in areas with Tier 2 HPSA designations are eligible to participate in the fully federally funded loan repayment and scholarship programs, partially funded state programs, or privately funded programs (NHSC, 2015). Health providers delivering services in areas with Tier 1 HPSA designations are only eligible for loan repayment programs that are partially state-funded, or privately funded. In 2016, there were more than 4,000 NHSC providers funded by the federal loan repayment program, and only 433 providers receiving loan repayment from state-funded programs (Reyes-Akinbileje, 2017).

Support for Tier 1 workforce shortages varies by state. States with fewer resources may have areas with Tier 1 HPSA designations that experience more prolonged workforce shortages because providers in these areas are not eligible for federal loan repayment programs. Prolonged workforce shortages may increase the demand for services on each individual provider and adversely affect the amount of time providers spend with each patient. Also, NHSC providers do not count in the population-to-provider ratios when HPSAs are reevaluated every three years (Fife, Buss, Steele, Kincheloe, 2016). Areas with Tier 2 HPSA designations are more likely to have NHSC providers that aren't being counted among the actual workforce when HSPAs are reevaluated, so areas with Tier 1 HPSA designations may experience more actual shortages that could adversely impact the delivery of primary care services.

Research Questions

The specific research questions addressed by this dissertation are: (1) To what extent are family socioeconomic resources associated with receipt of family-centered care? (2) To what extent are Tier 1 primary care workforce shortages associated with receipt of family-centered care? (3) Is receipt of family-centered care associated with positive child well-being? (4) Is the association between family-centered care and child well-being stronger for children from families with fewer socioeconomic resources?

It is hypothesized that: (1a) families with public or no health insurance will be less likely than those with private insurance to receive FCC; (1b) families with less

parental education will be less likely than those with more parental education to receive FCC; (1c) families with incomes below 200% of the federal poverty line will be less likely than those with income above this line to receive FCC; (1d) a lower score on a cumulative index of socioeconomic resources will be associated with a decreased odds of receiving FCC; (2) as the number of primary care workforce shortage designations that are ineligible for federally funded National Health Service Corps (i.e., Tier 1 HPSA) decrease, the odds of receiving FCC will increase; (3) multiple indicators of well-being will be higher among children who receive FCC than among those who receive care that is not FCC; (4) the relationship between FCC and child well-being will be stronger in families with fewer socioeconomic resources.

Chapter 3: Methods

Description of the Data

This study will be a secondary analysis of the 2016 data from the National Survey of Children’s Health (NSCH). NSCH is funded and directed by the Health Resources and Services Administration’s Maternal and Child Health Bureau (MCHB) in collaboration with the National Center for Health Statistics at the Centers for Disease Control, Child and Adolescent Health Measurement Initiative, and a National Technical Expert Panel (CAHMI, 2016). The survey was conducted every four years between 2003 and 2012, but annually beginning in 2016, to “assess how well each state and the nation as a whole are meeting the Bureau’s strategic plan goals,” which include, “acquiring the best available evidence to develop and promote guidelines and practices to assure a social, emotional and physical environment that supports the health and well-being of women and children” (CAHMI, 2016).

NSCH randomly selects representative samples of children under 18 years of age in each state and the District of Columbia (Blumberg et al., 2005). Administrative data sources (e.g., federal tax data, Social Security benefits, Public and Indian Housing records,) were used to identify households with, or likely have, children. Households with likely to have children were marked as Stratum 1; households without children were marked as Stratum 2 (US Census, 2018). Sixty-one percent of the sample was drawn from Stratum 1 and 39% of the sample was drawn from Stratum 2 to increase efficiency (US Census, 2018). If two or more children lived in

the household, children 0-5 years and children with special health care needs had a higher probability of being selected (US Census, 2018).

Data Collection

Prior to 2016 the NSCH was conducted using the State and Local Area Integrated Telephone Survey (SLAITS) system, which used random digit dialing to sample mostly landline telephone numbers (US Census, 2018). Beginning in 2016, telephone-based sampling was discontinued due to the declining proportion of households using landlines and decreasing participation in phone-based surveys (US Census, 2018). NSCH's updated sampling design for the 2016 survey used address-based sampling (US Census, 2018). A sample of 364,150 households was mailed an invitation to complete a web-based screening survey (U.S. Census Bureau, 2018). The invitation included the website URL, a unique 8-digit username, and an 8-digit password (U.S. Census Bureau, 2018). One third of the sample received a \$5 bill as incentive to complete the survey, one third received a \$2 bill, and one third received no incentive (U.S. Census Bureau, 2018).

After logging into the survey, respondents verified their address and were asked about the number of children under 18 years old residing at the address (U.S. Census Bureau, 2018). If the respondent's address did not match the one selected for the sample, or if no children resided at the address, the survey ended (U.S. Census Bureau, 2018). If the address matched and at least one child resided at the address, the respondent was asked screening questions about each child for up to four children from youngest to oldest (U.S. Census Bureau, 2018). Only one child per household was selected as the focus for the questionnaire. If multiple children resided at the

residence, they were sorted first by special health care needs status, then by age from youngest to oldest (US Census, 2018). The age-specific survey was provided (U.S. Census Bureau, 2018). Non-responders were mailed a paper version of the survey (U.S. Census Bureau, 2018). A total of 138,009 screener questionnaires were completed, 67,046 were eligible to complete the survey, and a total of 50,212 completed the survey (US Census Bureau, 2018). The final sample size of children aged 0-17 years without special health care needs was 38,820; 12,812 children were 0-5 years; 11,162 children were 6-11 years; and 14,846 children were 12-17 years (CAHMI, 2016).

Survey Measures

The survey gathered data on each child's physical, social, emotional, cognitive and behavioral health and the contexts in which they are situated. The screener questionnaire asked questions about child demographics, the primary language spoken, and health conditions (U.S. Census Bureau, 2018). There were three age-specific surveys with tailored questions for each age category (i.e., 0-5-years, 6-11 years, and 12-17 years). The survey asked questions about the child's health as an infant (i.e. birth weight, breastfeeding); the child's use of health care in the last 12 months; experiences with the child's health care providers (i.e. FCC, satisfaction, preparation for transition to adult care); the child's health insurance coverage and cost of care in the past 12 months; the child's early learning or school experiences; household activities and the child's sleeping and electronic use patterns; family routines and substance use; neighborhood resources and safety; if the child

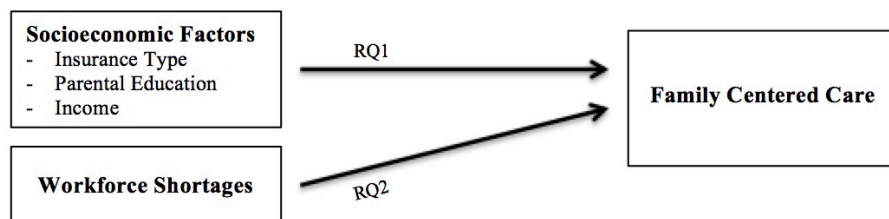
ever experienced any adverse childhood experiences; and parental demographics and family income information (U.S. Census Bureau, 2018).

The public can access summary data from the NSCH website. To obtain de-identified individual data, a written request outlining the objectives of the proposed study was submitted to HRSA’s Data Resource Center for Child and Adolescent Health. Approval was granted on March 5, 2018 and an SPSS file of the data was provided.

Study Design

Figure 1 shows the variables that will be used in research questions 1 and 2 to explore predictors of FCC. It is hypothesized that after controlling for race/ethnicity, special health care needs, parental mental health, and family structure—families with fewer socioeconomic resources will be less likely to receive FCC. It is hypothesized that families living in states with more primary care workforce shortages will be less likely to receive FCC than families living in states with fewer primary care workforce shortages because physician shortages increase wait times and reduce the amount of time physicians spend with each patient (Kirch, Henderson, & Dill, 2012).

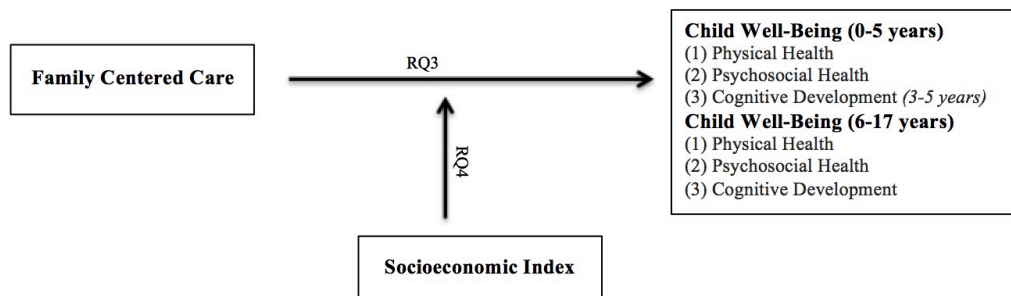
Figure 1: Conceptual Model, Predictors of FCC



Covariates: race/ethnicity, special health care need, parent mental health, and family structure

Figure 2 shows the variables that will be used in research questions 3 and 4 to explore the associations between FCC and child well-being. It is hypothesized that receipt of FCC will be positively associated with child well-being across multiple domains, including physical health, psychosocial health, and cognitive development after adjusting for other factors known to be associated with child well-being or receipt of FCC, including: race/ethnicity, special health care needs, parental mental health, and adverse childhood experiences. When families with low socioeconomic resources receive FCC, it is hypothesized that their children will benefit more from FCC than children in families with more socioeconomic resources.

Figure 2: Conceptual Model, Associations with Child Well-Being



Covariates: race/ethnicity, special health care need, parent mental health, family structure, and adverse childhood experiences

This study uses a condensed version of Moore, Murphey, and Bandy's (2012) measures for children 6-17 years. Their disease-specific indicators (e.g., asthma, diabetes, depression; Moore, Murphey, & Bandy, 2012) will not be used for this study because a population of interest is children without special health care needs. Also, the psychological and social health domains, which were strongly correlated (0.81; Moore, Murphey, & Bandy, 2012), were combined into one psychosocial domain. Also changes to indicators of child well-being were made to reflect updates

to measures used on the NSCH survey (i.e., flourishing items added in 2011-2012). For children age 6-17 years, the specific indicators of physical health are: overall health status, BMI (10-17 years) or weight concern (6-9 years), oral health status, and health promoting behaviors (i.e., adequate sleep, limited screen time, and exercise). The indicators of psychosocial health are: flourishing, making and keeping friends, bullying others, and getting bullied. The indicators of cognitive development are: problems at school, grade repetition, cares about doing well in school, and does required homework.

Using the same domains Moore, Murphey, and Bandy (2012) created for older children (i.e., physical, psychosocial, and cognitive), age appropriate indicators were identified for children 0-5 years using the NSCH interactive guide to topics and questions for 0-5 year olds. For children age 0-5 years, the specific indicators of physical health are: overall health status, oral health status, weight concern, and health promoting behaviors (i.e., adequate sleep and limited screen time). The indicators of psychosocial health are: flourishing, transitioning between activities (3-5 years), empathy (3-5 years), and plays well with others (3-5 years). The indicators of cognitive development are: learning to do things for self (3-5 years), keeps working until finished (3-5 years), follows instructions to complete simple tasks (3-5 years), and ability to explain things (3-5 years).

Study Measures: Research Questions 1 and 2

Dependent Variable

Family-Centered Care (FCC) was measured by asking parents with children who received care in the previous 12 months 5 questions: “During the past 12 months, how often did this child’s doctors or health care providers: (1) spend enough time with this child, (2) listen carefully to you, (3) show sensitivity to your family’s values and customs, (4) provide the specific information you needed concerning this child, and (5) help you feel like a partner in this child’s care?” Response options included “always,” “usually,” “sometimes,” or “never.” For the composite measure, this study uses NHSC’s coding for receipt of FCC as ‘yes’ if all five responses were always or usually, or no’ if any response was sometimes or never.

Independent Variables

Insurance Type was measured by asking, “Is this child covered by any of the following types of health insurance or health coverage plans?” Response options included: “Insurance through a current or former employer or union,” “Insurance purchased directly from an insurance company,” “Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or disability,” “Indian Health Service,” or “Other.” Families with insurance through a current or former employer or union, or with insurance purchased directly from an insurance company, either alone or in combination with any another form of insurance were categorized as ‘2=private or private/public.’ Families with Medicaid, Medical Assistance, or any kind of government assistance plan for those with low incomes or

disabilities alone, and/or Indian Health Service were categorized as '1=public only insured.' Uninsured families were categorized as 0=uninsured.

Parental Education was measured by asking the respondent to complete the question for the two adults in the household who are this child's primary caregivers; and if there is just one adult, provide the answers for that adult. The question was, "What is the highest grade you have completed?" Response options included, "8th grade or less," "9th-12th grade, no diploma," "High School Graduate or GED completed," "Completed a vocational, trade, or business school program," "Some College Credit, but No Degree," "Associate Degree," "Bachelor's Degree," "Master's Degree," or "Doctorate or Professional Degree." This study used NHSC's coding for highest level of education among reported adults, which is "0=high school/GED or less," "1=some college or technical school," and "2=college degree or higher."

Income was measured by asking, "Think about your total combined income in the last calendar year for all members of the family. What is the amount before taxes?" Responses were categorized according the federal poverty line (FPL) guidelines for 2016, 0=0-199% FPL, 1=200-399% FPL, or 2=400% FPL or greater.

Socioeconomic Index. A total score for the number of socioeconomic resources will be calculated by adding the responses from insurance type, parental education, and income. Scores will range from 0-6. Scores will be categorized as low, medium, or high socioeconomic resources (i.e., 0=low, 1-5=medium, 6=high). Low socioeconomic resources are families with a high school education or below, income below 200% the federal poverty line (i.e., \$48,500 for a family of 4), and no insurance. High socioeconomic resources are families with a bachelor's degree or

above, income above 400% the federal poverty line (i.e., \$97,000 for a family of 4), and private insurance. Medium socioeconomic resources are any other combination of resources.

Moderating Variable

Workforce Shortages were measured by counting the number of Tier 1 health professional shortage area designations in each state. This count answers the question, “How many areas/populations have been identified as having a primary health care professional shortage in the state, but do not qualify for support from the federally funded National Health Service Corps (NHSC)?”

Health professional shortage area (HPSA) designation data are publicly available online at HRSA’s Data Warehouse, including the HPSA type (i.e. medical, dental, mental health), designation status (i.e., designated, withdrawn), Tier (i.e., score), location, and designation date. An Excel spreadsheet of Tier 1 medical primary care HSPAs in every state and the District of Columbia between least January 1-December 31, 2016 was downloaded. HPSA designations for correctional facilities were removed because physicians at these facilities do not provide services for the general population of children. The remaining Tier 1 HPSAs were counted for each state. I added a variable reflecting the total number of shortages for the state in which each child resided to the NSCH SPSS dataset. Shortages were then categorized low, medium, high based on the distribution of the total number of HPSA designations in each state (i.e., low= 0-59; medium=61-92; high= 93-356).

State. Each child's address was collected. Street locations were removed from the dataset provided to protect the privacy of survey participants. However, the state of residence was included in the provided NSCH dataset for this analysis.

Study Measures: Research Questions 3 and 4

Dependent Variables Children 0-5 years

Physical Health Score. A total score for physical health will be measured by adding the responses for each item (i.e., overall health status, oral health status, weight concern, and health promoting behaviors). Each item is worth 25% (25 points) of the physical health score. Higher scores indicate better physical health.

Overall health status was measured by asking, "In general, how would you describe this child's health?" Responses options ranged from 0=poor to 4=excellent. Responses were assigned a point value—0=0 points, 1= 6.25 points, 2=12.5 points, 3=18.75 points, and 4= 25 points. Higher points indicate better overall health.

Oral health status was measured by asking, "How would you describe the condition of this child's teeth?" Response options ranged from 0=poor to 4=excellent. Responses were assigned a point value—0=0 points, 1= 6.25 points, 2=12.5 points, 3=18.75 points, and 4= 25 points. Higher points indicate better oral health.

Concern for weight was measured by asking, "Are you concerned about this child's weight?" Response options were 0= yes, it's too high, or yes, it's too low; or 1=no, not concerned. Responses were assigned a point value—0= 0 points, and 1= 25 points. Higher scores indicate no concern for the child's weight.

Health Promoting Behavior was measured by adding the number of healthy behaviors across two domains: adequate sleep and limited screen time. Participants

were categorized as having 0, 1, or 2 health-promoting behaviors. The number of health promoting behaviors were assigned points—0= 0 points, 1=12.5 points, and 2= 25 points. Higher scores indicate more health promoting behaviors.

Adequate sleep was measured by asking, “During the past week, how many hours of sleep did this child get on an average weeknight?” Response options included: “less than 6 hours, 6 hours, 7 hours, 8 hours, 9 hours, 10 hours, or 11 or more hours.” Responses were coded as adequate or not adequate based on age-specific recommendations from the American Academy of Pediatrics (i.e., 11 or more hours for children 0-2, 10-13 hours for children 3-5, 9-12 hours for children 6-12 years, and 8-10 hours for children 13-17 years; CAHMI, 2016).

Limited screen time was measured by asking two questions: “On an average weekday, about how much time does this child usually spend with computers, cell phones, handheld video games, and other electronic devices, doing things other than schoolwork,” and “On an average weekday, about how much time does this child usually spend in front of a TV watching TV programs, videos, or playing video games?” Response options included: “none, less than 1 hour, 1 hour, 2 hours, 3 hours, and 4 or more hours.” Responses from both questions were added together and categorized as 1 hour or less per day or more than 1 hour per day based on the American Academy of Pediatrics’ recommendation for children 2 to 5 years to have no more than 1 hour of screen time per day (AAP, 2016).

Psychosocial Health Score. A total score for psychosocial health will be measured by adding the weighted response for each item (i.e., flourishing, transitions

between activities, empathy, and plays well with others). Each item is worth 25% of the total psychosocial health score. Higher scores indicate better psychosocial health.

Flourishing was measured by four questions that aimed to capture curiosity and discovery about learning, resilience, attachment with their parent, and being content with life (CAHMI, 2016). Parents were asked how well each of the following phrases describes their child: “This child is affectionate and tender with you;” “This child bounces back quickly when things don’t go his/her way;” “This child shows interest and curiosity in learning new things;” and “This child smiles and laughs a lot.” Response options included, “Definitely true,” “Somewhat true,” or “Not true.” Flourishing score was coded as a count ranging from 0-4 items that the respondent rated as definitely true. Responses were assigned point values, 0= 0 points, 1= 6.25 points, 2=12.5 points, 3=18.25 points, and 4= 25 points. Higher scores indicate more flourishing.

Transitioning between activities was measured by asking caregivers how often “This child becomes angry or anxious when going from one activity to another?” Responses options included “all of the time,” “most of the time,” “some of the time,” or “none of the time.” Responses were reverse coded from 0=all of the time to 3=none of the time. Responses were assigned point values—0= 0 points, 1= 8.333 points, 2= 16.666 points, and 3= 25 points. Higher numbers indicate fewer problems transitioning between activities.

Empathy was measured by asking the caregiver how often “This child shows concern when others are hurt or unhappy?” Response options included “all of the time,” “most of the time,” “some of the time,” or “none of the time.” Responses were

coded from 0=none of the time to 3=all of the time. Responses were assigned point values—0= 0 points, 1= 8.333 points, 2= 16.666 points, and 3= 25 points. Higher numbers indicate more empathy.

Plays well with others was measured by asking caregivers, “How often does this child play well with others?” Response options included “all of the time,” “most of the time,” “some of the time,” or “none of the time.” Responses were coded from 0=none of the time to 3=all of the time. Responses were assigned point values—0= 0 points, 1= 8.333 points, 2= 16.666 points, and 3= 25 points. Higher numbers indicate more ability to play well with others.

Cognitive Health Score (3-5 years). A total score for cognitive development will be measured by adding responses for each item (i.e., learning to do things for self, keeps working until finished, follows instructions, and ability to explain things so you can understand). Each item is worth 25% of the total cognitive health score. Higher scores indicate more positive cognitive development.

Learning to do things for self was measured by asking, “How well is this child learning to do things for him or herself?” Response options included, “very well,” “somewhat,” “poorly,” or “not at all.” Responses were coded from 0=not at all to 3=very well. Responses were assigned a point value—0= 0 points, 1=8.333 points, 2= 16.666 points, and 3= 25 points. Higher numbers indicate that the child is better able to learn to do things for himself or herself.

Keeps working until finished was measured by asking, “How often does this child keep working at something until he or she is finished?” Response options included “all of the time,” “most of the time,” “some of the time,” or “none of the

time.” Responses were coded from 0=none of the time to 3=all of the time. Responses were assigned a point value—0= 0 points, 1=8.333 points, 2= 16.666 points, and 3= 25 points. Higher numbers indicate more consistency in working until tasks are finished.

Follows instructions was measured by asking, “When he or she is paying attention, how often can this child follow instructions to complete a simple task?” Responses were categorized as “all of the time,” “most of the time,” “some of the time,” or “none of the time.” Responses were coded as 0=none of the time to 3=all of the time. Responses were assigned a point value—0= 0 points, 1=8.333 points, 2= 16.666 points, and 3= 25 points. Higher numbers indicate more consistency in following instructions to complete a simple task.

Ability to explain things was measured by asking, “How often can this child explain things he or she has seen or done so that you get a very good idea of what happened?” Responses were coded from 0=none of the time to 3=all of the time. Responses were assigned a point value—0= 0 points, 1=8.333 points, 2= 16.666 points, and 3= 25 points. Higher numbers indicate more ability to explain things.

Dependent Variables for Children 6-17 years

Physical Health Score. A total score for physical health will be measured by adding the responses for each item (i.e., overall health status, oral health status, BMI (10-17years) or weight concern (0-9years), and health promoting behaviors). Each item is worth 25% of the total physical health score. Total scores range from 0 to 100. Higher scores indicate better physical health.

Overall Health Status was measured by asking, “In general, how would you describe this child’s health?” Responses options ranged from 0=poor to 4=excellent. Responses were assigned a point value—0=0 points, 1= 6.25 points, 2=12.5 points, 3=18.75 points, or 4= 25 points. Higher scores indicate better overall health.

Oral Health Status was measured by asking, “How would you describe the condition of this child’s teeth?” Response options ranged from 0=poor to 4=excellent. Responses were assigned a point value—0=0 points, 1= 6.25 points, 2=12.5 points, 3=18.75 points, or 4= 25 points. Higher scores indicate better oral health.

Concern for weight (6-9 years) was measured by asking, “Are you concerned about this child's weight?” Response options were 0= yes, it’s too high, or yes, it’s too low; or, 1=no, not concerned. Responses were assigned a point value—0= 0 points, or 1= 25 points. Higher scores indicate no concern about the child’s weight.

Body Mass Index (BMI) (10-17 years) was measured by asking, “What is your child’s current height” and “How much does this child currently weigh?” BMI’s were calculated and categorized according to the Centers for Disease Control’s age-specific guidelines, which are 0= unhealthy for BMIs less than 5th percentile or more than 95th percentile, 1= overweight for BMIs between the 85th and 95th percentiles, and 2=healthy for BMIs between the 5th percentile and the 85th percentile. BMI’s based on parent report for children under 10 years were not considered reliable (CAHMI, 2016). BMI’s were assigned a point value—0= 0 points, 1= 12.5 points, or 2= 25 points. Higher scores indicate a healthier weight.

Health Promoting Behaviors was measured by counting the number of positive healthy behaviors (0-3) across three domains: adequate sleep, limited screen

time, and exercise. The number of health promoting behaviors was assigned points— 0= 0 points, 1=8.333 points, 2= 16.666 points, or 3= 25 points. Higher scores indicate more health promoting behaviors.

Adequate Sleep was measured by asking, “During the past week, how many hours of sleep did this child get on an average weeknight?” Response options included: “less than 6 hours, 6 hours, 7 hours, 8 hours, 9 hours, 10 hours, or 11 or more hours.” Responses were dichotomized as 0=no or 1=yes based on age-specific recommendations from the American Academy of Pediatrics (i.e., 11 or more hours for children 0-2, 10-13 hours for children 3-5, 9-12 hours for children 6-12 years, and 8-10 hours for children 13-17 years; CAHMI, 2016).

Limited Screen Time was measured by asking two questions: “On an average weekday, about how much time does this child usually spend with computers, cell phones, handheld video games, and other electronic devices, doing things other than schoolwork,” and “On an average weekday, about how much time does this child usually spend in front of a TV watching TV programs, videos, or playing video games?” Response options included: “none, less than 1 hour, 1 hour, 2 hours, 3 hours, and 4 or more hours.” Responses from both questions were added together and categorized as 0=no, more than 3 hours, and 1=yes, 3 hours or less. The American Academy of Pediatrics’ recommendation for children 6 and above is to set consistent limits on screen times and have media free times and locations (AAP, 2016).

Adequate Exercise was measured by asking, “During the past week, on how many days did this child exercise, play a sport, or participate in physical activity for

at least 60 minutes?” This study follows the NSCH coding, which dichotomized responses into ‘not adequate’ for 0-3 days, or ‘adequate’ for 4-7 days.

Psychosocial Health Score. A total score for psychosocial health will be measured by adding responses to each item (i.e., flourishing, making and keeping friends, bullying others, getting bullied). Each item is worth 25% of the total physical health score. Total scores range from 0 to 100. Higher scores indicate better psychosocial health.

Flourishing was measured by three questions that aimed to capture curiosity and discovery about learning, resilience, and self-regulation (CAHMI, 2016). These were captured by asking, “How well does each of the following phrases describe your child: “This child shows interest and curiosity in learning new things,” “This child works to finish tasks he or she starts,” and “This child stays calm and in control when faced with a challenge.” Response options included, “Definitely true,” “Somewhat true,” or “Not true.” Responses were categorized as either definitely true to 0, 1, 2, or 3 items. Responses were assigned a point value—0= 0 points, 1= 8.333, 2= 16.666, or 3= 25 points. Higher scores indicate more flourishing.

Making and keeping friends was measured by asking, “Compared to other children his or her age, how much difficulty does this child have making or keeping friends? Response options included “No difficulty,” “A little difficulty,” “A lot of difficulty.” Responses were reverse coded from 0=a lot of difficulty, 1= a little difficulty, and 2=no difficulty. Responses were assigned a point value—0= 0points, 1=12.5 points, or 2= 25 points. Higher scores indicate less difficulty making friends.

Being a bully was measured by asking how well the phrase, “This child bullies others, picks on them, or excludes them,” describes this child. Response options included, “Definitely true,” “Somewhat true,” or “Not true.” Responses were reverse coded from 0=definitely true to 2=not true. Responses were assigned a point values, 0= 0points, 1=12.5 points, or 2= 25 points. Higher scores indicate fewer problems bullying others.

Getting bullied was measured by asking how well the phrase, “This child is bullied, picked on, or excluded by other children,” describes this child. Response options included, “Definitely true,” “Somewhat true,” or “Not true.” Responses were categorized as “Definitely true or somewhat true,” or “Not true.” Responses were reverse coded from 0=definitely true to 2=not true. Responses were assigned a point value—0= 0points, 1=12.5 points, or 2= 25 points. Higher scores indicate fewer problems being bullied.

Cognitive Health Score. A total score for cognitive development will be measured by adding responses for each item (i.e., problems at school, grade repetition, cares about doing well in school, and does required schoolwork). Each item is worth 25% of the total physical health score. Total scores range from 0 to 100. Higher scores indicate more positive cognitive development.

Problems at school were measured by asking, “During the past 12 months, has this child’s school contacted you or another adult in your household about any problems he or she is having at school?” Response options were 0=yes or 1=no. Responses were assigned a point value—0=0 points, or 1= 25 points. Higher scores indicate no problems at school.

Grade repetition was measured by asking, “Since starting kindergarten, has this child repeated any grades?” Response options were 0=yes or 1=no. Responses were assigned a point value—0=0 points, or 1= 25 points. Higher scores indicate no grade repetition.

Cares about doing well in school was measured by asking how well the phrase, “This child cares about doing well in school,” describes the child. Responses included 0=not true, 1=somewhat true, or 2= definitely true. Responses were assigned a point value—0=0 points, 1= 12.5 points, or 2= 25 points. Higher scores indicate more caring about doing well in school.

Does required homework was measured by asking how well the phrase, “This child does all required homework” describes the child. Responses included 0=not true, 1=somewhat true, or 2= definitely true. Responses were assigned a point value—0=0 points, 1= 12.5 points, or 2= 25 points. Higher scores indicate the child does more required homework.

Independent Variable

Family-Centered Care (FCC) was measured by asking parents with children who received care in the previous 12 months 5 questions: “During the past 12 months, how often did this child’s doctors or health care providers: (1) spend enough time with this child, (2) listen carefully to you, (3) show sensitivity to your family’s values and customs, (4) provide the specific information you needed concerning this child, and (5) help you feel like a partner in this child’s care?” Response options included “always,” “usually,” “sometimes,” or “never.” For the composite measure,

this study uses NHSC's coding for receipt of FCC as 'yes' if all five responses were always or usually, or no' if any response was sometimes or never.

Moderating Variable

Socioeconomic Index. A total score for the number of socioeconomic resources will be calculated by adding the responses (0,1, or 2) from insurance type, parental education, and income. Scores will range from 0-6. Scores will be categorized as low, medium, or high socioeconomic resources (i.e., 0=low, 1-5=medium, 6=high). Low socioeconomic resources are families with a high school education or below, income below 200% the federal poverty line (i.e., \$48,500 for a family of 4), and no insurance. High socioeconomic resources are families with a bachelor's degree or above, income above 400% the federal poverty line (i.e., \$97,000 for a family of 4), and private insurance. Medium socioeconomic resources are any other combination of resources.

Covariates

Race/Ethnicity was categorized as "Hispanic," "White-non-Hispanic," "Black, non-Hispanic," "Asian, non-Hispanic," or "Other/Multiracial, non-Hispanic."

Special Health Care Need. Children with special health care needs were defined by answering one or more of the following five groups 'yes' to all of its questions. Group 1—Medication— "Does this child currently need or use medicine prescribed by a doctor, other than vitamins; Is this child's need for prescription medicine because of any medical, behavioral, or other health condition; If yes, is this a condition that lasted or is expected to last 12 months or longer?" Group 2—

Services— “Does this child need or use more medical care, mental health, or educational services than is usual for most children of the same age; Is this child’s need for medical care, mental health, or educational services because of any medical, behavioral, or other health condition; If yes, is this a condition that has lasted or is expected to last 12 months or longer?” Group 3—Limited Ability— “Is this child limited or prevented in any way in his/her ability to do the things most children of the same age can do; Is this child’s limitation in abilities because of ANY medical, behavioral, or other health condition; If yes, is this condition that has lasted or is expected to last 12 months or longer?” Group 4—Special Therapy— “Does this child need or get special therapy, such as physical, occupational, or speech therapy; Is this child’s need for special therapy because of any medical, behavioral, or other health condition; If yes, is this a condition that has lasted or is expected to last 12 months or longer?” Group 5—Treatment or Counseling— “Does this child have any kind of emotional, developmental, or behavioral problem for which he or she has needs treatment or counseling; If yes, has his or her emotional, developmental, or behavioral problem lasted or is it expected to last 12 months or longer?”

Parent Mental Health was measured by asking the respondent to complete the question for the two adults in the household who are this child’s primary caregivers; and if there is just one adult, provide the answers for that adult. The question was, “In general, how is your mental or emotional health?” Response options included “excellent,” “very good,” “good,” “fair,” “poor.” Following NSCH coding, responses were dichotomized into ‘good health’ if the primary caregiver(s) had excellent or very

good mental and emotional health, or ‘poor health’ if at least one primary caregiver had good, fair, or poor mental and emotional health.

Family structure was measured by asking the respondent to complete the question for the two adults in the household who are this child’s primary caregivers; and if there is just one adult, provide the answers for that adult. The question was, “What is your marital status?” Response options included: “married,” “not married, but living with a partner,” “never married,” “divorced,” “separated,” “widowed.” Russell et al., (2018) found differences based on married versus not married, so responses were categorized as “1=two parents, currently married,” or “0=two parents, not currently married; single mother (currently separated, formerly married, or never married); or other family type.”

Adverse Childhood Experiences were measured by asking nine questions. The first eight questions were: “To the best of your knowledge, has this child ever experienced any of the following: (1) Parent or guardian divorced or separated, (2) Parent or guardian died, (3) Parent or guardian served time in jail, (4) Saw or heard parents or adults slap, hit, kick punch one another in the home, (5) Was a victim of violence or witnessed violence in neighborhood, (6) Lived with anyone who was mentally ill, suicidal, or severely depressed, (7) Lived with anyone who had a problem with drugs or alcohol, or (8) Treated or judged unfairly because of his or her race or ethnic group?” Response options for all eight questions were yes or no. The last ACE question was, “(9) Since this child was born, how often has it been very hard to get by on your family’s income – hard to cover the basics like food or housing? Response options included “very often,” “somewhat often,” “rarely,” or

“never.” A response of “somewhat often” or “very often” was coded as an adverse childhood experience. This study follows the NSCH coding of 0, 1, or 2 or more ACEs.

Analysis

SPSS version 23.0 will be used to perform the analyses. Data will be weighted using the NSCH’s “final weight for surveyed children” to be nationally representative (U.S. Census, 2018). The weight accounts for the base sampling weight and adjusted for screener nonresponse, child’s race and ethnicity, child’s sex and age group, household poverty, household size, respondent’s education, and child’s special health care need status (U.S. Census, 2018). Descriptive data will be generated for all variables to determine the distribution of each variable. Composite scores for socioeconomic factors and each domain of child well-being will be calculated. Descriptive data will be generated for composite measures. Bivariate associations between socioeconomic factors, child well-being, workforce shortages, and family-centered care (FCC) will be calculated using ANOVA and chi-square as appropriate to determine the strength of the association between measures. Then, a series of multiple logistic and linear regression models will be ran to answer the research questions. To answer question 1, to what extent are family socioeconomic resources associated with receipt of family-centered care— each socioeconomic factor will be added to a logistic regression model to assess the odds and adjusted odds of receiving FCC. To assess the cumulative effect of combined socioeconomic resources, the socioeconomic index score will be entered into a separate unadjusted and adjusted

model for the receipt of FCC. To answer question 2, to what extent are Tier 1 primary care workforce shortages associated with receipt of family-centered care—workforce shortages will be added to a regression model with socioeconomic factors and covariates to assess the odds and adjusted odds of receiving FCC. The state fixed effect will also be added to the model to account for state variation aside from workforce shortages. To answer question 3, is receipt of family-centered care associated with positive child well-being— socioeconomic variables, FCC, and covariates will be entered into linear regression models to assess their independent and cumulative influence on each domain of child well-being. To answer question 4, is the association between family-centered care and child well-being stronger for children from families with fewer socioeconomic resources—the PROCESS plugin for SPSS (Hayes, 2017) will be used to test for an interaction effect between FCC and SES predicting each domain of child well-being. Hayes’s PROCESS plugin will (1) create dummy codes for different levels of FCC and SES; (2) create interaction terms between the FCC and medium and high SES; (3) tests for a moderation effect by running a regression model that includes FCC, dummy codes, and covariates for adjusted models; then adds each of the interaction terms to determine if each interaction is significant; and if $p < .10$ for the interaction (4) run a simple slope analysis (Aiken & West, 1991) to determine if the slopes of FCC on child outcome are statistically significantly different (Field, 2018).

Chapter 4: Results

Research Question 1: To what extent are family socioeconomic resources associated with receipt of family-centered care?

In 2016, 86.3% of children usually or always received family-centered health care (FCC) in the United States. Approximately 13.7%, or 8.4 million, children (0-17 years) who received medical care in 2016 did not receive FCC (CAHMI, 2016).

Table 1 presents the receipt of FCC by child and household characteristics. Receipt of FCC was significantly higher among: children without special health care needs (87.3% vs. 82.6%), White children (90.8% vs. 78.6% among Hispanic children), children in families with two married parents (88.3% vs. 82.6%), children in families with parent(s) who reported excellent or very good mental health (90.0% vs. 84.5%), and children with private health insurance (89.9% vs. 72.9% among uninsured children). As parental education and income increased, the percentage of children receiving FCC also increased. The percentage of children receiving FCC ranged from 69.3% of children in families with the fewest combined socioeconomic resources (SES) to 93.5% of children in families with the most SES.

Low SES families were defined as having with a high school education or below, income below 200% the federal poverty line (i.e., \$48,500 for a family of 4), and no insurance. High SES families had a bachelor's degree or above, income 400% or above the federal poverty line (i.e., \$97,000 for a family of 4), and private insurance. Medium SES families had any other combination of resources. Fifty-four percent of families in the medium SES had income below 200% the poverty line,

37% had income between 200-399% FPL, and 9% had income 400% FPL; 4% had no insurance, 44% had public insurance, and 52% had private health insurance; and 35% had a high school education or below, 30% had some college, and 35% had a college degree.

TABLE 1: Bivariate relationships between FCC, child health, family characteristics, and socioeconomics factors, 2016 National Survey of Children’s Health weighted data

	Total	Not FCC	FCC	(p)	
All Children, %	61,440,752	13.7	86.3	--	
Child Health and Family Characteristics					
Special Health Care Need, %					
	Yes	12,954,332	17.4	82.6	.000
	No	48,486,422	12.7	87.3	
Race, %					
	White, non-Hispanic	33,615,792	9.2	90.8	.000
	Hispanic	13,432,166	21.4	78.6	
	Black, non-Hispanic	7,871,133	19.4	80.6	
	Asian, non-Hispanic	2,519,409	16.3	83.7	
	Other/Multiple, non-Hispanic	4,002,252	12.4	87.6	
Family Structure, %					
	Married	40,470,739	11.7	88.3	.000
	Not Married, Single, Other	19,455,347	17.4	82.6	
Parental Mental Health, %					
	One or Both excellent/very good	2,966,372	15.5	90.0	.000
	One or both NOT excellent/very good	31,957,735	10.0	84.5	
Socioeconomic Factors					
Parental Education, %					
	High School/GED or less	14,544,253	20.1	79.9	.000
	Some College/ Technical School	13,692,534	15.6	84.4	
	College Degree or Higher	31,302,957	9.4	90.6	
Income, %					
	0-199%	24,775,472	19.8	80.2	.000
	200-399%	16,980,789	12.3	87.7	
	400% or greater	19,684,491	7.2	92.8	
Insurance Type, %					
	Not insured	2,349,198	27.1	72.9	.000
	Public only	18,977,098	19.2	80.8	
	Private with or without public	39,211,610	10.1	89.9	
SES Index, %					
	Low	931,302	30.7	69.3	.000
	Medium	42,211,843	15.5	84.5	
	Large	15,587,078	6.5	93.5	

Table 2 presents the odds ratios and adjusted odds ratios of receiving FCC for each socioeconomic variable, controlling for all covariates. Children in households

with a parental education of high school education or less (OR= 0.705, 95% CI 0.704, 0.707), or some college or technical degree (OR= 0.797, 95% CI 0.795, 0.799), were less likely to receive FCC than children in households with parental education of college degree or more. The difference in odds between the lowest and highest educated households increased by 7.2% after adjusting for covariates. Children living in low-income households were less than half as likely (OR = 0.461, 95% CI 0.460, 0.462) to receive FCC compared to children living in households with high-incomes. This ratio persisted after adjusting for race/ethnicity, special health care need status, parental mental health, and family structure. After adjusting for covariates, uninsured children and children with public insurance were less likely than children with private insurance to receive FCC (OR = 0.485, 95% CI 0.482, 0.487; and OR = 0.825, 95% CI 0.822, 0.828).

Table 2: Odds Ratios (95%CI) and Adjusted Odds Ratios (95%CI) for FCC socioeconomic indicators, 2016 National Survey of Children’s Health weighted data

Predictors	Unadjusted ^a			Adjusted ^b		
	p	OR	95% CI	p	OR	95% CI
Highest household education						
College Degree & Above	.000	Ref	--	.000	Ref	--
Some college/Tech Degree	.000	.797	.795, .799	.000	.735	.733, .737
High School or Below	.000	.705	.704, .707	.000	.633	.631, .635
Income						
High (400%+FPL)	.000	Ref	--	.000	Ref	--
Middle (200-399% FPL)	.000	.633	.632, .635	.000	.720	.718, .722
Low (0-199% FPL)	.000	.461	.460, .462	.000	.494	.493, .496
Insurance Type						
Private	.000	Ref	--	.000	Ref	--
Public	.000	.790	.788, .792	.001	.825	.822, .828
No Insurance	.000	.455	.453, .456	.000	.485	.482, .487

^a Unadjusted model includes: highest household education, federal poverty line, and insurance type.

^b Adjusted model also includes: race/ethnicity, child’s special health care need status, parental mental health, and family structure

Table 3 presents the odds ratios and adjusted odds ratios of receiving FCC based on the cumulative index of socioeconomic resources. The odds of receiving FCC increased as socioeconomic resources increased. This pattern persisted after adjusting for race and ethnicity, child’s special health care needs status, parental mental health, and family structure. After adjusting for covariates, the odds of receiving FCC among children in households with the fewest resources compared to children in households with the most resources increased by 8.7% (OR = 0.247, 95% CI 0.245, 0.249).

Table 3: Odds Ratios (95% CI) and Adjusted Odds Ratios (95% CI) for FCC combined socioeconomic indicators, 2016 National Survey of Children’s Health weighted data

Predictors	Unadjusted			Adjusted ^a		
	p	OR	95% CI	p	OR	95% CI
Socioeconomic index						
High	.000	Ref	--	.000	Ref	--
Medium	.000	.381	.381, .382	.000	.450	.448, .451
Low	.000	.158	.157, .158	.000	.247	.245, .249

^a Adjusted model includes: race/ethnicity, child’s special health care need status, parental mental health, and family structure

Research Question 2: To what extent are Tier 1 primary care workforce shortages associated with receipt of family-centered care?

Figure 3 displays the percentage of children in each state who received FCC. The percentage of children receiving FCC ranged from 78.5% in Nevada to 93.4% in New Hampshire. Ten states (NH, VT, UT, PA, OH, IA, ND, WI, NE, KY; CAMI, 2016) had significantly higher percentages of children receiving FCC than the national average (86.3%, CI 85.5,87.1; CAHMI, 2016). Five states (NV, TX, NM, FL, AZ; CAHMI, 2016) had significantly lower percentages of children receiving FCC than the national average. Children in states in the Northeast were significantly

more likely to receive FCC than the national average. Children in states in the Southwest were significantly less likely to receive FCC than the national average.

Figure 3: Percent of children receiving family-centered care by state

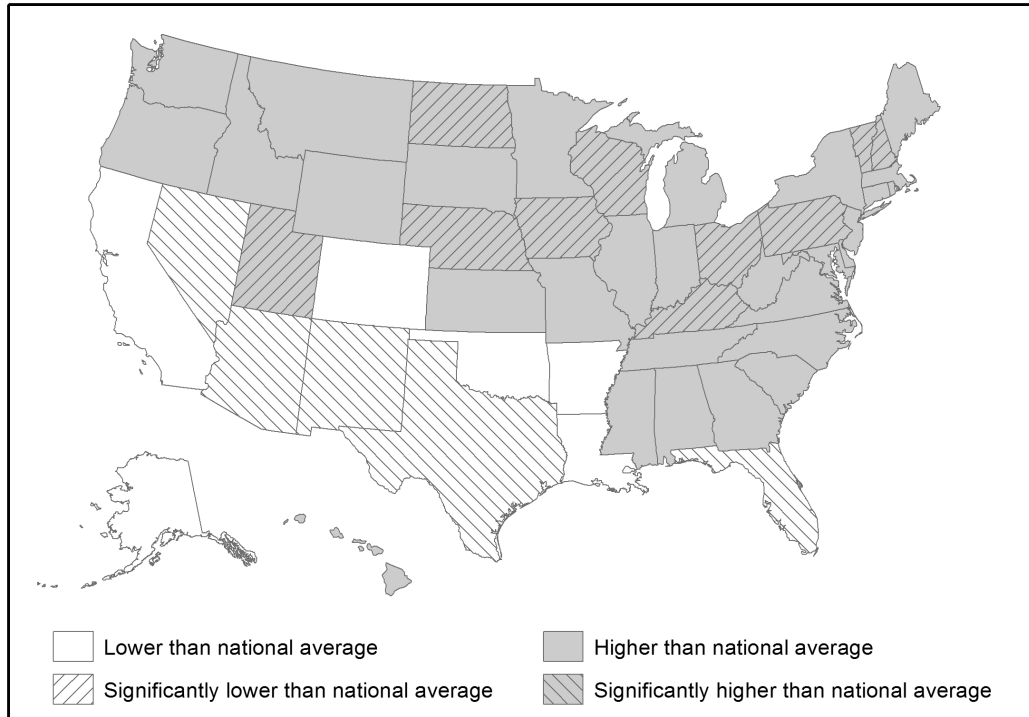


Table 4 displays the receipt of FCC by state-managed primary care workforce shortages. Higher percentages of children receiving FCC lived in states with a low or medium number of Tier 1 HPSA designations compared to children living in states with a high number of Tier 1 HPSA designations (87.6%, 88.2% vs. 83.1%).

Table 4: Bivariate relationship between FCC and Tier 1 primary care workforce shortages in the U.S. in 2016

	Total	Not FCC	FCC	(p)
Tier 1 HPSA, %				
High	20,152,648	16.9	83.1	.000
Medium	20,938,284	11.8	88.2	
Low	20,349,820	12.4	87.6	

Table 5 presents the adjusted ratios of receiving FCC based on the cumulative index of socioeconomic resources, workforce shortages, and the state fixed effect. When workforce shortages were added to the model, they significantly predicted receipt of FCC ($\beta = .324, p = .000$). Comparing to children living in areas with the highest workforce shortages, children living in medium and low shortages were more likely to receive FCC (AOR=1.640, $p = .000$; AOR=1.383, $p = .000$). Children in areas with medium shortages had the highest odds of receiving FCC.

Table 5: Odds Ratios (95%CI) for FCC socioeconomic indicators, workforce shortages, and state fixed effects, 2016 National Survey of Children’s Health weighted data

Predictors	^a Model 1			^b Model 2			^c Model 3		
	B	AOR	95% CI	B	AOR	95%CI	B	AOR	95% CI
Step1: SES									
High	--	Ref	Ref	--	Ref	Ref	Ref	Ref	Ref
Medium	-.726	.484	.422, .424	-.719	.487	.486, .489	-.719	.455	.453, .456
Low	-1.16	.230	.228, .232	-1.106	.331	.328, .334	-1.106	.251	.249, .253
Step 2: Workforce									
High				Ref	Ref	Ref	Ref	Ref	Ref
Medium				.495	1.640	1.635, 1.644	.496	1.642	1.635, 1.644
Low				.327	1.383	1.379, 1.387	.327	1.386	1.382, 1.390
Step 3:									
State							.000	.000	1.000, 1.000

^a Model 1: socioeconomic index, race/ethnicity, child special health care needs status, parental mental health, family structure; ^b Model 2: socioeconomic index, race/ethnicity, child special health care needs status, parental mental health, family structure, workforce shortages; ^c Model 3: socioeconomic index, race/ethnicity, child special health care needs status, parental mental health, family structure, workforce shortages, state fixed effect

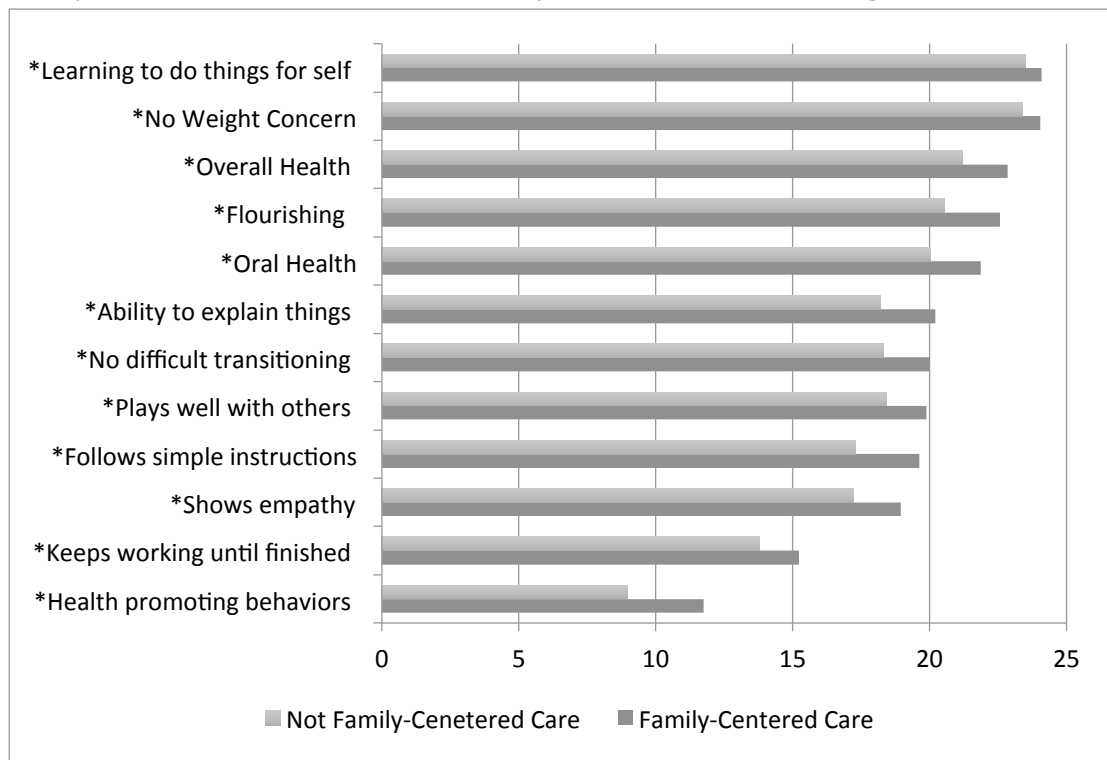
Research Question 3: Is receipt of family-centered care associated with positive child well-being?

Children 0-5 years

Figure 4 shows the average score for each indicator of well-being among children 0-5 years by receipt of family-centered care. Children receiving FCC had

higher scores for every indicator. Children in both groups have high scores (15-25) in 10 of the 12 indicators. The highest scores for children in both groups were in learning to do things for self (24.1 among FCC and 23.5 among not FCC). The lowest scores for children in both groups were in health promoting behaviors (11.8 among FCC and 9.0 among not FCC). Only 27.3% of all children had limited screen time, and 67% got the recommended amount of sleep.

Figure 4: Average score for indicators of well-being of children 0-5 years by receipt of family-centered care, 2016 National Survey of Children’s Health weighted data



* p<.001 between groups

Bivariate relationships between FCC and child well-being for children 0-5 years are provided in Table 6 and Figure 5. The scale for each domain of child well-being (i.e., physical, psychosocial, cognitive) ranged from 0-100 with higher scores indicating better health or functioning. Children 0-5 years receiving FCC had higher scores in physical health (75.3 vs. 66.6) and psychosocial health (80.9 vs 73.9) than

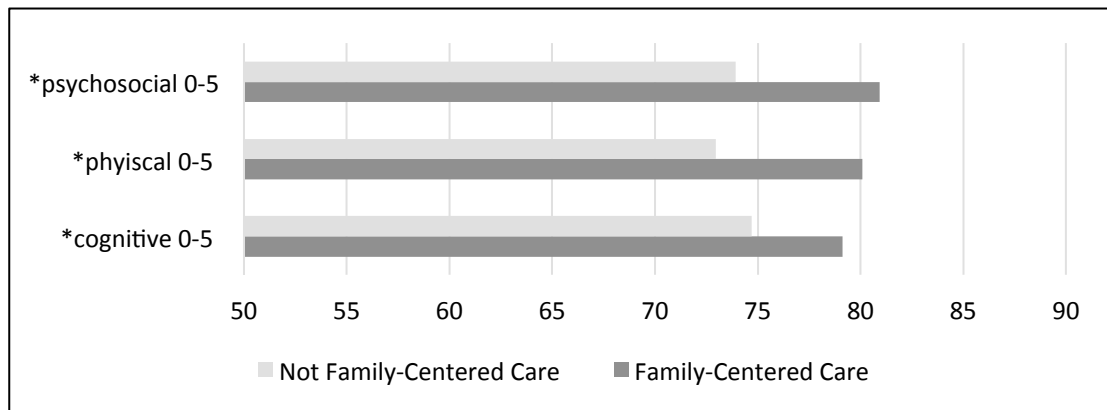
children not receiving FCC. Children 3-5 years receiving FCC had higher scores in cognitive development (79.1 vs 74.7) than children not receiving FCC.

TABLE 6: Bivariate relationships between FCC and child well-being among children 0-5 years, 2016 National Survey of Children’s Health weighted data

	Total	Not FCC	FCC	(p)
Physical Health,^a M (SD)	74.1 (15.7)	66.6 (17.8)	75.3 (14.9)	.000
Excellent/Very Good Overall Health, ^b M (SD)	21.7 (4.8)	19.7 (5.7)	22.1 (4.5)	.000
Excellent/ Very Good Oral Health, ^b M (SD)	19.5 (5.8)	16.8 (6.2)	20.0 (5.6)	.000
No Weight Concern, ^b M(SD)	21.5 (8,7)	19.6 (10.3)	21.8 (8.4)	.000
Health Promoting Behaviors, ^{b,c} M (SD)	9.6 (7.2)	7.9 (6.9)	9.9 (7.2)	.000
Psychosocial Health,^a M (SD)	80.0 (14.8)	73.9 (19.9)	80.9 (13.6)	.000
Flourishing, ^{b,d} M (SD)	22.3 (4.4)	20.5 (5.5)	22.6 (4.2)	.000
No Difficulty Transitioning, ^b M (SD)	19.8 (5.2)	18.3 (6.4)	20.0 (5.0)	.000
Shows Empathy, ^b M (SD)	18.7 (6.2)	17.2 (7.4)	19.0 (5.9)	.000
Plays well with others, ^b M (SD)	19.7 (5.2)	18.4 (6.6)	19.9 (4.9)	.000
Cognitive Develop (3-5 years),^a M (SD)	78.6 (14.7)	74.7 (17.0)	79.1 (14.3)	.000
Learning to do things for self, ^b M (SD)	24.0 (2.9)	23.5 (3.6)	24.1 (2.8)	.000
Keeps working until finished, ^b M (SD)	15.0 (5.6)	13.8 (6.3)	15.2 (5.4)	.000
Follows simple instructions, ^b M (SD)	19.3 (5.6)	17.3 (6.8)	19.6 (5.3)	.000
Ability to explain things, ^b M (SD)	19.9 (6.2)	18.2 (7.8)	20.2 (5.9)	.000

^a Range 0-100; ^b Range 0-25; ^c recommended sleep and limited screen time; ^d tender and affectionate with parent, smiles and laughs a lot, shows interest and curiosity, bounces back when things don’t go their way

Figure 5: Average score for physical, psychosocial, and cognitive health of children 0-5 years by receipt of family-centered care, 2016 National Survey of Children’s Health weighted data



*p<.001 between groups

Regression analyses (Table 7) showed that covariates and FCC significantly predicted physical health scores of children 0-5 years. Covariates accounted for 10.9% of the variance in physical health scores of children 0-5 years. When FCC was added to the regression model, it was a significant predictor of physical health ($\beta = .101$, $p = .000$), accounting for an additional 1.1% of the variance.

Table 7: Standardized regression coefficients for PHYSICAL HEALTH (0-5 years) regressed on covariates and family-centered care, 2016 National Survey of Children's Health weighted data

Predictors	Model 1	Model 2	R ² increase	R ² total
Step 1: Covariates			.109***	.109***
Race/Ethnicity				
White	--	--		
Hispanic	-.145***	-.127***		
Black	-.113***	-.104***		
Asian	-.117***	-.109***		
Other	-.026***	-.027***		
Special Health Care Need	.180***	.174***		
Parental Mental Health	-.017***	-.012***		
Adverse Childhood Experiences	-.140***	-.126***		
Family Structure	.035***	.041***		
Step 2: Family-Centered Care			.011***	.119***
All components		.101***		

* $p < .05$, ** $p < .01$, *** $p < .001$

Regression analyses (Table 8) showed that covariates and FCC significantly predicted psychosocial health scores of children 0-5 years. Covariates accounted for 4.6% of the variance in psychosocial health scores of children 0-5 years. When FCC was added to the regression model, it was a significant predictor of psychosocial health ($\beta = .107$, $p = .000$), accounting for an additional 1.1% of the variance

Table 8: Standardized regression coefficients for PSYCHOSOCIAL (0-5 years) regressed on covariates and family-centered care, 2016 National Survey of Children's Health weighted data

Predictors	Model 1	Model 2	R ² increase	R ² total
Step1: Covariates			.046***	.046***
Race/Ethnicity				
White	--	--		
Hispanic	.016***	.036***		
Black	.015***	.025***		
Asian	-.022***	-.013***		
Other	.045***	.046***		
Special Health Care Need	.167***	.160***		
Parental Mental Health	-.017***	-.012***		
Adverse Childhood Experiences	-.103***	-.089***		
Family Structure	-.084***	-.079***		
Step 2: Family-Centered Care			.011***	.057***
All components		.107***		

*p<.05, **p<.01, ***p<.001

Regression analyses (Table 9) showed that covariates and FCC all significantly predicted cognitive health scores of children 0-5 years. Covariates accounted for 9.2% of the variance in cognitive health scores of children 0-5 years. When FCC was added to the regression model, it was a significant predictor of cognitive health ($\beta=.045$, $p=.000$), and accounted for an additional .2% of the variance.

Table 9: Standardized regression coefficients for COGNITIVE (3-5 yrs) regressed on covariates and FCC, 2016 National Survey of Children's Health weighted data

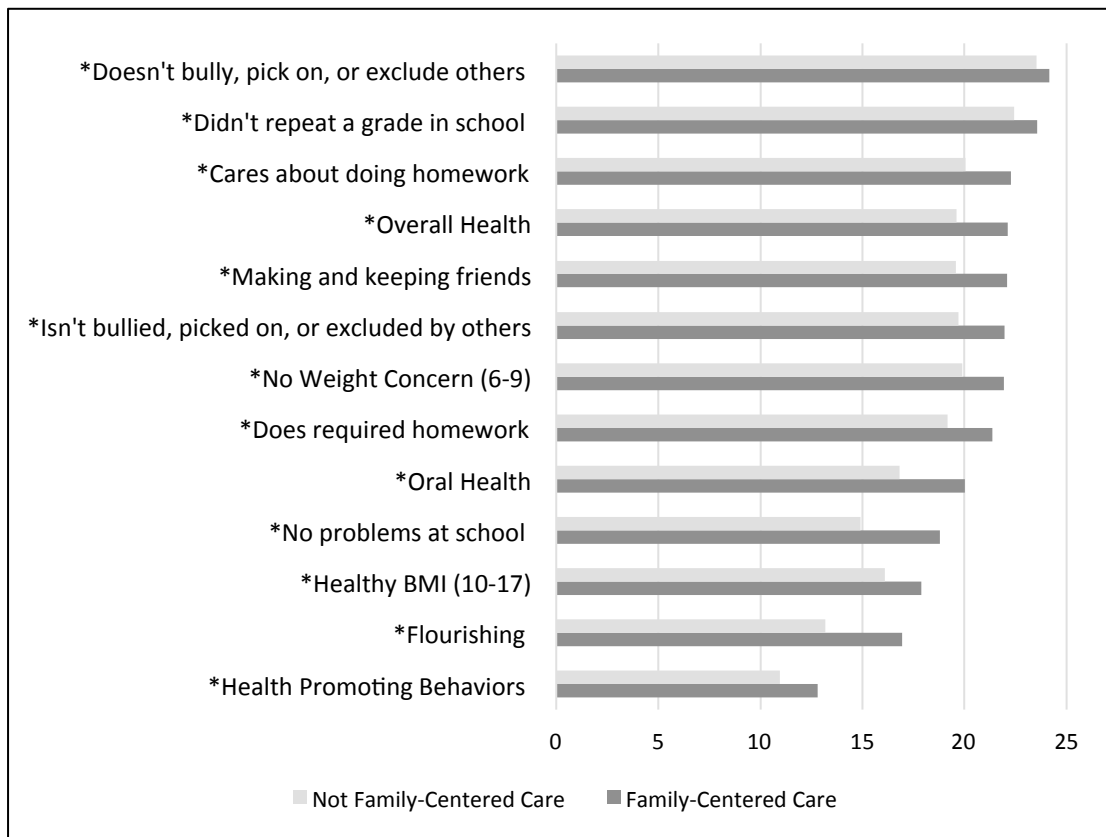
Predictors	Model 1	Model 2	R ² increase	R ² total
Step1: Covariates			.092***	.092***
Race/Ethnicity				
White	--	--		
Hispanic	.069***	.071***		
Black	.019***	.022***		
Asian	-.041***	-.037***		
Other	.017***	.018***		
Special Health Care Need	.220***	.216***		
Parental Mental Health	-.028***	-.025***		
Adverse Childhood Experiences	-.169***	-.165***		
Family Structure	.015***	.016***		
Step 2: Family-Centered Care			.002***	.094***
All components		.045***		

*p<.05, **p<.01, ***p<.001

Children 6-17 years

Figure 5 shows the average score for each indicator of well-being among children 6-7 years by receipt of family-centered care. Children receiving FCC had higher scores for every indicator. Children in both groups have high scores (15-25) in 11 of the 13 indicators. The highest scores for children in both groups was in doesn't bully, pick on, or exclude others (24.17 among FCC, and 23.52 among not FCC). The lowest scores for children in both groups were in health promoting behaviors (12.8 among FCC and 11.0 among not FCC). Approximately 30% of 6-17-year olds had limited screen time (<3 hours /day), 54% exercised for 60 minutes 4 or more days a week, and 67% got the recommended amount of sleep.

Figure 6: Average score for indicators of well-being of children 6-17 years by receipt of family-centered care, 2016 National Survey of Children's Health weighted data



*p<.001 between groups

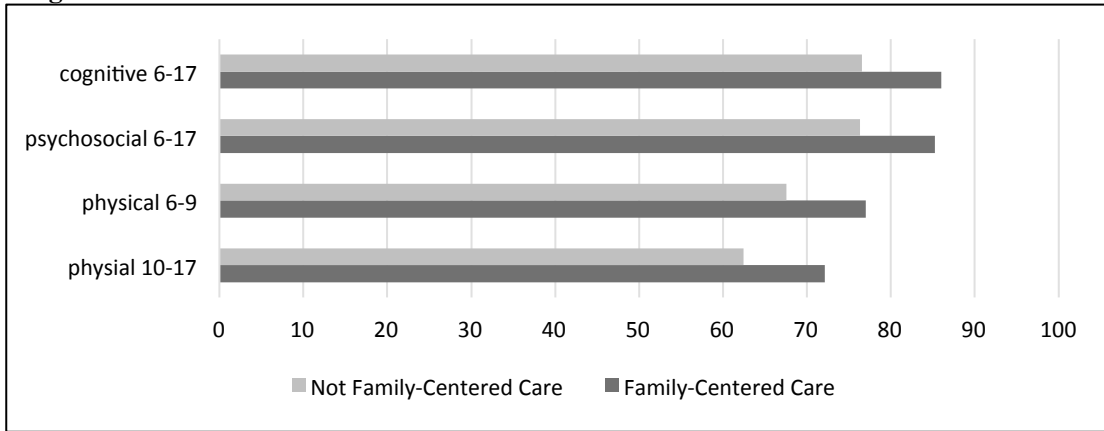
Bivariate relationships between FCC and child well-being for children 6-17 years are provided in Table 10 and Figure 7. The scale for each domain of child well-being ranged from 0-100 with higher scores indicating better health or functioning. Children receiving FCC had higher scores in physical health (77.0 compared to 67.6 among 6-9-year olds; and 72.1 compared to 62.4 among 10-17-year olds). Children 6-17 receiving FCC had higher psychosocial scores (85.3 vs 76.3) and cognitive scores (86.0 vs 76.6) than children not receiving FCC.

TABLE 10: Bivariate relationships between FCC and child well-being among children 6-17 years, 2016 National Survey of Children’s Health weighted data

	Total	Not FCC	FCC	(p)
Physical Health 6-9, ^a M (SD)	75.6 (17.2)	67.6 (19.3)	77.0 (16.4)	.000
Physical Health 10-17, ^a M (SD)	70.8 (17.8)	62.4 (19.1)	72.1 (17.2)	.000
Excellent/Very Good Overall health, ^b M (SD)	22.6 (4.2)	20.8 (5.7)	22.8 (3.9)	.000
Excellent/Very Good Oral health, ^b M (SD)	21.4 (5.2)	19.4 (6.6)	21.6 (4.9)	.000
No Weight Concern, ^b M (SD)	23.9 (5.1)	23.4 (6.1)	23.9 (4.9)	.000
Body Mass Index, ^b M (SD)	17.6 (10.3)	16.1 (11.0)	17.9 (10.2)	.000
Health Promoting Behaviors, ^{b,c} M (SD)	12.5 (7.5)	11.0 (7.5)	12.8 (7.5)	.000
Psychosocial Health, ^a M (SD)	84.0 (17.8)	76.3 (20.1)	85.3 (17.1)	.000
Flourishing, ^{b,d} M (SD)	16.4 (8.7)	13.2 (9.0)	16.9 (8.5)	.000
Making and keeping friends, ^b M (SD)	22.0 (6.3)	19.9 (7.9)	22.4 (6.0)	.000
Isn’t bullied by others, ^b M (SD)	21.6 (6.7)	19.7 (7.9)	21.9 (6.4)	.000
Doesn’t bully others, ^b M (SD)	24.1 (3.8)	23.5 (4.6)	24.2 (3.6)	.000
Cognitive Develop, ^a M (SD)	84.6 (21.0)	76.6 (24.8)	86.0 (20.0)	.000
Cares about doing well in school, ^b M (SD)	21.9 (6.1)	20.0 (7.3)	22.3 (5.8)	.000
Does required homework, ^b M (SD)	21.0 (7.0)	19.2 (8.0)	21.3 (6.8)	.000
No problems at school, ^b M (SD)	18.2 (11.1)	14.9 (12.3)	18.8 (10.8)	.000
Didn’t repeat a grade in school, ^b M (SD)	23.4 (6.1)	22.4 (7.6)	23.6 (5.8)	.000

^a Range 0-100; ^b Range 0-25; ^c recommended sleep, limited screen time, and adequate exercise; ^d shows interest and curiosity in learning new things, stays calm and in control when faced with a challenge, and finishes tasks they start

Figure 7: Average score for physical, psychosocial, and cognitive health of children 0-5 years by receipt of family-centered care, 2016 National Survey of Children’s Health weighted data



Regression analyses (Table 11) showed that there was a significant relationship between FCC and physical health of children 6-9 years. Covariates accounted for 13.3% of the variance in physical health scores ($R^2=.133$, $p=.000$). When FCC was added to the model, it was a significant predictor of physical health scores ($\beta= .109$, $p=.000$), accounting for an additional 1.1% of the variance in physical health.

Tables 11: Regression coefficients for PHYSICAL HEALTH (6-9 years) regressed on covariates and FCC, 2016 National Survey of Children’s Health weighted data

Predictors	Model 1	Model 2	R^2 increase	R^2 total
Step1: Covariates			.133***	.133***
Race/Ethnicity				
White	--	--		
Hispanic	-.164***	-.149***		
Black	-.116***	-.112***		
Asian	-.070***	-.066***		
Other	-.007***	-.008***		
Special Health Care Need	.218***	.216***		
Parental Mental Health	-.069***	-.066***		
Adverse Childhood Experiences	-.163***	-.157***		
Family Structure	.003***	.001***		
Step 2: Family-Centered Care			.011***	.144***
All components		.109***		

* $p<.05$, ** $p<.01$, *** $p<.001$

Regression analyses (Table 12) showed that there was a significant relationship between FCC and physical health of children 10-17 years. Covariates accounted for 10.0% of the variance in physical health scores ($R^2=0.100$, $p=.000$). When FCC was added to the regression model, it was a significant predictor of physical health scores ($\beta= .097$, $p=.000$), accounting for an additional .9% of the variance in physical health.

Tables 12: Regression coefficients for PHYSICAL HEALTH (10-17 years) regressed on covariates and family-centered care, 2016 National Survey of Children’s Health weighted data

Predictors	Model 1	Model 2	R^2 increase	R^2 total
Step1: Covariates			.100***	.100***
Race/Ethnicity				
White	--	--		
Hispanic	-.137***	-.127***		
Black	-.137***	-.135***		
Asian	-.065***	-.062***		
Other	.001***	.001***		
Special Health Care Need	.171***	.169***		
Parental Mental Health	-.071***	-.065***		
Adverse Childhood Experiences	-.136***	-.131***		
Family Structure	.015***	.012***		
Step 2: Family-Centered Care			.009***	.109***
All components		.097***		

* $p<.05$, ** $p<.01$, *** $p<.001$

Regression analyses (Table 13) showed that there was a significant relationship between FCC and psychosocial health of children 10-17 years. Covariates accounted for 15.0% of the variance in psychosocial scores ($R^2=0.150$, $p=.000$). When FCC was added to the model, it predicted psychosocial health scores ($\beta= .128$, $p=.000$), and accounted for an additional 1.6% of the variance in psychosocial health scores.

Tables 13: Regression coefficients for PSYCHOSOCIAL (6-17 years) regressed on covariates and family-centered care, 2016 National Survey of Children’s Health weighted data

Predictors	Model 1	Model 2	R ² increase	R ² total
Step1: Covariates			.150***	.150***
Race/Ethnicity				
White	--	--		
Hispanic	.010***	.027***		
Black	.016***	.020***		
Asian	.002***	.007***		
Other	.007***	.007***		
Special Health Care Need	.321***	.320***		
Parental Mental Health	-.056***	-.053***		
Adverse Childhood Experiences	-.176***	.168***		
Family Structure	-.048***	.051***		
Step 2: Family-Centered Care			.016***	.166***
All components		.128***		

*p<.05, **p<.01, ***p<.001

Regression analyses (Table 14) showed that there was a significant relationship between FCC and cognitive health of children 10-17 years. Covariates accounted for 11.6% of the variance in cognitive scores ($R^2=0.116$, $p=.000$). When FCC was added to the model, it was a significant predictor of cognitive scores ($\beta= .083$, $p=.000$), and accounted for an additional 0.7% of the variance in cognitive health.

Tables 14: Regression coefficients for COGNITIVE (6-17 years) regressed on covariates and family-centered care, 2016 National Survey of Children’s Health weighted data

Predictors	Model 1	Model 2	R ² increase	R ² total
Step1: Covariates			.116***	.116***
Race/Ethnicity				
White	--	--		
Hispanic	.008***	.019***		
Black	-.040***	-.037***		
Asian	.160***	.019***		
Other	-.011***	-.011***		
Special Health Care Need	.258***	.257***		
Parental Mental Health	-.032***	-.030***		
Adverse Childhood Experiences	-.182***	-.177***		
Family Structure	-.016***	-.017***		
Step 2: Family-Centered Care			.007***	.123***
All components		.083***		

*p<.05, **p<.01, ***p<.001

74 Additional regression analysis found that FCC had a significant influence on flourishing of children 0-5 years ($R^2=.034$, $p=.000$; $\Delta R^2= .019$, $p=.000$) and children 6-17 years ($R^2=.096$, $p=.000$; $\Delta R^2= .010$, $p=.000$) after adjusting for race/ethnicity, special health care need status, adverse childhood experiences, parental mental health, and family structure.

Research Question 4: Is the association between family-centered care and child well-being stronger for children from families with fewer socioeconomic resources?

Physical Health

Figures 8, 10, and 12 show the interaction between FCC and socioeconomic status (SES) predicting physical health of children 0-5 ($R^2=.055$, $p=.000$; $\Delta R^2= .001$, $p=.009$), children 6-9 years ($R^2=.059$, $p=.000$; $\Delta R^2= .001$, $p=.000$), and children 10-17 years ($R^2=.068$, $p=.000$; $\Delta R^2= .000$, $p=.039$). Figures 9, 11, and 13 show the interaction between FCC and household SES predicting physical health of children 0-17 years after adjusting for race/ethnicity, special health care needs status, adverse childhood experiences, family structure, and parental mental health. After adjusting for covariates, the interaction between FCC and SES predicting physical health remained significant for children 0-5 ($R^2=.086$, $p=.000$; $\Delta R^2= .001$, $p=.002$) and children 6-9 years ($R^2=.106$, $p=.000$; $\Delta R^2= .000$, $p=.019$). After adjusting for covariates, the interaction on physical health for children 10-17 years ($R^2=.094$, $p=.000$; $\Delta R^2= .000$, $p=.164$) was not significant.

FCC had the largest effect on the physical health of children 0-5 years in low SES households ($b=16.927$, $p=.000$, $95\%CI=8.955, 24.899$), followed by children in medium SES households ($b=6.169$, $p=.000$, $95\%CI= 5.308, 7.084$), then children in high SES households ($b=4.880$, $p=.000$, $95\%CI= 3.316, 6.444$). The difference was significant between children in low SES households and children in medium or high SES households, but not between children with medium SES and children with high SES. After adjusting for covariates, the effect of FCC on physical health of children 0-5 years followed the same pattern with the largest effect among children in households with the fewest socioeconomic resources (low SES, $b=25.466$, $p=.000$, $95\%CI= 11.263, 39.671$; medium SES, $b=4.430$, $p=.000$, $95\%CI= 3.290, 5.571$; high SES $b=2.536$, $p=.004$, $95\%CI= 0.811, 4.262$). The difference remained significant between children with low SES and children with medium or high SES, but not between children with medium SES and children with high SES

The interaction between FCC and SES on the physical health of children 6-9 years was marginally significant for low SES ($b= 5.164$, $p=.077$, $95\%CI= -.558, 10.886$). FCC had larger effect on physical health of children 6-9 years old in medium SES households ($b=8.265$, $p=.000$, $95\%CI= 7.543, 8.987$) than children in high SES households ($b=4.626$, $p=.000$, $95\%CI= 3.373, 5.879$). The difference between children in medium SES households and children in high SES households was significant. After adjusting for covariates, the interaction between FCC and low SES was insignificant ($b=6.163$, $p=.143$, $95\%CI= -2.088, 14.415$), and the effect between FCC and medium and high SES followed the same pattern with a significantly larger effect of FCC on physical health of children 6-9 years among children in medium

SES households compared to children in high SES households (medium SES, $b=5.026, p=.000, 95\%CI= 4.044, 6.010$; high SES $b=2.651, p=.000, 95\%CI= 1.293, 4.010$).

FCC had the largest effect on the physical health of children 10-17 years in low SES households ($b= 9.769, p=.007, 95\%CI= 2.704, 16.836$), followed by children in medium SES households ($b=7.345, p=.000, 95\%CI= 6.446, 8.244$), then high SES households ($b=5.164, p=.000, 95\%CI= 3.632, 6.695$). The differences between SES groups were not significant. After adjusting for covariates, the interaction between FCC and SES on the physical health of children 10-17 years was not significant.

Figures 8 & 9: Interactions between FCC and socioeconomic status on PHYSICAL HEALTH of children 0-5 years, 2016 National Survey of Children’s Health weighted data

Figure 8: Unadjusted

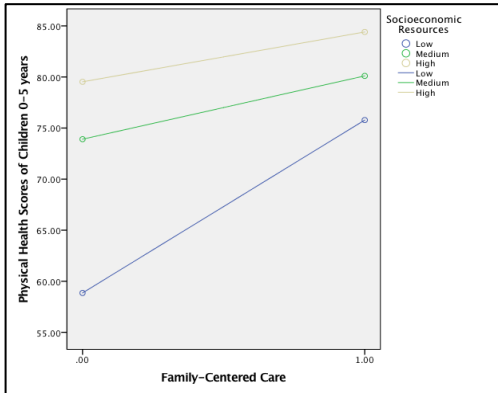
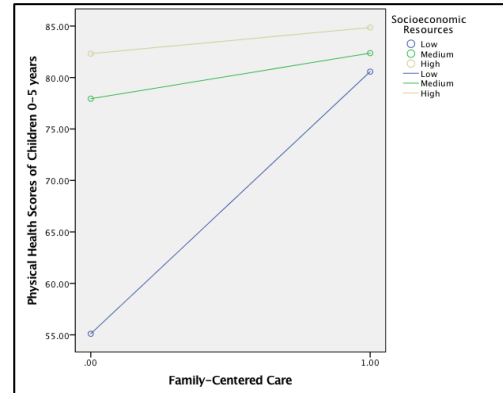


Figure 9: Adjusted



Figures 10 & 11: Interaction between FCC and socioeconomic status on PHYSICAL HEALTH of children 6-9 years, 2016 National Survey of Children’s Health weighted data

Figure 10: Unadjusted

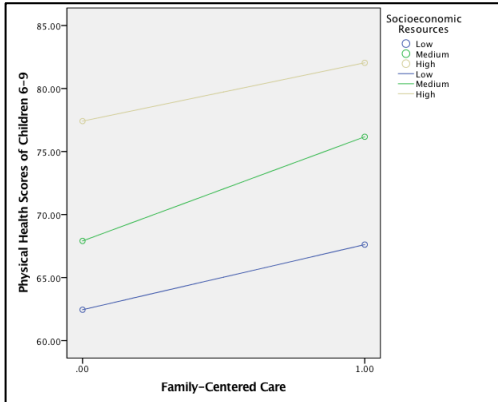
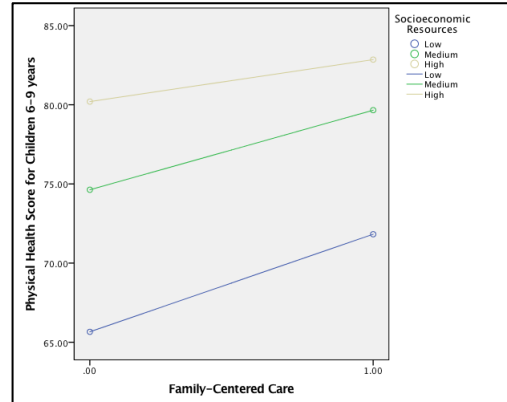


Figure 11: Adjusted



Figures 12 and 13: Interaction between FCC and socioeconomic status on PHYSICAL HEALTH of children 10-17 years, 2016 National Survey of Children’s Health weighted data

Figure 12: Unadjusted

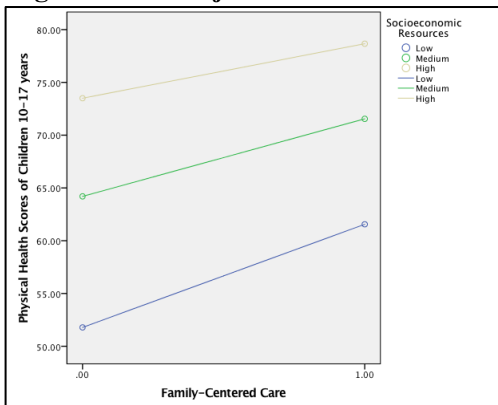
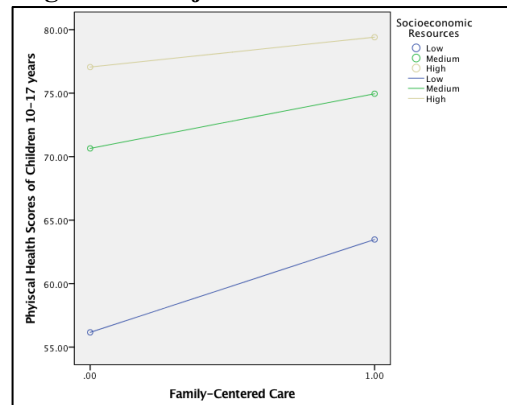


Figure 13: Adjusted



Psychosocial Health

Figures 14 and 16 show the interaction between FCC and socioeconomic status (SES) predicting psychosocial health of children 0-5 ($R^2=.017, p=.000; \Delta R^2=.001, p=.010$) and children 6-17 years ($R^2=.043, p=.000; \Delta R^2=.000, p=.672$). Figures 15 and 17 show the interaction between FCC and SES after adjusting for

race/ethnicity, special health care needs status, adverse childhood experiences, family structure, and parental mental health. After adjusting for covariates, the interaction remained significant for children 0-5 years ($R^2=.042$, $p=.000$; $\Delta R^2= .002$, $p=.008$). After adjusting for covariates, the interaction between FCC and SES on psychosocial health for children 6-17 years ($R^2=.154$, $p=.000$; $\Delta R^2= .000$, $p=.739$) was not significant.

In the unadjusted model, FCC had the largest effect on psychosocial health of children 0-5 years in low SES households ($b=10.603$, $p=.055$, $95\%CI= -.215, 21.421$), followed by children in medium SES households ($b=6.134$, $p=.000$; $95\%CI= 4.876, 7.392$), then children in high SES households ($b=2.334$, $p=.042$; $95\%CI= .082, 4.587$). The difference between children in medium SES households and children in high SES households was significant. After adjusting for covariates, the interactions between FCC and low SES or high SES on psychosocial health of children 0-5 years were not significant (low SES, $b=0.221$, $p=.981$, $95\%CI= -18.057, 18.499$; high SES, $b=-0.158$, $p=.905$, $95\%CI= -2.730, 2.415$), but the effect of FCC on psychosocial health of children 0-5 years was significant for children in medium SES households (medium SES, $b=4.667$, $p=.000$, $95\%CI= 2.977, 6.362$). Additional analysis showed that parental mental health was the primary driver of the change in the effect of FCC on psychosocial health of children 0-5 years in low and high socioeconomic homes. When parental mental health was left out of the adjusted model that included all other covariates— the effect of FCC on psychosocial health of children 0-5 years in low SES homes was highest ($b=10.71$, $p=.1061$), followed by the effect on children in medium SES homes ($b=5.11$, $p=.000$), and lowest among children in high SES

($b=1.78$, $p=.118$). The results were similar when the adjusted model included each covariate independently. The effect size was highest among the children in low SES homes, followed by children in medium SES homes, and lowest among children in high SES homes for all covariates independently (*i.e., race/ethnicity, special health care need, adverse childhood experiences, and family structure*), except parental mental health. In the model that adjusted only for parental mental health, the effect of FCC on psychosocial health among children in low SES homes was negative and insignificant ($b=-1.45$, $p=.933$), significantly positive for children in medium SES homes ($b=5.26$, $p=.000$), and insignificant for children in high SES homes ($b=.329$, $p=.812$).

The effect of FCC on psychosocial health of children 6-17 years did not differ significantly based on household socioeconomic resources in the unadjusted or adjusted models.

Figures 14 and 15: Interaction between FCC and socioeconomic status on PSYCHOSOCIAL HEALTH of children 0-5 years, 2016 National Survey of Children’s Health weighted data

Figure 14: Unadjusted

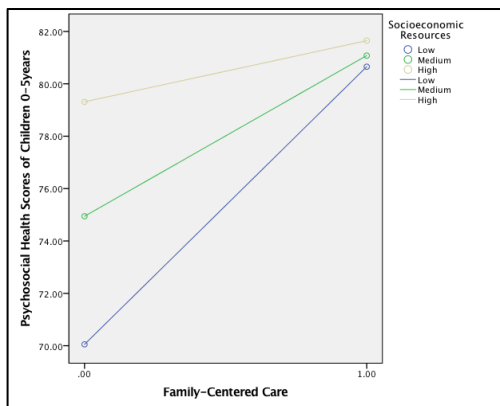
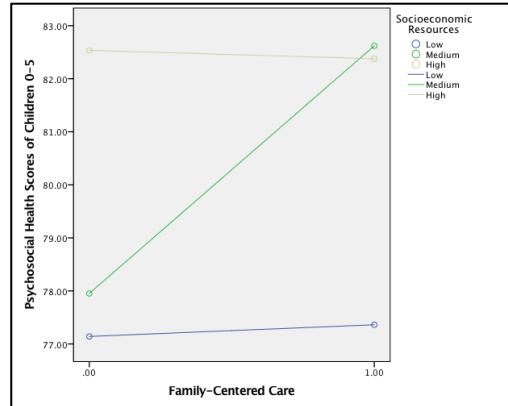


Figure 15: Adjusted



Figures 16 and 17: Interaction between FCC and socioeconomic status on PSYCHOSOCIAL HEALTH of children 6-17, 2016 National Survey of Children's Health weighted data

Figure 16: Unadjusted

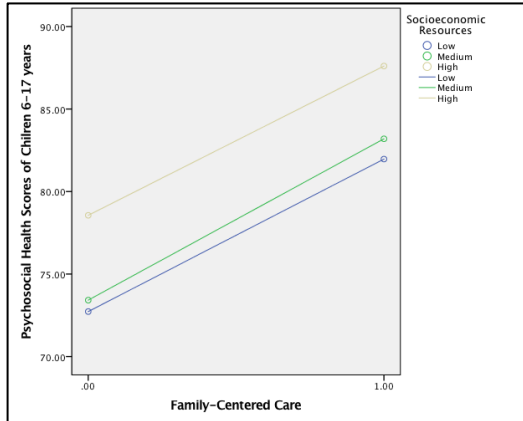
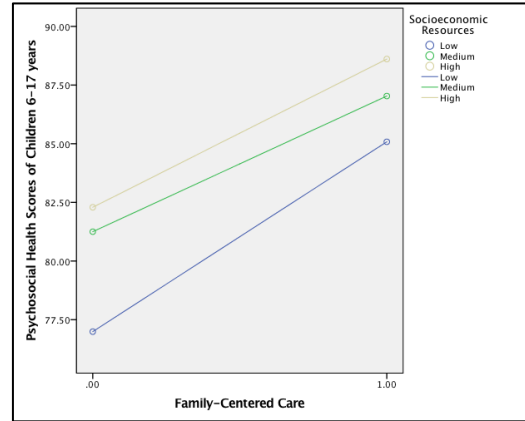


Figure 17: Adjusted



Cognitive Health

Figures 18 and 20 show the interactions between FCC and socioeconomic status (SES) predicting cognitive health of children 0-5 ($R^2=.018$, $p=.000$; $\Delta R^2= .001$, $p=.021$) and children 6-17 years ($R^2=.036$, $p=.000$; $\Delta R^2=.000$, $p=.230$). Figures 19 and 21 show the interactions after adjusting for race/ethnicity, special health care needs status, adverse childhood experiences, family structure, and parental mental health. After adjusting for covariates, the interaction between FCC and SES predicting cognitive health of children 0-5 remained significant ($R^2=.074$, $p=.000$; $\Delta R^2= .002$, $p=.035$). After adjusting for covariates, the interaction between FCC and SES on cognitive health for children 6-17 years ($R^2=.124$, $p=.000$; $\Delta R^2= .000$, $p=.870$) remained insignificant.

FCC had the largest effect on cognitive health of children 0-5 years among children in low SES households ($b=11.46$, $p=.046$; 95%CI= .232, 22.685), followed by children in medium SES households ($b=6.206$, $p=.000$, 95%CI= 4.884, 7.527), then children in high SES households ($b=2.65$, $p=.029$, 95%CI= .278, 5.020). The difference between children in medium SES households and children in high SES households was significant. After adjusting for covariates, the interactions between FCC with low SES or high SES were not significant (low SES, $b=-2.412$, $p=.788$, 95%CI -20.011, 15.187; high SES $b=-.305$, $p=.823$, 95%CI= -2.0981, 2.370), but the effect of FCC on cognitive health of children 0-5 years in medium SES households was significant ($b=3.815$, $p=.000$, 95%CI= 2.072, 5.558). Additional analysis showed that parental mental health was the primary driver of the change in the effect of FCC on cognitive health of children 0-5 years in low and high socioeconomic homes. When parental mental health was left out of the adjusted model that included all other covariates—the effect of FCC on cognitive health of children 0-5 years in low SES homes was $b=11.55$, $p=.119$, medium SES homes was $b=4.99$, $p=.000$, and high SES was $b=1.92$, $p=.099$). The results were similar when the adjusted model included each covariate independently. The effect size was highest among the children in low SES homes, followed by children in medium SES homes, and lowest among children in high SES homes for all covariates independently (*i.e., race/ethnicity, special health care need, adverse childhood experiences, and family structure*), except parental mental health. In the model that adjusted only for parental mental health, the effect of FCC on psychosocial health among children in low SES homes was negative and insignificant ($b=-2.41$, $p=.794$), significantly positive for children in medium SES

homes ($b=3.815$, $p=.000$), and insignificant for children in high SES homes ($b=-.3055$, $p=.812$).

The effect of FCC on cognitive health of children 6-17 years did not significantly differ based on household socioeconomic resources in the unadjusted or adjusted models.

Figures 18 and 19: Interaction between FCC and socioeconomic status on COGNITIVE health of children 0-5 years, 2016 National Survey of Children’s Health weighted data

Figure 18: Unadjusted

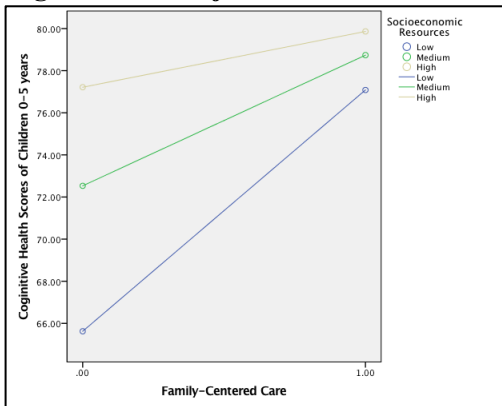
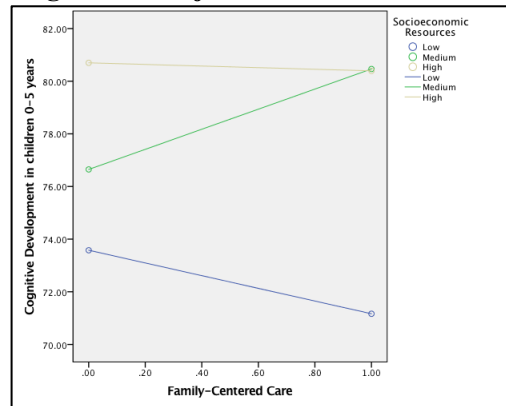


Figure 19: Adjusted



Figures 20 and 21: Interaction between FCC and socioeconomic status on COGNITIVE health of children 6-17 years, 2016 National Survey of Children’s Health weighted data

Figure 20: Unadjusted

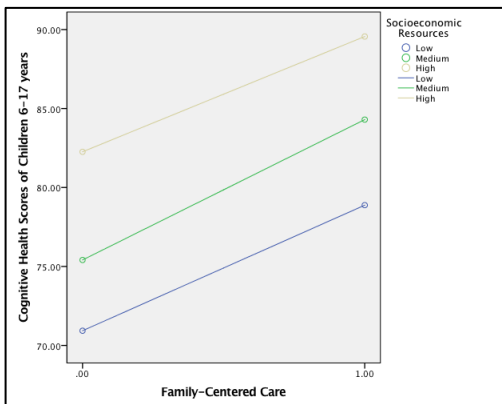
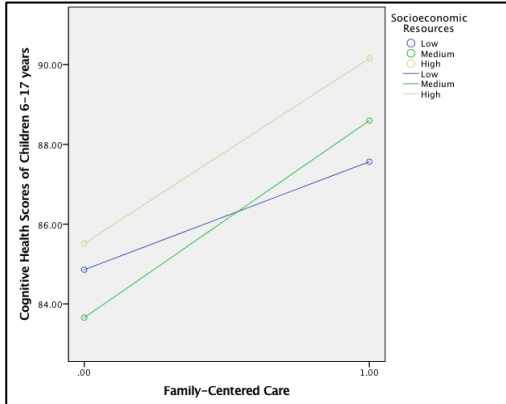


Figure 21: Adjusted



Chapter 5: Discussion

Research question 1: To what extent are family socioeconomic resources associated with receipt of family-centered care?

A primary purpose of this study was to identify whether there are socioeconomic disparities in the receipt of family-centered care (FCC) after implementation of the Affordable Care Act (ACA). Previous research found that uninsured or publicly insured children, children in households with income below 200% of the federal poverty line (i.e., \$48,500 for a family of 4; Guerrero et al., 2010; Bleser et al., 2017), and children of parents with a high school education or below (Guerrero et al., 2010) were most vulnerable to not receiving FCC. The ACA expanded health insurance coverage to 22 million Americans (Obama, 2016). Since implementation of the ACA, Ortega et al (2018) found a significant increase in well-child visits. However, the quality of health care visits varies. It was hypothesized that socioeconomic disparities in receipt of FCC would continue to exist: (1) children with public or no health insurance would be less likely than children with private insurance to receive FCC; (2) children in households with less parental education would be less likely than children in households with more parental education to receive FCC; and (3) children in households with income below 200% the FPL would be less likely than children in households with higher income to receive FCC. In addition, it was hypothesized that as the cumulative measure of socioeconomic resources increased, odds of receiving FCC would also increase.

Overall, the majority (86.3%) of children in the United States receive FCC. However, significant disparities in receiving FCC exist. Consistent with previous research, this study found that socioeconomic resources, measured in several different ways, consistently predicted receiving FCC, even after adjusting for known covariates including race/ethnicity, special health care need status, family structure, and parental mental health. The odds of receiving FCC increased as parental income and education increased. Also consistent with previous research, children with public insurance had lower odds of receiving FCC than children with private insurance. Uninsured children had the lowest odds of receiving FCC compared to children with private or public insurance. Finally, as hypothesized, there was a graded relationship between the combination of socioeconomic resources and the odds of receiving FCC. The combination of the lowest levels of income, education, and insurance type was associated with lower odds of receiving FCC than any one resource alone.

These findings suggest that socioeconomic resources, beyond health insurance alone, are important factors in accessing quality pediatric health care. The strongest independent socioeconomic predictor of FCC, after adjusting for covariates, was health insurance. Health insurance is a critical mechanism by which Americans access health care, but insurance companies put limitations on which health care providers patients can see, and how much providers get paid. As suggested by Allen et al. (2017), the finding that publicly insured children had lower odds of receiving FCC compared to privately insured children might reflect insurance-based discriminatory practices due to lower reimbursement rates from public insurance providers. In addition, higher copays for ‘out-of-network’ providers may limit a

family's ability to select providers who are a better fit for their schedule, communication style, or health needs.

Higher household incomes may provide more flexibility for families to select providers, and/or travel to providers further away from their work or home. In rural areas, bypassing a local provider to seek care elsewhere may require traveling long distances (Fife et al., 2016). Higher income may also provide more time for families to schedule and attend health care appointments, or to seek a second opinion if their health needs are not being met. Higher education may help parents know what questions to ask providers, understand the information provided to them from physicians, or may give them confidence to ask for clarification or more information when needed. Education may also enable parents to choose providers who are more likely to provide FCC.

Health care providers who deliver FCC may have more control of their time and practice decisions. Salaried providers may have institutional demands in terms of the number of patients they are required to see each day, making it difficult to provide FCC. Providers who deliver care to more uninsured or publicly insured patients at a lower cost may be required to see more patients per day to generate income. These providers may have less flexibility in their schedules to spend adequate time with publicly insured children who have a higher prevalence, complexity, and severity of health problems (Bethell et al., 2011), and less parental education (Aiken, Freed, & Davis, 2004), both of which require more time and attention from providers to identify and communicate health issues and treatment options.

Research question 2: To what extent are Tier 1 primary care workforce shortages associated with receipt of family-centered care?

Another purpose of this study was to explore the influence of primary care workforce shortages on access to FCC. Previous research found significant differences in receipt of FCC by state (Bethell et al., 2011; Allen et al., 2017; Guerrero et al., 2010). Multiple researchers suggested exploring system-level barriers to the implementation of FCC by exploring state-level differences in the delivery or receipt of FCC (Allen et al., 2017; Guerrero et al., 2010). A potential system-level barrier to the delivery of FCC is workforce shortages. Shortages increase wait times and reduce the amount of time physicians spend with each patient (Kirch, Henderson, & Dill, 2012). One aspect of FCC is “how often does this child’s doctors or health care providers spend enough time with this child?” This study hypothesized that as the number of workforce shortage designations decreased, the odds of receiving FCC would increase.

Consistent with previous research, this study found significant differences in the receipt of FCC by state. In general, states in the Northeastern part of the United States had significantly higher percentages of children receiving FCC than the national average, and Southwestern states had a significantly lower percentage of children receiving FCC than the national average (Figure 3). As hypothesized, children in states with low and medium numbers of shortages were more likely to receive FCC than children in states with high numbers of shortages. However, contrary to the hypothesis, the odds of receiving FCC did not increase as shortages

increased. Children in states with a medium number of shortages, not children in states with the lowest number of shortages, had the highest odds of receiving FCC.

These findings are mixed. While there is evidence to suggest that the highest number of shortages decreased the odds of receiving FCC, the odds did not continuously increase as shortages decreased. Children in medium states had the highest odds of receiving FCC compared to states with a high number of shortages. Understanding the extent to which workforce shortages impact the delivery and receipt of FCC requires additional research and more specific measurement of workforce shortages than was available for this study. Measurement of shortages in this study was the state level, and therefore assumed that provider availability was consistent for every child in each state. However, some children may live in areas of a state with no shortages. To be more accurate, additional research should match more localized workforce shortage designations to the home address of each child.

Attempts were made to identify or develop a robust measure of workforce shortages with existing data beyond a count of Tier 1 HPSAs by using HPSA scores that are intended to indicate the severity of shortage. Current scoring criteria used to categorize Tier 1 and Tier 2 workforce shortages accounts for population size and geographic size in relation to the number and distribution of providers to some degree. A measure of the sum of scores for Tier 1 HPSAs was considered, rather than dichotomizing based on the Tier 1 cut off value of 13, but summing the scores does not account for the numerous HPSAs that have a score of 0. Matching street addresses of each child with HPSA scores will allow a comparison between zeros in every state to thirteens, and every number in-between.

Additional consideration can be given to how workforce shortages are currently measured and collected. Existing measures used to determine HPSA scores do not capture important shortage-related factors that may reflect how health professionals and/or patients respond to shortages over time. For example, HPSA scores do not capture the length of time communities experience shortages or the frequency of provider turnover. Communities without a provider for many years may have more unmet needs and demand than communities without a provider for a couple months. To understand how long communities have actually gone without providers, National Health Service Corps (NHSC) providers need to be counted in population-to-provider ratios. They currently do not count in these ratios. Also, NHSC is associated with frequent workforce turnover because providers often leave after they complete their two-year commitment. This frequent turnover may decrease utilization of health services. If vacancies are not filled immediately and services are not available when parents need them, they may turn to other sources to meet their needs. Also, parents may not feel it is worth their time to fully explain their circumstances if they will just have to explain everything to a different provider again after a few visits. Parents in these communities may be skeptical of new providers perceived to only be there to pay off student loans. Discontinuous care and mistrust may interfere with open communication between families and health providers, a key characteristic of FCC.

Current criteria that are used to determine workforce shortage area score also need to be refined to reflect the more complete spectrum of distance to the next nearest provider. Current scoring criteria allows a maximum score of 5 points for

distance compared to 10 points for population size. Scoring for distance maxes out at 50 miles (Health Resources and Services, n.d.b). Large geographic states like Texas or Montana have small towns with clinics located 200 to 300 miles from the next nearest provider. The distance between 50 and 200 is significant when recruiting and retaining providers. Some providers are willing to commute for work, and while fifty miles or below may be commutable, 200 miles is significantly more limiting. Two hundred miles isolates providers and their families, many of whom have young families wanting to live in a community with shopping, resources for children, and/or employment for spouses (Baker, Schmitz, MacKenzie, Morris, & Epperly, 2014). This isolation contributes to frequent provider turnover and longer duration of shortages. Distance also impacts patients' ability to select a provider, other than the one closest to them, who may be a better match for their health and communication needs, or schedule.

Research Question 3: Is receipt of family-centered care associated with positive child well-being?

Another purpose of this study was to explore associations between FCC and child well-being. Previous research found that FCC was associated with various measures of child well-being (e.g., fewer missed days of school, increased access to specialty care, or more satisfaction with care) among specific subgroups of children (e.g., children with special health care needs, or children with asthma). However, there has been no research to date that more globally explores associations between FCC and measures of child well-being across multiple aspects development, among a nationally representative sample of children without special health care needs. This

study explored the association between FCC and indices of physical, psychosocial, and cognitive health among children with and without special health care needs in the United States. It was hypothesized that: (1) multiple indicators of well-being would be higher among children who receive FCC than among those who receive care that is not FCC, and (2) the relationship between FCC and child well-being would be stronger among children from families with fewer socioeconomic resources.

Overall the majority of children 0-17 years in the United States had high scores in physical, psychosocial, and cognitive health, with average index scores ranging between 74.1 out of 100 for physical health of 0-5-year-olds to 84.6 out of 100 for cognitive health of children 6-17 years. As hypothesized, FCC was positively associated with child well-being across every individual and cumulative indicator of well-being among children with and without special health care needs, in every race/ethnicity, in every family structure, with and without adverse childhood experiences, and with and without parents who have excellent or very good mental health. Regression analyses showed that FCC had a small but significant positive influence on physical, psychosocial, and cognitive development of children 0-17 years across all levels of socioeconomic resources. This relationship remained significant after adjusting for covariates.

These findings suggest that family-centered care, beyond basic health care, has a positive impact on the physical, psychosocial, and cognitive well-being of children 0-17 years. FCC had the smallest impact on the cognitive health of children (0.2% for children 0-5 years and 0.7% among children 6-17years). This may be due to additional school or preschool factors (i.e., teacher competency, classroom

environment, peer groups) not measured in this study. Physical, and especially psychosocial variables, may be more directly influenced by families. Families are a child's primary source of support for basic necessities like food, and the context in which children learn healthy or unhealthy habits that are measured in the physical health domain. Also, parents or caregivers have the most frequent interactions with their children. These interactions lay the foundation for social and emotional development.

The *Strengthening Families Framework* explains that building social and emotional competence is the primary goal of early childhood because it underlies all other development domains (Harper Browne, 2014). The framework was used to describe multiple ways pediatricians can promote child well-being in families. FCC can build parental resilience by offering support to parents when they face parenting challenges and/or help them anticipate and understand how to respond well to developmental changes. Health care providers are an important social connection as keepers and distributors of critical health and development information. They are trusted experts where families can turn for support when they practice FCC, which makes them feel respected, heard, and like a valued partner in their child's care. Pediatricians are also gatekeepers to additional social connections. They refer parents and caregivers to specialists to meet their child's, or even their own, health needs. For example, many pediatricians have begun to routinely screen mothers of newborns for postpartum depression and make referrals (Bauer, Childers, & Curtin, 2016; AAP, 2012). Health care providers increase parents' knowledge of parenting and child development when they offer age-specific anticipatory guidance. They also provide

concrete support in times of need. When providers practice FCC, families are engaged in the decision-making process. Families that feel valued feel encouraged to ask questions to obtain the specific information they need. Finally, many pediatricians now routinely screen for social and emotional delays and adverse childhood experiences, and provide parents with information about positive parent-child interactions. While this study did not test specific parent pathways by which FCC influences child well-being, the consistency of the findings suggest that the parent-provider relationship may be an important partnership for promoting multiple aspects of child well-being.

Numerous researchers have highlighted the lack of positive indicators in research on child well-being, and have argued that maximizing a child's potential goes beyond minimizing adverse conditions (Guzman, Lippman, Moore, & O'Hare, 2003; Lippman, Moore, & McIntosh, 2011; Moore, Murphey, & Bandy, 2012). As pediatric healthcare practices shift from solely preventing infectious diseases and treating acute illnesses to promoting the optimal development of children, positive indicators of development are needed to measure the efficacy of pediatricians' positive health and wellness promotion efforts. One positive indicator of child well-being used in this study was the NSCH's measure for flourishing. Flourishing is a measure of social and emotional characteristics that enable children to positively adapt to the many different challenges of life (Kandasamy, Hirai, Chandour, & Kogan, 2018; Harper Browne, 2014). Regression analysis found that FCC has a significant influence on flourishing among children 0-5 years, potentially helping lay the foundation for healthy coping, resilience, and learning. Additional research is

needed to understand the specific pathways between FCC and flourishing or other indicators of positive development.

Research Question 4: Is the association between family-centered care and child well-being stronger for children from families with fewer socioeconomic resources?

The final purpose of this study was to explore the role of family socioeconomic resources in the relationship between family-centered care and child well-being. It was hypothesized that the positive relationship between FCC and child well-being would be stronger for children from families with lower socioeconomic resources. Children in less resourced homes may generally have more need for pediatric services. There is a strong link between poverty and poor child health outcomes (Chaudry & Wimer, 2016). Children from low socioeconomic status (SES) households are more likely to experience health problems requiring medical intervention, including injury, asthma, ear infections, and chronic conditions such as diabetes (Roubinoy, Hagan, Boyce, Alder, & Busch, 2018; Evans & Marcynyszyn, 2004; Evans, 2003). Also, parents living in poverty may, in general, be more in need of parenting support. They likely have the least education about child development and experience the most parental stress (Pereira et al., 2012), which is associated with less warm, and more inconsistent and punitive parenting practices (Callahan, Scaramella, Laird, & Sahr-Preson, 2011; Deater-Deckard, Wang, Chen, & Bell, 2012). They also may have the least amount of time and energy and other resources to invest in stimulating child activities (Chaudry & Wimer, 2016). Parents with limited SES access pediatric services even when they don't access other community

resources due to limited time, money, or stigma (Zero to Three, 2016). The growth of FCC is, in part, a response to this recognition, by expanding the role of pediatric primary care in enhancing and promoting well-being, particularly for children from low SES families, that goes well beyond the traditional boundaries of treating illness and injury.

The early years (0-5) are a period when parents are learning how to be parents, when they are more likely to seek more guidance, and when foundational habits are being formed. It is therefore not surprising that it is in this early age group that the relationship between receipt of FCC and child well-being was strongest for children from low SES households. As hypothesized, the physical health of young children in families with the fewest socioeconomic resources benefitted most from FCC, even after adjusting for covariates. Among children not receiving FCC, there was a 21.4% difference between average physical health scores of lowest SES and highest SES compared to an 8.6% difference among children receiving FCC. This finding indicates that FCC can play a role in reducing socioeconomic disparities in physical health outcomes. The relationship between FCC and young child well-being in both the psychosocial and cognitive domains was stronger for children in families with low or medium socioeconomic resources as compared to those from families with the highest level of socioeconomic resources. However, contrary to the hypothesis, after adjusting for covariates the only interaction that remained significant for psychosocial and cognitive health was between FCC and medium SES households.

Parental mental health was the primary driver of the change in the association, and may reflect differences in families' access to supportive community resources beyond health care. Families in the highest and lowest SES groups may have more access to resources that help parents cope with and overcome family hardships that contribute to poor parental mental health. High SES families have the means to access additional supports as needed. Low SES families are often eligible for means tested programs, or are targeted by programs, designed to offer various forms of support for families. Families in the middle may not have the means to access help themselves, and are often ineligible for public services, making health care a particularly important resource for parental and family support.

These findings may also reflect the reality that families categorized by this study as being in the middle socioeconomic range still had very few resources and needed support in most areas of the United States. This study categorized low SES as children living in households with a parental education level of high school or less, income below 200% the federal poverty line (i.e., \$50,200 per year for a family of four), and no health insurance. High SES households had a parent with a bachelors' degree or above, income above 400% of the federal poverty line (i.e., \$97,000 per year for a family of four), and private insurance. Medium SES households were a combination of anything in between. Families with children have higher costs of living than childless households. For a two-parent, two-child family in Washington D.C., it costs \$10,331 per month (\$123,972 per year) for an adequate standard of living compared to only \$3,550 per month for a single person (Gould, Mokhiber, & Bryant, 2018). The average cost per month varies based on location, but even in one

of the cheapest states, Mississippi, it costs approximately \$5,496 per month (\$65,952 per year) for a family of four (Gould, Mokhiber, & Bryant, 2018). Childcare is often the most expensive cost, exceeding housing and food expenses. In 2017, the cost of center-based childcare infant care exceeded one-year's tuition and fees at an in-state university in 28 states and the District of Columbia (ChildCare Aware, 2018). These costs are a significant burden to all families, especially those in low and medium SES households not receiving additional support. The cost of childcare may place an additional burden on families of young children. Adjusting definitions of socioeconomic resources to reflect variations in the cost of living across states and regions might provide a more nuanced understanding of the role of economic stressors on child well-being and the role of FCC or other services in addressing disparities caused by socioeconomic inequality.

The relationship between poor parental mental health, FCC, and SES on child well-being of children 0-5 years adds to the numerous studies that find a strong and persistent association between child well-being and parental mental health and/or parenting behaviors (Madigan et al., 2018; Coyl, Roggman & Newland, 2002; Stark, & Chazan-Cohen, 2012; Center for the Developing Child at Harvard, 2009). This consistent body of research is the basis for the *Strengthening Families Framework's* approach to improving child well-being by building parental resilience, which is thought to be a mechanism by which FCC improves child well-being. As parental resilience increases, their mental health may also improve. Therefore, parental mental health may mediate the relationship between FCC and child well-being. Additional research is needed to test this pathway.

Contrary to our hypothesis, household SES did not significantly interact with FCC to influence child well-being among children 6-17 years. There are a number of possible explanations for this finding. First, parents of young children may face greater financial burdens due to the need for childcare, either reducing their available income or their ability to work. Second, parents of young children, particularly those with fewer resources and more stressors associated with fewer resources, may also experience greater stress as they adjust to the parenting role and the greater physical demands of parenting young children. They may therefore benefit more from the support provided by FCC. Third, children are more likely to be diagnosed with a special health care need as they age and enter school. Supportive developmental screenings and referrals provided by schools may overlap with family-centered services provided by physicians, making it more difficult to identify the impact of family-centered health care on child outcomes. Finally, this finding may also be related to the static measure of SES in this study. The timing and duration of poverty significantly affect child well-being. The rapidly developing brains of very young children are especially vulnerable to the negative effects of poverty, and these negative effects persist even after families' incomes increase (Chaundry & Wimer, 2016). It may be that some of the children age 6-17 years lived in a context of low socioeconomic resources during their early years, but weren't living in low SES households at the time of the survey. These children may continue to experience the negative effects of living in poverty on their health and well-being, even though they were later categorized as medium or high SES, making it more difficult to identify a difference in the relationship between FCC and child well-being based on SES.

Limitations

It is important to note several limitations of this study. First, the data are cross-sectional, and therefore can't be used to make causal associations. From this dataset it can't be determined whether FCC leads to increased child well-being, or parents of children with fewer health and behavior issues are more likely to perceive or receive FCC. This study accounted for some health and behavior needs by adjusting for special health care needs status of children. However, this measure does not capture children with undiagnosed needs. Prospective longitudinal studies would be needed to fully disentangle these issues. Nonetheless, the associations found in this study highlight the importance of the partnership between parents and health providers in caring for children, and lend support to a growing body of research on the benefits of FCC for children and families.

Second, these data were parents' report of both family-centered care and child well-being. The data may therefore be subject to response bias based on lack of knowledge or recall. Families in different SES groups may rate health and functioning differently based on their knowledge or the social norms they experience. For example, parents may be less likely to be concerned about their child's weight if many of the children their child interacts with are overweight or obese.

Third, the variables used for this study, and the ways in which they were measured, are limited based on the availability of secondary data. Previously described problems with available measurements for workforce shortages, or the lack

of a measurement for undiagnosed health concerns, will need to be addressed in future research.

Finally, this study has methodological limitations. The NSCH switched from collecting data via telephone to the Internet and print in 2016. Because of this change in data collection methods, results from this study can't be compared to previous waves of NSCH data. Also, there may be a nonresponse bias based on data collection methods. Poor and rural populations have more limited access to the Internet and experience more problems (e.g., slow speed, lost signal) than wealthy urban populations (Martin, 2018). However, NSCH survey weights were used in this study to offset nonresponse bias.

Future Research

Additional research is needed to understand the root causes of socioeconomic disparities in receiving family-centered care (FCC). Previous research assessed the receipt of each individual aspect of FCC (*i.e., spend enough time with child, listens carefully to you, shows respect for your family's values and customs, provides the specific information you needed concerning this child, and helps you feel like a partner in this child's care*) among parents from different race/ethnicities (Guerrero et al., 2010; Blesser et al., 2017). Blesser and colleagues (20107) found that parents of Hispanic children were more likely than parents of White to report doctors treated them with respect, but less likely to report that the doctor spent enough time with them. Similar research should be done with parents from different socioeconomic backgrounds to determine which specific aspect(s) of FCC are problematic for

families with low education, income, and/or public or no insurance. This research would inform which aspect(s) of FCC to target to improve for vulnerable families.

Beyond research using existing quantitative data, qualitative research would be useful to determine how parents with different socioeconomic backgrounds define/experience support from their health provider, how they define being valued and respected, how they describe providers making them feel like partners, and how that support influences their parenting beliefs, attitude, and practices. Qualitative research should also explore how parents respond to not receiving family-centered care and what they do to address barriers to receiving quality health care for their child. This information would inform practices to establish, maintain, and regain trust between providers and families.

The perceptions and experiences of health providers should also be explored to better understand enabling factors and barriers they face in delivering family-centered care and health promotion education to parents with different socioeconomic resources, especially messages aimed at teaching parents how to practice healthy habits and facilitate positive social and emotional development. To identify and expand successful FCC practices, research could include providers who consistently deliver family-centered care could examine beliefs, attitudes, and enabling factors for the delivery of FCC. Research should examine what providers and institutions do to address these barriers and the efficacy of their strategies. Future research should also identify institutional policies and practices that promote the delivery of family-centered care to families with limited socioeconomic resources specifically.

More research is needed to determine the extent to which workforce shortages influence the quality of health care delivery. This initial exploration of the influence of workforce shortages on receipt of FCC used existing publicly available measurements for convenience, but future research should refine workforce shortage measurements as previously described by: (1) matching children's street addresses with specific shortage designations; (2) refining the distance criteria used for HPSA scores to reflect a broader spectrum of distance to the next nearest provider; (3) creating HPSA score criteria for the frequency of provider turnover and the amount of time a community goes without a provider; and (4) including National Health Service Corps providers in the population-to-provider ratios used to calculate HPSA scores. Improving the way workforce shortages are measured will improve research on healthcare access and utilization beyond family-centered care.

Additional research is needed to understand the specific pathways between FCC and child well-being. The *Strengthening Families Framework* was used to describe multiple ways that FCC may support parents, but this study did not test specific pathways. Findings from this study indicate that parental mental health may mediate the relationship between FCC and psychosocial and cognitive health of children 0-5 years. This pathway should be further explored. Additional research should also assess if FCC increases parental resilience, social connections, knowledge of parenting and child development, support in times of need, and/or parenting behaviors that improve the social and emotional competence of children that result in improved child outcomes.

The relationship between FCC and child well-being can be further assessed within the NSCH dataset by assessing the association between each individual component of FCC (*i.e., spends enough time with child, listens carefully to you, shows sensitivity to your family's values and customs, provides specific information you needed concerning this child, and helps you feel like a partner*) with each individual and cumulative indicator of child well-being. Additional research should explore which individual and/or combination of the components of FCC are associated with positive indicators of development like flourishing to understand how FCC can be used to promote the well-being of children without special health care needs. Qualitative research should explore why and how parents translate family-centered care into parenting practices to improve child outcomes.

All studies on family-centered care and child well-being should account for the influence of family socioeconomic resources. More accurate measures of socioeconomic resources would accurately reflect the cost of living burdens experienced by each parent that vary within and across states and regions of the United States. Indicators of socioeconomic resources could also be improved by measuring resources over time to better understand how FCC interacts with the duration and timing of children's exposure to poverty.

Policy and Practice Implications

Policies and practices should work to address disparities in the receipt of family-centered pediatric care. This study found significant racial/ethnic and socioeconomic disparities. Hispanic children, and children in families with parental

educational attainment of high school graduation or less, with an annual income of 200% of the federal poverty line or less, or with no health insurance, are most vulnerable to not receiving FCC. Current practices aimed at improving family-centered pediatric should focus on these more vulnerable families. For example, some health organizations have family advisory councils that inform their policies and practices (Children's National Health System, 2019). These councils should include Hispanic parents, and parents with limited socioeconomic resources.

Policies that increase families' ability to select providers that match their communication, health, or scheduling needs may increase the quality of health care children receive. For example, Medicaid could empower families to select providers they trust, or can easily access, by allowing them to choose their child's "passport providers". When families enroll in Medicaid, they are often assigned to a "passport provider" who acts as their gatekeeper to specialty services. The intent of this practice is to keep costs low by addressing needs with the most basic services first. However, it may also reduce the opportunity for families to select providers that work best for them. Insurance policies could incentivize in-network providers to provide family-centered care, and identify ways to increase their in-network provider selection. These would reduce the likelihood of families needing a second opinion, but increase families' ability to access second opinions, additional information, or better scheduling.

Another way Medicaid could increase family-centered care for families with limited resources is to pay for enabling services such as transportation, interpreters, care coordination, and/or emotional support services like doulas. Enabling services

increases access to providers or can help facilitate smoother and more trusting relationships between providers and patients. Recent research found improvements in infant health when their mothers utilize doulas prior to their birth (Kozhimannil et al., 2016). Medicaid in several states (e.g., Minnesota, Oregon, and California) now cover the cost of doulas to support women of color who are at risk for preterm birth (Chen, 2018). For children, enabling services could include paying for mental health screening, referral, and treatment for their parents. Increasingly, providers are incorporating these services into the delivery of pediatric health care delivery (AAP, 2019). The delivery of supportive services to parents through pediatricians will continue to expand if the services are paid for and future research continues to demonstrate improved health outcomes for children.

Medicaid could also improve the delivery of family-centered care to low-income families by increasing payments to providers for services, and paying for services like health promotion counseling that are not typically reimbursed. Future research linking the counseling provided by pediatricians to positive indicators of social and emotional development would support this policy. Improving payment for all services, and paying for counseling services, would enable and motivate providers to spend more time ensuring that they have all the necessary information from parents, that parents' questions are answered, and that the information they provide to parents is understood.

Institutions and independent providers could increase access to family-centered care by allowing and encouraging providers to provide care for all children regardless of payment type, spend enough time with each child, connect families with

additional medical and social services, and improve proactive follow-up. One example of institutional support for FCC is a “Family-Centered Care Provider of the Year” award to physicians who consistently deliver FCC (Children’s National Hospital, 2019). The nomination and award process could be used to highlight FCC success stories from vulnerable families. These stories could be disseminated to pediatricians as a way to incentivize and motivate FCC provision. There are other possible changes in practice that can move providers closer to FCC. For example, instead of waiting for families to return if there is another problem or no improvement, having a nurse or other support personnel call to check on them and provide reassurance may be helpful. This type of proactive communication by the provider or clinic may be especially helpful for vulnerable families who may be less likely to call with follow-up questions or concerns.

Institutions that train the medical workforce can also increase education about family-centered care and communication skills. Public health practitioners should identify ways to increase health literacy and child development education for parents, especially outside of formal education settings, to equip them with a foundation for identifying problems, communicating concerns, and asking the right questions. Medical schools can improve physicians’ communication skills by screening for caring characteristics during the admission process, teaching explicitly about the FCC model, and repeatedly exposing students to the delivery of FCC for families from diverse backgrounds (Parent, Jones, Phillips, Stojan, & House, 2016). In a landmark article on quality health care, Peabody (1984) stated, “One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in

caring for the patient.” Beyond having an interest in humanity, medical schools can increase the skills of providers by incorporating the teaching communication skills in a way that is engaging. To understand how to engage students in learning about patient-centered care, a focus group was conducted with first year medical students at the University of Michigan (UM) Medical School. Over half of the students intended to become surgeons and were unsure if family-centered care even mattered to the practice of surgeons. In response, the UM Medical School invited surgeons to share real life stories about family-centered care at orientation (Parent et al., 2016).

Storytelling, personal coaching, small group discussions, simulation training, case studies, shadowing patients and families, and interactive exercises are used to create a human connection, develop an understanding of the differences between empathetic and sympathetic interactions, build communication skills, and motivate them to provide family-centered care (Parent et al., 2016).

Conclusion

This study extends previous work on the role of FCC in promoting child well-being by using a nationally representative sample of children, measuring well-being across multiple domains, and including those children without special health care needs. This study makes an important contribution to our understanding of FCC by demonstrating the associations between FCC and positive child well-being that are found consistently in other studies of children with more specific health care needs are also seen among healthy and typically developing children, and that these associations are found across all domains of development.

This study contributes important additional evidence to a growing body of research showing that family-centered pediatric care (FCC) improves child well-being, beyond treating physical illness. This study found that FCC is particularly beneficial for young children (0-5 years), and children in households with low to moderate socioeconomic resources, making it a potentially meaningful tool to help reduce health disparities for children from households with more limited socioeconomic resources. Future research should identify specific pathways by which FCC improves child outcomes by supporting parents.

While the majority of children in the United States were reported to receive FCC, there is still work to be done to ensure equitable receipt of quality pediatric care. This study found significant race/ethnicity and socioeconomic disparities. To address disparities in receipt of FCC by socioeconomic resources, additional research is needed to identify specific aspects of FCC that are problematic for children in families with low education, income, and/or uninsured. Future research, and policies and practices aimed at improving the delivery of family-centered care should include and emphasize the experiences of Hispanic families and families with limited education, income, and public or no insurance.

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