

Families of Children with Autism Spectrum Disorder:
The Role of Family-Centered Care in Perceived Family Challenges

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Abstract

Using Andersen's (1968) behavioral model of health services use as a guiding conceptual framework, this study examined how receipt of family-centered care relates to the perceived family challenges for families of children with autism spectrum disorder (ASD). Data from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) were analyzed for 812 parents of children with ASD. Multiple regression analyses provided substantive statistical evidence that a child's race, the adequacy of a family's insurance, and the stability of child's health care needs significantly contribute to predicting his or her receipt of family-centered care. Further results suggest a relationship between receipt of family-centered care and the perception of challenge for these families; families receiving family-centered care perceive fewer challenges and feel less unmet need for child health services. Family-centered professionals are critical in the development of policies and programs geared toward improving the health outcomes of children with ASD and their families.

Keywords: autism, Andersen's behavioral model of health services use, family-centered care, National Survey of Children with Special Health Care Needs

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Families of Children with Autism Spectrum Disorder:
The Role of Family-Centered Care in Perceived Family Challenges

Chapter One: Introduction

Over eleven million children in the United States have special health care needs according to estimates by the National Survey of Children with Special Health Care Needs (NS-CSHCN) 2009-2010. Children with special health care needs are those children who have or are at risk for “chronic, physical, developmental, behavioral, or emotional conditions and who require health and related services of a type and amount beyond that required by children generally” (McPherson et al., 1998, p. 138).

Within the population of children with special health care needs, those with an autism spectrum disorder (ASD) comprise one of the most critical and increasing populations (Gabovitch & Curtin, 2009). ASD is a cluster of lifelong neurodevelopmental disorders composed of Autistic Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger’s Syndrome, Childhood Disintegrative Disorder, and Rett Syndrome. These disorders are marked by significant qualitative limitations in social interactions, verbal and nonverbal communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities (American Psychiatric Association [APA], 2000). The majority of individuals with autism also have one or more co-occurring health conditions, such as Attention Deficit Hyperactivity Disorder [ADHD], a seizure disorder, sensory integration disorder, or a sleep disorder (Barbarese, Katusic, & Voigt, 2006). Consequently, nearly all children with ASD qualify as CSHCN, because they experience at least one type of ongoing condition that results in a more-than-routine need for health care services (McPherson et al., 1998).

Estimates from the 2009-2010 NS-CSHCN indicate that over 800,000 children ages 2–17 have a diagnosis of ASD. Further, a recent prevalence study by the Centers for Disease Control (CDC) found that one in every 88 children has a diagnosis of ASD, including one in every 54 boys; this marks a 23% increase since 2009 and a 78% increase since 2007 (CDC, 2012b). There are several existing theories to account for the increase in prevalence, including changes in diagnostic criteria; increases in awareness of the condition among parents, health care, and education professionals; differences in diagnostic measures and interpretations of diagnostic criteria; valid increases in the population; or combinations of these factors (Fombonne, 2005; Williams, Higgins, & Brayne, 2006; Wing & Potter, 2002). The increases in diagnoses of ASD have particularly important implications for family practitioners, pediatric health care professionals, families, and communities.

Perceived Family Challenges of Families of Children with ASD

Individuals with ASD may share several characteristics, such as possible delayed or disordered language development, impaired reciprocal communication skills, stereotypic behaviors, a tendency toward rigidity and perseverative behavior, and other sensory and behavioral difficulties, all of which can exist on a spectrum from mild to severe (CDC, 2012a). Regardless of level of severity, the nature of ASD is such that it places tremendous demands on families as they strive to meet the needs of their children and to maintain healthy family functioning (Abbeduto et al., 2004; Gray, 2003; Montes & Halterman, 2007).

Having a child with ASD can affect several areas of family functioning. The majority of primary caregivers report that parenting stress has affected family factors, by

lessening time for family activities and decreasing spontaneity or flexibility because, for example, of the need to plan ahead, (Hutton & Caron, 2005). Parents of children with ASD may also experience strained marital and extended family relationships, social isolation, resentment, challenging educational arrangements, and grief related to the restricted opportunities for their children (Glover-Graf, 2011). Further, parents of children with ASD also report job-related stress, with fathers citing career restrictions and mothers reporting limitations on their ability to maintain employment or pursue outside activities (Gray, 2003; Montes & Halterman, 2007). Parents have also reported giving up other aspects of family life, such as family outings and vacations (Hutton & Caron, 2005; Montes & Halterman, 2007).

Research consistently shows that children with ASD have significantly greater health care needs than children without ASD or children with other special health care needs (NS-CSHCN, 2009-2010; Tomanik, Harris, & Hawkins, 2004). As a result, parents of children with ASD tend to experience additional demands when compared to parents of typically developing children.

Family-Centered Care

A diagnosis of ASD affects more than the diagnosed individual; it affects the entire family. To serve children with ASD, research suggests that best practice is to provide family-centered care (Beatson, 2006; Beatson, 2008; Prelock, Beatson, Bitner, Broder, & Ducker, 2003). Family-centered care is an approach to health care characterized by an ongoing collaboration among patients, families, and health care professionals (Coker, Rodriguez, & Flores, 2010). Family-centered care uses a family-systems approach and includes a broad definition of family, meaning that siblings and

non-biologically-related family members may be included in the health care team. Hence, family-centered care is particularly well suited for children with ASD and their families because of the complexity of ASD symptoms and related health care concerns (Beatson, 2006; Prelock et al., 2003) and inclusion of diverse family structures. Chapter 2 discusses the complexities of defining family-centered care.

Unmet Needs for Child Health Services

Although health care professionals agree that family-centered care is important and, in fact, the best practice, health care providers do not consistently and regularly provide such care to families who need it (Petersen, Cohen, & Parsons, 2004). Children with special health care needs are at increased risk for experiencing challenges accessing health care services. Compared to children with other special health care needs, children with ASD are more likely to have an unmet need for specific health care services or family support services; they may receive delayed care, may forego care, may have difficulty receiving referrals or may receive care that is not family-centered (Kogan et al., 2008). According to a recent national study on unmet needs for children with special health care needs, over half of parents (51%) reported a need for subspecialty physician care (e.g., physical, occupational, or speech therapy); of the parents surveyed, 7.3% reported their children did not receive all of the specialty care they needed (Mayer, Skinner, & Slifkin, 2004).

The 2010 national survey conducted by The Arc, Family and Individual Needs for Disability Supports (FINDS), shows that families supporting individuals with ASD were more likely to report negative outcomes, such as physical, financial, and emotional strain than were caregivers supporting individuals with another intellectual or developmental

disability (Anderson, Larson, & Wuorio, 2011). Family caregivers supporting people with ASD were also more likely to receive fewer services and less support than those supporting individuals with an intellectual or developmental disability, resulting in increased unmet family-level needs for those families affected by ASD (Anderson et al., 2011).

Purpose of the Study

Studies have shown that family-centered care and family support services are effective tools that reduce families' perceived challenges around ASD. Moreover, research has confirmed that family-centered care is best practice for children with ASD. However, no studies have examined the intersection of family-centered care, child unmet needs for health care services, and family-level outcomes. It is unclear how child unmet needs for health care services are associated with the relationship between family-centered care and perceived family challenges.

There are associations between receipt of family-centered care for children with special health care needs and particular sample characteristics. Specifically, previous research has found that younger and White children with special health care needs, whose parents had a higher education level and were not in poverty, and who had a usual source of care were more likely to receive family-centered care (Coker et al., 2010; Kuo, Bird, & Tilford, 2011a; Ngui & Flores, 2006). In general, though previous studies have focused on the presence of family-centered care for children needing special health care, neither the receipt nor the outcome of family-centered care specific to children with ASD has been examined at the family level.

Scholars have identified a need to develop studies to address this issue (Gabovitch & Curtin, 2009). This study aims to fill that gap by exploring how family-centered care is related to family-level outcomes for families of children with ASD. Results will contribute to the knowledge base in this area and may be helpful to guide the development of public policies and programs geared to improve the health care outcomes of children with ASD and their families.

This study analyzed data from a sample selected from the 2009-2010 NS-CSHCN database with the purpose of determining relationships between family-centered care, child unmet needs, and perceived family challenges for families of children with ASD. More information about the 2009-2010 NS-CSHCN, in addition to detailed information regarding sample size and methods of analyses used in this study, are provided in Chapter 3.

Research Questions

Research questions for this study were:

Research Question 1: What sample characteristics, such as age of child, poverty status, and stability of child's health care needs, can be used to predict whether families of children with autism receive family-centered care?

Research Question 2: What is the relationship between received family-centered care and perceived family challenges for families of children with autism?

Research Question 3: Do the unmet needs for child health care services mediate the relationship between family-centered care and perceived family challenges for families of children with autism?

Conceptual Framework

Several studies on health services and outcomes for children with special health care needs use variations of Andersen's (1968) behavioral model of health services use (e.g., Drummond, Looman, & Phillips, 2011; Ganz & Tendulkar, 2006; Kuo et al., 2011a), which was initially designed to explain the use of formal personal health services (Andersen, 1995). Over the past four decades, the model has been adapted, revised, and further developed (e.g., Aday & Andersen, 1974; Andersen, 1995; Andersen & Newman, 1973). The model's basic assumption is that an individual's use of health services is a function of the predisposition to use services, the factors that enable or impede such use, and the need for care (Andersen, 1995). See Figure 1 for an illustration of how Andersen's behavioral model of health services as a conceptual framework guides the current study.

Definitions of Terms

Family

Though the definition of *family* is not discussed in most of the literature on family-centered care, a working definition of the term used throughout the remainder of this paper is provided. For the purpose of this study, the following definition of family is adopted from the Institute for Patient- and Family-Centered Care website (2012): "The word 'family' refers to two or more persons who are related in any way—biologically, legally, or emotionally. Patients and families define their families." In family-centered care, individuals receiving care determine the degree of the family's involvement in their health care, provided they are developmentally mature and competent to do so. In the case of infants and young children, the Institute for Patient- and Family- Centered Care

(2012) defines family members as the individual's parents or guardians. Accordingly, the 2009-2010 NS-CSHCN operationally defines family as a child's parent or guardian, as parent respondents are the only family members to participate in the NS-CSHCN (responding on the child's behalf).

Perceived Family Challenges

Of the literature discussing challenges experienced by those families that include a person with an intellectual or developmental disability, much uses the term *family burden* (e.g., Ghandour, Perry, Kogan, & Strickland, 2011; Kogan et al., 2008; Kuhlthau, Hill, Yucel, & Perrin, 2005). Naturally, the focus on a family's burden adds to the stigma that a disability inflicts significant difficulty and strain on families' lives. Though families of children with ASD likely experience some level of struggle, characterizing a family's experience solely as burdensome does not capture a family's joys and celebrations. Therefore, in an attempt to move the field forward, the remainder of this paper uses the term *perceived family challenges*. Though a more comprehensive definition of perceived family challenges is limited by the specific questions asked in the 2009-2010 NS-CSHCN, offering a new term will hopefully facilitate a new conceptualization of the way researchers and other professionals think about the experiences of families with an individual with a disability. For the purposes of this study, the term *perceived family challenges* is defined as parents' perceptions of the impact autism has had on their family, specifically related to employment, time, finances, and unmet needs for family support services.

Family-Centered Care

Considered to be pioneers in the field of family-centered care, Shelton, Jepson, and Johnson (1987) first articulated its core tenets to include: 1) the family as the constant, 2) the family and professional collaboration, 3) the exchange of information between professionals and the family, 4) the diversity of families, 5) the coping and support provided to the family, 6) the peer networking opportunities for the family, 7) the family and service coordination and supports, and 8) the family appreciated as a family. Although much of the literature continues to use the definition of Shelton et al. (1987), the conceptualization of family-centered care has been further developed and refined within the health care community.

One organization that has been working to expand the practice of family-centered care is the Committee on Hospital Care and Institute for Patient- and Family- Centered Care (hereafter referred to as the Committee), a committee within the American Academy of Pediatrics (AAP). The Committee recently published a policy statement articulating the AAP's policy for patient- and family-centered care (2012). Since the AAP is widely recognized by both health care professionals and the general public as a leader in guiding and defining the child health care system (AAP, 2012), this study followed The Committee's outline for family-centered care: 1) to listen to and respect each child and his or her family; 2) to ensure that services can be tailored to the needs, beliefs, and cultural values of each child and family; 3) to share complete, honest, and unbiased information with patients and their families; 4) to provide and ensure formal and informal support (e.g., peer-to-peer support) for the child and family; 5) to collaborate with patients and families at all levels of health care; and 6) to recognize and

build on the strengths of individual children and families. See Appendix A for comprehensive definitions for each of these six key elements of family-centered care.

Chapter Two: Literature Review

Diverse search engines including Psych Info, Academic Search Premier, Web of Science, MedLine (OVID), Scopus, and Google Scholar were used in the literature search. Key search terms included autism, autism spectrum disorder, autistic, ASD, children with special health care needs, CSHCN, family-centered care, family centered care, family impact, unmet needs. Some of these keywords were combined with the “CSHCN” or “ASD” terms in order to limit the articles to those that related to this population only. Articles were searched for the past 10 years. Older articles were generally excluded from the research, except in cases where the article contained original research or information of relevance to the present study. Articles that did not address children with ASD or the topics under study were excluded from the review. Several governmental and other websites were also searched for information on children with ASD and CSHCN, including the Centers for Disease Control website and the Data Resource Center for Child and Adolescent Health of the Oregon Health and Science University. Additional resources on family-centered care included The Arc, a report from the Wingspread Family Support Summit 2011, and the Institute for Patient- and Family-Centered Care.

This section provides a background of research on the elements considered important in the adequate care for children with special health care needs, particularly children with Autism Spectrum Disorder (ASD). The chapter uses Andersen’s behavioral model of health services use as an organizing framework by using key components of health services, by first describing sample characteristics, then discussing the way that families use health services and perceive challenges surrounding ASD.

Sample Characteristics

Andersen's behavioral model of health services use suggests that a number of conditions contribute to the utilization of health services, resulting in some specific outcome (Andersen, 1995). These conditions include a) the individual's or family's predisposition to use services, b) their ability to secure services, and c) their need for such services (Andersen, 1995). Though the unit of analysis for the 2009-2010 NS-CSHCN was children with special health care needs aged 0–17 years, parent participants reported household information that allowed some analysis at the family level. Family as the unit of analysis has been considered appropriate for Andersen's behavioral model of health services use due to changing needs for medical care throughout the family life cycle and because the family as a unit often is involved in the health care decisions of their family member (Andersen, 1995).

Predisposing Characteristics

Some families are more likely to use health services than other families. Receipt of family-centered care can be predicted by characteristics that exist prior to the onset or diagnosis of a health condition, such as ASD. These characteristics, labeled as predisposing characteristics in Andersen's model, include child's age, child's race or ethnicity, and parent education.

Child's age. According to the DSM-IV, ASD symptoms must be observed prior to the child reaching age 3 in order to receive a diagnosis of ASD (APA, 2000). Symptoms of ASD can sometimes be detected in children aged 18 months or younger, though a diagnosis is typically not given until a child is at least 2-years old (CDC, 2012a; Mandell et al., 2009). Because a medical test (such as a blood test), is not available to

diagnose ASD, health care professionals must rely on observational data and parent reports to make a diagnosis (CDC, 2012a).

Child's race or ethnicity. ASD occurs in all racial and ethnic groups (CDC, 2012a); there is no consensus in the literature if the prevalence of ASD is equal among various races or ethnicities (Bhasin & Schendel, 2007; Newschaffer et al., 2007). Some studies have found that White children are more likely than Black or Hispanic children to be identified as having ASD (Autism and Developmental Disabilities Monitoring Network, 2012; Kogan, Strickland, & Newacheck, 2009; Mandell et al., 2009). Researchers suggest this disparity may exist because children of a racial or ethnic minority generally are diagnosed with ASD at older ages than White children (Mandell, Listerud, Levy, & Pinto-Martin, 2002; Mandell et al., 2009). Hispanic children generally are less likely than White children to be diagnosed with ASD (CDC, 2006). Other studies have found that the prevalence of ASD does not vary by race (Yeargin-Allsopp et al., 2003).

Studies have shown that health care providers' diagnostic and treatment decisions are influenced by patients' race or ethnicity and the stereotypes associated with them (Gance-Cleveland, 2005; Liptak, Stuart, & Auinger, 2006a). Minority parents generally report poorer relationships with physicians (Stevens & Shi, 2002). According to a study using data from the 2001 NS-CSHCN, parents of Black and Hispanic children with special health care needs were significantly more likely to be dissatisfied with care and to report problems with ease of service use than parents of White children with special health care needs (Ngui & Flores, 2006). This may be partly due to a lack of training for

physicians and other health care providers in providing culturally appropriate, family-centered care.

Parent education. Children whose parents have received a post-secondary-level of education have traditionally been more likely to have a diagnosis of ASD. Kogan et al. (2008; 2009) found that children whose parents had less than a high school degree were half as likely to be reported as having ASD as those children whose parents had higher levels of education. Other studies have found similar results, suggesting that children whose mothers had more years of education were likely to receive more frequent doctor visits, educational services, and psychosocial services, while children whose mothers had fewer years of education were likely to receive doctor's visits only (Leventhal, Brooks-Gunn, McCormick, & McCarton, 2000).

Enabling Characteristics

Even though families may be predisposed to use health services, some means must be available for them to do so (Aday & Andersen, 1974). Enabling conditions that increase access to health service resources include poverty status, adequacy of health care coverage, and having a usual source of care.

Poverty status. In a study that examined sociodemographic risk factors for ASD, researchers found that higher maternal education combined with residence in neighborhoods with higher median family income significantly correlated with a diagnosis of ASD for children (Bhasin & Schendel, 2007). Previous studies have also demonstrated that children from families who are of middle- to high-socioeconomic status (SES) are more likely to receive a diagnosis of ASD at an earlier age than children from families with low SES (Mandell et al., 2002; Mandell et al., 2009). Findings from a

study that examined the prevalence and characteristics of children with special health care needs suggest that children in low-income families experience disproportionate barriers to accessing health care services and have lower rates of access to care (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004).

Adequacy of health insurance. Research consistently shows that adequate health insurance is a predictor of health care utilization by children with special health care needs. Across studies, research cites lack of health insurance and lower levels of family income as the most common reasons for children with special health care needs to have unmet health care needs (Newacheck, McManus, Fox, Hung, & Halfon, 2000; van Dyck et al., 2004). Moreover, Tippy, Meyer, Aronson, and Wall (2005) found that children with special health care needs who had adequate health insurance were two times more likely to have comprehensive coordinated care compared to children with inadequate health insurance. According to the Health Resources and Services Administration (2007), an estimated 38% of children with special needs lack adequate health insurance to cover the services they need.

Usual source of care. Previous research has considered the usual source of care for children with special health care needs to be an enabling characteristic; having a regular place to go for health care services can facilitate or prohibit the children's receipt of family-centered care (e.g., Ganz & Tendulkar, 2006; Kuo et al., 2011a). Findings from the 2005-2006 NS-CSHCN suggest that most (97.5%) parents of children with special health care needs have reported having one or more usual sources of care (Kuo et al., 2011a). The majority (95.5%) of parents reporting one or more usual sources of care for their children with special health care needs also reported receiving family-centered care.

Need Characteristics

Assuming the presence of predisposing and enabling characteristics, a need for health services must be perceived by the family or the health care system in order for them to use the health services (Andersen, 1995). Need characteristics include a family's perception of a diagnosis or illness and the severity and stability of the family member's health condition. Since this study included only parent participants who reported that their children with special health care needs currently had ASD, need characteristics only included the severity of the disorder and the stability of child's health care needs.

Severity of health condition. The severity of a child's health condition has been found to be associated with receipt of family-centered care. For example, results from the 2001 NS-CSHCN indicated that roughly one-fourth of families (24%) who indicated the symptoms of their children's health conditions were mild reported not receiving family-centered care, whereas almost half of families (46%) whose children's symptoms were more significant and had an impact on daily life reported that they did not receive family-centered care (DRC, 2012).

Stability of child's health care needs. Receipt of family-centered care has also been associated with more stable health care needs. Specifically, families of children with special health care needs who reported receipt of family-centered care also reported more stable child health care needs and lesser severity of difficulties caused by the child's health (Beatson, 2008; Kuo et al., 2011a). Receipt of family-centered care may be particularly important for families of children with ASD whose health care needs are unstable.

Utilization of Health Services

The utilization of health services can be categorized in terms of type, site, purpose, and the time interval involved (Aday & Andersen, 1974). Consistent with previous research (Drummond et al., 2011; Kuo et al., 2011a), this study defined health services use as receipt of family-centered care.

Models of Service Delivery

Previous research in early intervention has identified four distinct models of health care service delivery that acknowledge the role of the family to varying degrees: professionally-centered or system-centered, family-allied, family-focused, and family-centered (Dunst, Trivette, & Hamby, 2007; Shelton & Stepanek, 1994). Though all four include families in health care service delivery, the assumptions of professionals about the importance of families and the inherent strengths of families, in addition to the health care professionals' perceptions of families' capabilities to make health care decisions, represent a vast continuum.

Professionally-centered or system-centered. Delivery models of health care service that operate on the premise that families need the help of professionals or systems in order to “function in a less dysfunctional manner” are said to be professionally-centered or system-centered (Shelton & Stepanek, 1994, p. 7). Professionals plan and implement interventions and the agency's needs or desired benefits drive the service delivery; professionals are seen as the experts and families are perceived as unable to problem-solve independently (Shelton & Stepanek, 1994).

Family-allied. In a family-allied model of health care service delivery, families are given opportunities to participate on their child's care team and may be responsible

for implementing interventions; however, professionals continue to decide when, where, how, and which services are delivered (Shelton & Stepanek, 1994).

Family-focused. Health care service delivery models that are family-focused in nature include greater collaboration between families and professionals than in the previous two models. Families are perceived as consumers of health care services, but are generally viewed as needing professional guidance and support; professionals are more likely to encourage formal resources and services rather than informal resources and existing supports (Shelton & Stepanek, 1994).

Family-centered. In a family-centered health care service delivery model, families' needs and desires dictate practices; the health care service "professionals are seen as the agents and instruments of families" (Dunst, Johnson, Trivette, & Hamby, 1991, p. 118). Efforts focus on developing sustainable supports for families and building active partnerships between families and health care professionals that are mutually beneficial (Shelton & Stepanek, 1994). A family-centered approach is characterized by (a) practices that treat families with dignity and respect; (b) information sharing so families can make informed decisions; (c) family choice regarding their involvement in and provision of services; and (d) parent/professional collaborations and partnerships as the context for family program relations (Dunst et al., 2007). In family-centered care, a professional's responsibility is to provide information and create opportunities for families to have choices and voices. A family-centered approach to health care service delivery represents a radical change from a professionally-centered or system-centered model and even a significant shift from a family-allied or family-focused model. Turnbull and Summers (1987, p.12) eloquently captured the magnitude of this change:

Copernicus came along and made a startling reversal—he put the sun in the center of the universe, rather than the earth...Let's pause to consider what would happen if we had a Copernican revolution in the field of disability. Visualize the concept: the family is the center of the universe, and the service delivery system is one of the many planets revolving around it. Do you see the difference? Do you recognize the revolutionary change in perspective? ...This is not a semantic exercise—such a revolution leads us to a new set of assumptions and a new vista of options for service.

History of Family-Centered Care

The impetus for the development of family-centered care in the health care field emerged from the consumer and family support movements of the 1960s and 70s (Craft-Rosenberg, Kelley, & Schnoll, 2006; Johnson, 2000). In the middle years of the 20th century, hospitals admitted children without their parents and withheld permission for parental visits or limited parent visitation by length of time, perhaps even allowing only a half-an-hour visit per week (Johnson, 2000). Patients and families began to seek more control over their children's care and family advocates voiced concerns about the restricted visiting policies; these family advocates provided leadership for change in pediatrics. Their efforts led to new state health regulations that required hospitals to allow 24-hour family contact in pediatrics (Johnson, 2000).

The leadership of U.S. Surgeon General Koop in the late 1980s also served as an important catalyst for the shift towards family-centered care (Johnson, 2000). Surgeon General C. Everett Koop's report in 1987 brought family-centered care to a prominent position in thinking about how families should be involved in the care and treatment of

their child with special health care needs; that same year, Shelton et al. (1987) articulated the core elements of family-centered care (Dunst et al., 2007).

Building on the work begun in the previous decade, the Institute for Family-Centered Care (now the Institute for Patient- and Family- Centered Care) was founded in 1992. Its purpose was to nurture the development of partnerships among patients, families, and health care professionals and to provide leadership for advancing the practice of family-centered care (Johnson, 2000). Also in 1992, Family Voices, a national grassroots organization of families and friends speaking on behalf of children with special health care needs, was founded . Today, the Institute for Patient- and Family-Centered Care and Family Voices remain active in advocating for family-centered care, with the aim to achieve this type of care for all children with special health care needs, by providing families resources to make informed decisions and build partnerships with health care professionals (Family Voices, 2012; Institute for Patient- and Family-Centered Care, 2012).

Since 1989, the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA), Department of Health and Human Services, has declared a national agenda for developing an optimal system of care for children with special health care needs; family-centered care is a core aspect of this system of care (U.S. Department of Human Services HSRA, 2001). Starting in the 1990s, the MCHB supported medical home collaborations, leading to family-to-family health information centers in every state. By 2003, the American Academy of Pediatrics had incorporated family-centered care into multiple policy statements and affirmed family-centered care as the standard of health care for all children (AAP, 2003).

A family-centered approach has become practice-of-choice not only in the field of health care, but also is advocated across a wide range of professions, including therapy services and family support programs, early intervention, early childhood education, special education, and general education (Dunst et al., 2007; Murray & Mandell, 2006; Stormshak, Dishion, Light, & Yasui, 2005). Family-centered care is now recognized as best practice in working with children and their families (e.g., AAP, 2003; Dunst et al., 2007).

Complexity of Defining Family-Centered Care

Family-Centered Care has long been an ambiguous term. In an effort to clarify the definition, Allen and Petr (1998) reviewed definitions of *family centered* across the disciplines of social work, health, and education. Based on a content analysis of 28 definitions in more than 120 peer-reviewed articles, Allen and Petr (1998) found that all definitions emphasized family as being the unit of attention, with approximately one third of the definitions including elements of family choice, family-professional relationship, family need, or individualized services and approximately one quarter of the definitions included a focus on family strengths. Though all definitions described the entire family as the unit of attention, the level to which family-centered elements were included or emphasized was not consistent. Ambiguity continues to remain regarding what specific provider and patient actions constitute family-centered care (as evidenced by articles such as Craft-Rosenberg et al., 2006; Jolley & Shields, 2009; King, Teplicky, King, & Rosenbaum, 2004). The lack of consensus in defining family-centeredness contributes to the inconsistency in the manners and degrees to which health care professionals adopt a family-centered approach to service delivery (Epley, Summers, & Turnbull, 2010).

In a meta-analysis of 47 studies on family-centered help-giving practices, Dunst et al. (2007) found multiple terms used synonymously with family-centered care, including *family-centered practices*, *family-centered services*, and *family-centered help giving*. A search for the origin of family-centered care found several other terms in use. According to Dunst and colleagues (2007), some interchangeable terms historically used in the health care literature include *parental participation*, *partnership in care*, *shared care*, and *partnership with parents*. A more recent study found that multiple terms for family-centered care also exist outside of the health care field, for example, the mental health field uses *family driven*, and in social work, *relationship-based* (Goldfarb et al., 2010).

The confusion about the meanings, components, and dimensions of terms in health care service delivery is not unique to family-centered care. In a paper from the Collaborative Care Research Network's Research Development Conference supported by the Agency for Healthcare Research and Quality (AHRQ), Peek (2011) reported that there are a number of terms used in health care that are more or less synonymous with *collaborative care*, such as *integrated care*, *shared care*, *coordinated care*, *primary care behavioral health*, and *integrated primary care*. Researchers in the field of collaborative care agreed that a shared vocabulary must be consistently used in order for the field to move forward. Subsequently, steps were taken to construct a universal lexicon of terms. Until similar movements happen in the area of family-centered care, confusion will remain among practitioners and patients receiving care.

There is consensus in the literature that the term *patient-centered care* represents an approach to health care service delivery that is different from family-centered care (Kuo et al., 2012). When providing services to families with children, family-centered

care is the term of choice, as families are most involved with their children; after the child becomes an adult, it is more likely that the services will shift to *patient-centered* and the individual's needs and desires will be prioritized over those of the family (Shields, Pratt, & Hunter, 2006).

Regardless of the name, all of these concepts share the same core principles: that professionals intentionally partner with families, seek family input for shared decision-making, view the family as the primary expert on the particular child, and respond to family concerns in a strengths-based manner that incorporates the unique needs of the family (AAP, 2003; Goldfarb et al., 2010).

Benefits of Family-Centered Care

Despite claims that there is no real evidence that family-centered care works or that it makes a difference to outcomes for children and families (Dunst et al., 2007; Shields, Pratt, Davis, & Hunter, 2007), the majority of literature confirms its efficacy and its many benefits to children, families, and health care providers (e.g., Beatson, 2008; Denboba, McPherson, Kenney, Strickland, & Newacheck, 2006). Research on health care service delivery to CSHCN indicates that family-centered practices may enhance a child's health and developmental outcomes (AAP, 2003; Beatson, 2008). In particular, this type of care is associated with psychological adaptation, behavioral functioning, and improved health-related quality of life, even when the severity of the condition is taken into account (Moore, Mah, & Trute, 2009). Family-centered care has also been associated with decreased hospitalizations (Beatson, 2008) and fewer emergency room visits for children with special health care needs (Kuo et al., 2011a).

Researchers have identified benefits of family-centered care for other members of the family system as well. In particular, it has been associated with enhanced parent psychosocial adjustment (Beatson, 2008), decreased parenting stress (Mitchell & Hauser-Cram, 2008), increased family involvement (Beatson, 2008), and adjustment to the child's health condition (Meleski, 2002). Family-centered practices have also been linked to parents' overall satisfaction with health care for their children with special health care needs (AAP, 2003; Beatson, 2008; Denboba et al., 2006; King et al., 2004; Ngui & Flores, 2006). Moreover, collaborative problem solving between health care providers and patients has been shown to increase parent confidence and personal control and empowerment, resulting in improved child behavior and improved quality of parent-child interactions (Regan, Curtin, & Vorderer, 2006).

Family-centered care also has been found to bestow benefits to pediatricians, including stronger alliances with patients (AAP, 2003), improved clinical decision-making (AAP, 2003), better follow-through on the part of patients (Schulz, Buchanan, & Ochoa, 2004), greater understanding of families' capacities, and improved communication with patients and their families (Kuhlthau et al., 2011).

Children with Special Health Care Needs and Family-Centered Care

The traditional professionally-centered or service-centered health care service delivery model in which the health care provider is the *expert* and the individual's role is to follow the health care professional's prescribed orders may be effective in cases of an acute illness, when an individual requires immediate treatment, or when a "cure" is likely (Beatson, 2006). However, for chronic illnesses and disorders that have no cure and require management throughout a lifetime, a family-centered approach is the

standard of care, as it has more to offer and encourages the individual and their family to be active members of the health care team (Renty & Roeyers, 2006).

Given that ASD is a neurodevelopmental disorder, it is often categorized under a broader term, Intellectual and Developmental Disabilities (IDD). Research and advocacy work done in the IDD field may also be relevant for families of children with ASD, particularly regarding service delivery. At the Wingspread Family Support Summit in 2011, a group of national leaders met to create a national agenda for supporting families with a member with an IDD. Participants were asked to describe a world that supports families with a family member with a disability. Leaders agreed that in such a world, families would: (a) have a positive family identity that is free from stigma; (b) have opportunities to explore and nurture a vision for their family member across the lifespan; (c) have access to support for the entire family; and (d) be confident in their ability to advocate for and achieve the dreams they have for their family (Wingspread Family Support Summit, 2011). Collectively, these elements describe a world that supports families through family-centered care. Participants also came to consensus as to what comprises “supporting the family.” Their agreed-upon definition is as follows:

The overall goal of supporting families, with all of their complexity and diversity, is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love, and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members (Wingspread Family Support Summit, 2011, p. 12).

Participants in the Wingspread Family Support Summit (2011) concluded that, when supporting families with a family member with IDD, best practice includes providing information and connecting families with other families, both of which are inherent in the conceptualization of family-centered care.

Families who have a child with special health care needs are likely to be involved in their child's life throughout his or her lifespan (Horst, Werner, & Werner, 2000) and provide most of the care the child receives. Nationally, an estimated 56% of all people with IDD receiving support live in the home of a family member (Larson, Ryan, Salmi, Smith, & Wuorio, 2012). Several states report even higher proportions of service recipients with IDD living in family homes, such as Arizona (85.5%), Idaho (74.6%), and South Carolina (71.7%) (Larson et al., 2012). Families may hire direct support professionals to help in the care of their child, though the turnover rate for the direct support workforce is high, averaging an annual turnover of 52% (Hewitt & Larson, 2007). Simply stated, there are not enough properly trained direct-support professionals to meet the growing need of community-based supports.

Previous research has examined the extent to which parents of children with special health care needs report receiving family-centered care. One study found that nearly 50% of parents reported experiencing challenges in receiving information about how to connect with other parents or opportunities for the entire family to receive information (Bellin, Osteen, Heffernan, Levy, & Snyder-Vogel, 2011). Moreover, findings from the 2005-2006 NS-CSHCN concluded that roughly one third of families with children with special health care needs did not feel they were partners in the care of

their child, particularly families with incomes below the poverty level and families without health insurance (AAP, 2012).

Families receive a disproportionately small share of government-provided financial support for informal caregiving services (Parish, Pomeranz-Essley, Braddock, & Taylor, 2003). Further, public dollars for family support have been overshadowed by spending for supported employment and supported living (Turnbull et al., 2007). When policy includes families with a member with a disability, it is most often focused on the well-being of the member with a disability, rather than the well-being of the family as a whole. This is particularly true when the family member with a disability is a child (Turnbull et al., 2007). Because family members are integral partners in the health care of children with disabilities (Horst et al., 2000, Murphy, Christian, Caplin, & Young, 2007), developing supports and service plans in collaboration with families and in support of families becomes critical in achieving desired long-term outcomes.

Autism Spectrum Disorder and Family-Centered Care

Research shows that when compared with typically developing children, children with ASD average significantly more yearly outpatient visits (41.5 vs. 3.3), physician visits (8.0 vs. 2.2), and number of prescribed medications (21.8 vs. 2.1) (Liptak et al., 2006a). Further, the current health care system for this population has been described as fragmented and families report difficulties in obtaining the necessary services and supports for their children (Roberts, Behl, & Akers, 2004). While there are some commonalities among children with ASD, no two children with ASD have the same symptoms or health care needs; thus, even with well-designed and individualized interventions implemented by trained clinicians and devoted parents, some children with

ASD may make only minimal progress and may continue to need significant supports throughout their lifetimes (Gabovitch & Curtin, 2009). Given that ASD is a complex disorder that requires multiple exchanges with systems of health care, research suggests that family-centered care may not only be particularly well-suited to the needs of families of children with ASD, but is also considered best practice (Beatson, 2006; Gabovitch & Curtin, 2009; Prelock et al., 2003). Although previous research has examined the receipt of family-centered care for families of children with special health care needs, there has been limited research specific to family-centered care for families of children with ASD (Gabovitch & Curtin, 2009).

According to findings from a national survey of family caregivers, more than half of family caregivers supporting a family member with ASD rated receiving help navigating services (53%) or receiving information about benefits and counseling (54%) and therapeutic services (54%) as important (Anderson et al., 2011). However, among family caregivers supporting someone with an intellectual or developmental disability, family caregivers supporting a person with ASD were the least likely to agree that they knew how to access this information and assistance when needed (Anderson et al., 2011).

Perceived Challenges of Families of Individuals with Special Health Care Needs

Over time, an individual's utilization of health care services is apt to influence his or her satisfaction with the system and other related outcomes (Aday & Andersen, 1974). Consistent with previous research (Kuo et al., 2011a), perceived family challenges was considered an outcome variable for this study.

In 2010, The Arc conducted the Family and Individual Needs for Disability Supports (FINDS) survey, a national survey disseminated to nearly 5,000 caregivers of people with intellectual disabilities, developmental disabilities, and ASD through a number of national IDD-related organizations and state and local chapters of The Arc (The Arc, 2011). Families from all 50 states and Washington D.C. completed the survey; the majority of respondents (95%) were family members, roughly three-fourths of whom were living with their family member with IDD.

Though not specific to *children* with IDD, findings indicated that families were taking on tremendous caregiving responsibilities for their family members with IDD and were experiencing significant economic and personal stress (The Arc, 2011). In this same study, the majority of families reported that they provided personal care for their family member with IDD, such as bathing and feeding (61%), administering medications (69%), providing direct financial support (72%), managing finances (78%), arranging or monitoring outside services (76%), making social arrangements (76%), cooking, cleaning and doing laundry (80%), arranging or providing transportation (84%) and providing emotional reassurance (86%). Consistent with previous research (e.g., Emerson, 2007), 58% of caregivers reported spending more than 40 hours per week providing support for their family member with IDD, including 40% spending more than 80 hours a week; nearly half (45%) of family caregivers of individuals with ASD reported providing more than 80 hours of support per week (Anderson et al., 2011; The Arc, 2011). Nearly half (46%) of caregivers reported that they had more caregiving responsibilities than they could handle, citing physical fatigue (88%), emotional stress (81%) and emotional upset or guilt (81%) some or most of the time. The majority of families (82%) reported

problems balancing other family responsibilities (e.g., marriage, other children, housework), and 81% of family care providers reported that they did not have time to attend to their personal needs.

In addition to reporting the challenge of limitation of time and increased personal stresses related to caregiving for their family member with IDD, families also reported experiencing financial strains. Roughly 20% of families reported that someone in the family had to quit their job to stay home and support the needs of their family member (The Arc, 2011); twenty-one percent of families reported spending \$1,000 or more per month for services and supports for their loved ones. For most families (63%), the money to support their family member with IDD came from the caregiver's personal income or savings or other family sources (The Arc, 2011). These circumstances imposed an enormous financial challenge for families; 80% of families reported that they did not have enough money to pay for the support or care their family member needs and 82% of families reported that their overall economic security was challenged (The Arc, 2011).

In a study that examined the association of family-centered care with health care service delivery outcomes for children with special health care needs, receipt of family-centered care was associated with improved health service access, reduced odds of parents spending more than one hour each week coordinating care, and resulted in reduced out-of-pocket costs for families (Kuo et al., 2011a). This type of care has also been associated with fewer perceived family challenges; families reporting family-centered care have described fewer unmet health care service needs and fewer financial challenges, including fewer hours devoted to care coordination and direct care, lower out-

of-pocket costs, and fewer instances of work stoppages to care for the child (Kuo et al., 2011a; Kuo, Frick, & Minkovitz, 2011b).

Perceived Family Challenges of Families of Children with Autism Spectrum Disorder

Research consistently shows that children with ASD have health care needs that are significantly greater than those children without special health care needs (e.g., Kogan et al., 2008; Liptak et al., 2006b). As a result, families are often faced with financial and employment challenges, which, in addition to unmet needs for family support services, can contribute to increased perceived family challenges.

Family support services. Research has consistently found that children with ASD are more likely to have unmet needs for family support services than children with other emotional, developmental, or behavioral conditions (e.g., Kogan et al., 2008). Family support includes services such as respite care, genetic counseling, and mental health care counseling. The stresses of caring for a CSHCN may be positively related to mental health care needs for parents and other family members. Ganz and Tendulkar (2006) found that if the child's health condition was more severe, if the child had an emotional, developmental, or behavioral condition, or if the child had unmet mental health care needs, other family members were likely to have unmet needs for family support services.

Finances. Using the 2005-2006 NS-CSHCN data set, Kogan et al. (2008) found that parents of children with ASD were more likely to report having financial problems, developing a need for additional income for their child's medical care, and paying more than \$1000 in the previous year for the child's care. Liptak et al. (2006b) conducted a

nationally representative study using three national surveys, and found that families of children with ASD spent significantly more than children with an intellectual or developmental disability or depression on total health care (\$6132 vs. \$860), total outpatient care (\$3992 vs. \$355), physician visits (\$869 vs. \$200), and prescription medications (\$971 vs. \$77). Further, children with ASD often have comorbid disorders, which require a broader range of services and can create additional financial difficulties, as well as increased stress for families (Barbaresi et al., 2006).

Employment. In a national survey comparing the experiences of family caregivers supporting a family member with ASD to those supporting a family member with IDD, caregivers supporting a family member with ASD were more likely to report that someone in the family had to quit their job to provide care for their family member (Anderson et al., 2011). Other research on families with a child with ASD has also reported reduction or discontinuation of work positions of parent because of the seriousness of their child's symptoms (Kogan et al., 2008).

Unmet Health Service Needs for Children with Special Health Care Needs

Receipt of family-centered care has been associated with positive outcomes, including reduced unmet health service needs. Previous research has indicated that families that never or sometimes felt like partners in the health-care process were at a significant increased risk for having children with unmet health needs compared to families that usually or always felt like partners in health care (Denboba et al., 2006).

According to Erickson-Warfield and Gulley (2006), children with chronic health conditions need access to high quality medical care in order to nurture their healthy development and well-being. Yet, children with special health care needs are at increased

risk for having difficulty accessing health care services. Using the 2001 NS-CSHCN, van Dyck et al. (2004) examined the needs and service use by children with special health care needs and their families. They found that 17.7% had an unmet need for one or more of 14 primary and specialty care services. Using the same dataset, Mayer et al. (2004) found that 3.2% of children who needed routine care did not receive it, while 7.2% of those who needed care from a specialist did not receive it.

Summary

There is scarce literature on Andersen's (1995) predisposing, enabling, and need characteristics, their association with receipt of family-centered care, and resulting perceived family challenges for families of children with ASD. Across the literature, researchers agree that families of a child with ASD experience greater challenges than do families of children with other special health care needs. Most studies on family-centered care focus on children with special health care needs in general and have consistently found positive associations between receiving family-centered care, reducing unmet health care needs for the CSHCN, and lessening perceived family challenges. The majority of studies on this area are secondary data analyses of the 2001 and 2005-2006 NS-CSHCN datasets. Only two studies used Andersen's behavioral model of health services use, naming family-centered care as the focus of study (Drummond et al., 2011; Kuo et al., 2011a). More research is needed to gain knowledge on family outcomes associated with family-centered care for children with ASD.

Guided by Andersen's behavioral model of health services use (1995), this study examined the relationship between receipt of family-centered care for children with ASD

and perceived family challenges, accounting for child unmet health care needs and other individual variables.

Chapter Three: Research Design and Approach

Research Questions and Hypotheses

Research Question 1: What sample characteristics, such as age of child, poverty status, and stability of child's health care needs, can be used to predict whether families of children with autism receive family-centered care?

H1: Among families of children with autism, there is a direct relationship between specific sample characteristics and the receipt of family-centered care.

Research Question 2: What is the relationship between received family-centered care and perceived family challenges for families of children with autism?

H2: Among families of children with autism, receipt of family-centered care is inversely associated with perceived family challenges, controlling for sample characteristics.

Research Question 3: Do the unmet needs for child health care services mediate the relationship between family-centered care and perceived family challenges for families of children with autism?

H3: Among families of children with autism, the relationship between receipt of family-centered care and perceived family challenges is mediated by unmet needs for child health services.

2009-2010 NS-CSHCN Data Set

This study was a secondary data analysis of the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). The NS-CSHCN is a national telephone survey conducted for a third time during 2009-2010; previous administrations of the survey took place in 2000-2001 and 2005-2006. The 2009-2010 NS-CSHCN

collected information through household telephone interviews with independent random samples of parents of CSHCN who were 0–17 years of age in all 50 states and the District of Columbia, between July 2009 and March 2011 (Data Resource Center for Child and Adolescent Health [DRC], 2012). The purpose of the 2009-2010 NS-CHSCN was twofold: 1) to assess the prevalence of children with special health care needs, and 2) to obtain information about children’s demographics, health conditions, functionality, health insurance coverage, program participation, health care needs, access to care, care coordination, family-centered care, and impact of special health care needs on the family (DRC, 2012). Participants were asked if their child had one or more of 20 specified health conditions, ranging from autism to blood problems to Down Syndrome to migraine headaches.

The 2009-2010 NS-CSHCN was sponsored by the Maternal and Child Health Bureau of the Health Resources and Services Administration and implemented by the CDC’s National Center for Health Statistics, and State and Local Area Integrated Telephone Survey (SLAITS) program (DRC, 2012). SLAITS is an approach developed by the National Center for Health Statistics to quickly and consistently collect information on a variety of health topics at the state and local levels.

Questionnaire Description

The 2009-2010 NS-CSHCN questionnaire was administered in five steps. During the first step of the questionnaire, an interviewer randomly called a household and asked if there were children in the house under the age of 18 and, if so, asked if the parent or caretaker was willing to participate in the survey. Households contacted by cell phone were considered eligible only if they did not have a landline telephone or the respondents

said they were unlikely to be reached through the landline if they had one. After gaining consent to be interviewed, the interviewer then moved on to the second step of the questionnaire and asked the parent or guardian about the age and gender for all the children in the household.

In the third step, all children in the household were screened for special health care needs. The interviewer asked the responding parent questions that addressed the following five areas: (a) use of prescription medications; (b) use of medical, mental health, and educational services; (c) limitation in abilities; (d) need for or receipt of physical, occupational, or speech therapies; and (e) emotional, developmental, or behavioral problem resulting in the need for treatment or counseling. Each question had four follow-up questions: (a) Was the need, use, or limitation due to a medical, behavioral, or health condition? (b) Had the condition lasted or was it expected to last, 12 months or longer? (c) Had the need, use, or limitation lasted or was it expected to last, 12 months or longer? (d) Was the child's need or use more than for most children of the same age? The child was regarded as having a special health care need if the parent or caregiver answered yes to any of the screening questions and the four follow-up questions. If no children in the household were found to have special health care needs, the interviewer moved on to the final step, asking questions related to household demographics, which were needed to create sampling weights. If there was more than one child with special health care needs in the house according to the screening, then one child was randomly selected to be the focus of the in-depth interview, which was the final step in the interview process.

The interview consisted of questions related to the child's health and functional status, access to care and unmet needs, care coordination, family-centered care, shared decision-making, transition to adulthood, developmental screening, health insurance, adequacy of health care coverage, impact of the family, and ADHD-specific medications and treatments. Participants were asked to consider the health care services their children with special health care needs received in the previous 12 months. Demographic information such as family structure, parent education, and geographic location were collected during the in-depth interview. For further description of the 2009-2010 NS-CSHCN data set, see Appendix B.

Sample

The sample for this study was parents of children with an autism spectrum disorder. Since autism spectrum disorders are typically not diagnosed before age 2, this sample includes children ages 2–17. To be included in the sample, parents needed to answer affirmatively to the survey question “Does (Sampled Child, [S.C.]) *currently* have autism or an autism spectrum disorder?” A query for families of children with autism or an autism spectrum disorder and no other health conditions yielded 132 families. Although this focused sample would allow for results specific to autism spectrum disorder, the small sample size would not have sufficient power to find a small effect size or statistically significant results given the number of variables included in the model (Cohen, 1992).

Therefore, a decision was made to include families with children with an autism spectrum disorder plus other special health care needs. This is consistent with findings from other studies that have shown that children with autism typically have other co-

occurring disabilities and multiple diagnoses (Barbaresi et al., 2006) In this dataset, 93.2% of children with ASD had at least one other condition from the list of 20 included in the 2009-2010 NS-CSHCN. See Table 1 for frequencies of other health conditions in children diagnosed with ASD. Using a sample of children with ASD and other health conditions that require similar levels of health care services yielded the most comprehensive and conclusive results specific to health care access for families of children with ASD. Therefore, the sample for this study included children with ASD and any of the following co-occurring neurologic health conditions: intellectual disability, ADD or ADHD, and developmental delay (n = 812). See Table 2 for frequencies of neurologic conditions combined with ASD. Characteristics of this sample are consistent with previous research on health care needs among CSHCN with neurologic disorders (Bitsko et al., 2009).

Nearly half (n = 392) of parent respondents reported their child was age 6–11. About a third of respondents (n = 246) reported their child was age 12–17, and less than a quarter (n = 174) reported their child with ASD was between the ages of 2–5. Consistent with current prevalence rates of ASD (CDC, 2012b), this sample included four times more male children (n = 652) than female children (n = 159). The majority of parent respondents reported their child's race and ethnicity as White, non-Hispanic (n = 562), less than a quarter reported their child's race or ethnicity as Hispanic (n = 112), and fewer than 10% reported their child's race and ethnicity as Black, non-Hispanic (n = 76) or other non-Hispanic (n = 62). Most of the parents in the sample reported that a parent in the household had more than a high school education (n = 693). Few parents reported that the highest education of a parent in the household was high school (n = 91) or less than

high school (n = 28). Over a third of parent respondents (n = 276) reported that their household income was 400% of the Federal Poverty Level (FPL) or greater, and nearly a third of respondents (n = 263) reported their household income as 200%–399% or greater. Approximately one fifth of respondents (n = 160) reported their household income as 100%–199% of the FPL, while just over 10% (n = 113) reported their household income as 0%–99% of the FPL. See Table 3 for further demographic characteristics of the sample.

Measures

Independent Variables

Guided by Andersen's (1995) model, this study included characteristics that have been shown to influence a) predisposing characteristics: child's age, child's race or ethnicity, and parent education; b) enabling characteristics: poverty status, adequacy of health insurance coverage, and usual source of care; and c) need characteristics: severity of ASD and stability of child's health care needs. See Table 3 for characteristics of this sample.

Predisposing characteristics.

Child's age. Child's age was coded in three categories (DRC, 2012): (1) 0–5 years, (2) 6–11 years, and (3) 12–17 years.

Child's race and ethnicity. Race and ethnicity included categories of Hispanic; White, non-Hispanic; Black, non-Hispanic; and other, non-Hispanic. The other, non-Hispanic category included Multiracial, Asian, Hawaiian, Pacific Islander, Native American, and Native Alaskan children. In this study, child's race or ethnicity will be

referred to as child's race. This variable was recoded as a dummy variable: (0) *non-White* and (1) *White, non-Hispanic*.

Parent education. Parent education was categorized according to the highest education level attained by any parent in the household: (1) *less than high school*, (2) *high school graduate*, and (3) *more than high school*.

Enabling characteristics.

Poverty status. Poverty status was a derived variable measuring how many children with special health care needs lived in households at specified levels of income according to the U.S. Department of Health and Human Services Federal Poverty Level Guidelines for 2010 (FPL). FPL is based on the number of people living in the household and the total combined household income for the past year. Poverty status categories were: (1) *0%–99% FPL*, (2) *100%–199% FPL*, (3) *200%–399% FPL*, and (4) *400% FPL or greater*.

Adequacy of health care coverage. Adequacy of health care coverage was measured by a composite variable indicating the extent to which health insurance benefits meet a child's needs, the reasonability of non-covered insurance charges, and the extent to which the child's insurance allows him or her to see needed providers. The measure assesses the overall adequacy of a child's private or public insurance to pay for needed services: (0) *current insurance is not adequate*, (1) *current insurance is adequate*. If participants responded "no" to any of the questions, they were coded as not having adequate insurance; participants who responded "yes" to all questions were coded as having adequate insurance. There were twenty-five respondents who indicated their child

had no insurance coverage at the time of the interview and were coded as (0) *current insurance is not adequate*.

Usual source of care. Two questions in the survey measured source of care including “Is there a place that [S.C.] USUALLY goes when [he/she] is sick or you need advice about [his or her] health?”; “Is there a place that [S.C.] USUALLY goes when [he or she] needs routine preventive care, such as a physical examination or well-child check-up?” From these, a composite variable was created to measure usual source of care based on the extent to which, overall, a child has a usual source (or usual sources) of care. If participants responded “no” to either question, they were coded as not having a usual source of care; participants who responded “yes” to both questions were coded as having a usual source of care. Usual source of care was a dichotomous variable using the following anchors: (0) *child does not have usual sources for sick and well care*, and (1) *child does have usual sources for sick and well care* (Ganz & Tendulkar, 2006; Kuo et al., 2011a).

Need characteristics.

Severity of ASD. Severity measured the intensity of the child’s ASD symptoms. Participants were asked, “Would you describe his or her autism or ASD as mild, moderate, or severe?” Responses included three categories: (1) *mild*, (2) *moderate*, and (3) *severe*. Previous research studies have used this continuous variable to measure special health care needs of children (Ganz & Tendulkar, 2006; Mayer et al., 2004).

Stability of child’s health care needs. Stability of child’s health care needs was the level of change in health care needs for the focal child. Respondents were asked, “Which of the following statements best describes [S.C.]’s health care needs?” Response

categories were: (1) *child's health care needs change all the time*, (2) *child's health care needs change only once in a while*, and (3) *child's health care needs are usually stable*.

Previous research also used this measure (Ganz & Tendulkar, 2006; Mayer et al., 2004).

Family-Centered Care

Family-Centered Care (FCC) was treated as a dependent variable for Research Question 1, and as an independent variable for Research Questions 2 and 3. A standard set of five items were used to indicate “Family-Centered Care” (Coker et al., 2010; Drummond et al., 2011; Ngui & Flores, 2006). Questions asked if health care providers: (a) spent enough time with the child; (b) listened carefully to the parents; (c) made parents feel like a partner in their child's care; (d) were sensitive to the family's customs and values; and (e) provided the specific information that the parent needed. These five FCC items were derived in part from the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey and in part by working within the American Academy of Pediatric's medical home framework (LeDonne, 2012, personal communication), and have been found to be highly reliable ($\alpha = 0.84$) (Drummond et al., 2011). Categories were: (1) *never*, (2) *sometimes*, (3) *usually*, and (4) *always*. Consistent with previous research (e.g., Kuo et al., 2012), participants were said to have received FCC if they responded “usually” or “always” on all five questions. Responses of “don't know” or “refused” on any of the five items were set to missing for this measure. See Appendix C for specific survey questions used to assess receipt of FCC. See Table 4 for FCC frequencies.

Dependent Variable

Perceived family challenges (PFC) was the dependent variable for Research Questions 2 and 3. PFC included the following two dimensions: a) reported unmet needs for family support services and b) family impact. Scores across unmet needs for family support services and family impact dimensions were aggregated to create one variable, PFC. Following is a description of each of the components of PFC.

Unmet needs for family support services. Unmet needs for family support services was defined as needing and not receiving any of the following three identified family support services in the prior 12 months: (a) respite care; (b) genetic counseling; and (c) mental health care or counseling related to the specified child's medical, behavioral, or other health condition. Response categories included *yes* (1) and *no* (0). Responses were totaled across the three family support services, resulting in a continuous variable with a range of values from 0–3 (0 = *no unmet needs* and 3 = *high unmet needs*).

Family impact. Family impact was the impact the child's medical, behavioral, or other health condition had on one or more family member's employment, hours spent providing or coordinating the CSHCN's care, and family finances.

Employment. The impact that the CSHCN's health condition had on one or more family member's employment was measured using two variables. Respondents were asked, "Have you or other family members stopped working because of [S.C.]'s health conditions?" and "Have you or other family members had to cut down on the hours you work because of [S.C.]'s health conditions?" Both employment variables were dichotomous and included categorical responses of (0) *no* and (1) *yes*.

Hours spent providing or coordinating care. Hours spent providing or coordinating care was measured by four categories: (1) *less than one hour*, (2) *one to four hours*, (3) *five to ten hours*, and (4) *11 or more hours*.

Finances. Family financial impact was measured using two variables. Respondents were asked, “Has [S.C.]’s health conditions caused financial problems for your family?” The category “Financial problems” was a dichotomous variable and included categorical responses of (0) *no* and (1) *yes*. Parent respondents were also asked how much money the family spent each year on medical care for the CSHCN. Yearly medical expenses included three categorical responses: (1) *more than \$5000*, (2) *\$1000–\$5000*, and (3) *less than \$1000*. To answer this question, participants first had to respond affirmatively that they paid more than \$500 in out-of-pocket expenses for the CSHSN’s medical care. Therefore, participants with legitimate skips were coded as a (3) to reflect that they paid between \$501 and \$1000. Scores were recoded so that a “1” indicated *low family impact*, a “2” indicated *medium family impact*, and a “3” indicated *high family impact*. Scores were summed across the family impact variables, resulting in a continuous variable with a range of values of 0–10 (0 = *no family impact* and 10 = *high family impact*). Given that in previous research reports demands on money and time are particularly challenging for families (e.g., Anderson et al., 2011; Emerson, 2007; The Arc, 2011), these two questions had more potential impact on overall perceived family challenges. See Appendix E for survey questions used to assess PFC.

Scores across both dimensions of PFC were summed, resulting in a continuous variable with a range of values of 0–13 (0 = *no perceived family challenges* and 3 = *high or many perceived family challenges*). See Table 5 for counts of PFC. Other researchers

using the NS-CSHCN data set have commonly combined these same variables (employment, hours spent providing or coordinating care, finances, and unmet needs) to measure perceived family challenges (e.g., Ghandour, Kogan, Blumberg, & Perry, 2010; Kogan et al., 2008; Kuo et al., 2011a).

Mediating Variable

Research Question 3 included a mediating variable, unmet needs for child health services (which refers to a parent-reported need for one of the 14 specific health care services and equipment identified in the survey in the past 12 months), and reporting not having received all of the needed services or equipment. Previous research has found receipt of family-centered care to be associated positively with fewer unmet needs for children with special health care needs and with decreased perceived family-challenges (Kuo et al., 2011a). The impact that child unmet needs has on perceived family challenges surrounding ASD, however, is not clear. Therefore, it is reasonable to test unmet needs for child health services as a mediating variable that is associated with family-centered care, which in turn is associated with perceived family challenges.

Parent participants were asked whether their child needed each of 14 different health care services or equipment during the past 12 months. A sampling of the 14 health services includes well-child visits, dental care, prescription medications, and therapy (see Appendix D for specific questions related to unmet needs for child health services). Respondents giving an affirmative answer to the need for a specific health care service or equipment were asked a follow-up question to determine if the child got all the care that he or she needed in that area. Possible responses included (1) *yes* and (2) *no*. Scores were summed across the 14 services, resulting in a continuous variable with a possible range of

values of 0–14. Responses of “don't know” or “refused” were coded as missing. In the current study, the highest number of reported unmet needs was 4, resulting in an effective range of 0–4 (0 = *no unmet needs* and 4 = *four unmet needs*); see Table 6.

Data Analysis

This section includes a description of the statistical analysis software and the statistical analyses used, a discussion of how missing data were handled, and the research questions and related hypotheses.

Statistical Analysis Software

The sampling design of the 2009-2010 NS-CSHCN is complex. The Data Resource Center for Child and Adolescent Health recommends using statistical software that considers complex sample designs in order to calculate variance estimations, standard errors, and confidence intervals for hypothesis testing; statistical software that uses simple random sampling arrives to standards errors that are low, which may result in misleading results from tests of statistical hypotheses (DRC, 2012). Therefore, as recommended by the DRC, SPSS version 20 was used.

Statistical Analysis Methods

Data were analyzed using multiple linear regression. The assumptions of linear regression are that (a) there is no multicollinearity, (b) the relationship between each of the independent variables and the dependent variable is linear, (c) homogeneity of variance of the residuals, (d) the data are normally distributed, and (e) there are no outliers (Morgan et al., 2007).

Correlations confirmed that there was no multicollinearity among variables. Boxplots and histograms were created for FCC and PFC to check normality and outliers.

FCC appeared to be moderately negatively skewed, and PFC appeared to be moderately positively skewed. To correct for moderate negative skewness, FCC was transformed using an SQRT operation (Tabachnick & Fidell, 2007). The assumption of a linear relationship between each independent variable and PFC was tested and met using a curve estimation on both the original FCC variable and the transformed FCC variable. A scatterplot was used to test homoscedasticity of residuals assumption, and the results were substantively the same. Therefore, the results using the untransformed FCC variable will be reported.

To correct for moderately positive skewness, PFC was transformed using SQRT. After the transformation, PFC appeared very slightly positively skewed, though much closer to meeting the assumption of normality. Therefore, results using the transformed PFC variable will be reported.

Research Questions

Research Question 1: What sample characteristics, such as age of child, poverty status, and stability of child's health care needs, can be used to predict whether families of children with autism receive family-centered care?

H1: Among families of children with autism, there is a direct relationship between specific sample characteristics and the receipt of family-centered care.

Multiple regression was used to test Hypothesis One (*H1*), and examine associations between the sample characteristics (IVs) and FCC. The dependent variable was receipt of FCC and the predictors were child's age, child's race or ethnicity, parent education level, poverty status, adequacy of health care coverage, usual source of care, severity of autism, and stability of child's health care needs. Prior to analysis, variables

were examined for missing data and fit between their distributions and the assumptions of multivariate analysis. All assumptions were met. Therefore, 763 complete cases were used for this analysis.

Research Question 2: What is the relationship between received family-centered care and perceived family challenges for families of children with autism?

H2: Among families of children with autism, receipt of family-centered care is inversely associated with perceived family challenges, controlling for sample characteristics.

Simple linear regression was used to test Hypothesis Two (*H2*), and examine the relationship between FCC (IV) and PFC (DV), controlling for sample characteristics. Prior to analysis, variables were examined for missing data and fit between their distributions and the assumptions of linear regression. All assumptions were met. Therefore, 772 complete cases were used for this analysis.

Research Question 3: Do the unmet needs for child health care services mediate the relationship between family-centered care and perceived family challenges for families of children with autism?

H3: Among families of children with autism, the relationship between receipt of family-centered care and perceived family challenges is mediated by unmet needs for child health services.

As recommended by Baron and Kenny (1986), a series of regression models was used to test Hypothesis 3 (*H3*), testing for unmet needs for child health services as a mediating variable between receipt of FCC and reduced PFC. The following four recommended steps were used to establish mediation: (1) to show the predictor variable

is correlated with the outcome variable; (2) to show the predictor variable is correlated with the mediating variable; (3) to show that the mediating variable affects the outcome variable, controlling for the predictor variable; and (4) to establish that the mediating variable completely mediates (or partially mediates) the relationship between the predictor variable and the outcome variable.

If analysis confirms that the relationship between receipt of FCC and PFC is mediated or partially mediated by unmet needs for child health services, the mediation (or partial mediation) must be significant in order for the null hypothesis to be rejected. An increasingly popular method of testing the significance of the mediation is bootstrapping (Shrout & Bolger, 2002). Bootstrapping involved resampling with replacement; for this analysis, resampling and replacement was done 1,000 times, which is considered standard (Shrout & Bolger, 2002). The indirect effect is computed using each of these samples, from which an overall confidence interval is computed. Mediation is considered significant if zero is not between the lower limit and the upper limit of the confidence interval.

Missing Data

The original dataset used for this study used imputed data for race, parent education, and household income (DRC, 2012). Therefore, there was relatively little missing data in the sample. Of the 812 participants, 2.3% ($n = 19$) had missing data for the Family-Centered Care measure; five of whom had a legitimate skip (parents reported their child did not have any doctor visits within the past 12 months on which to report). Missing data for the PFC variable ranged from 0–3.4%. For the variable of unmet needs for child health services, missing data ranged from 0–1.6%. Cases with “none of the

above,” don’t know,” “refused,” or “missing” values on items in any of the measures were set to “missing” for the composite measure; response categories of “don’t know” and “refused” were coded as missing values (99).

Patterns of missing data were examined using the Missing Value Analysis in SPSS. Results from Little’s Missing Completely At Random (MCAR) test suggest that data was not missing completely at random ($p = .000$), therefore the data may have been missing at random (MAR) or not missing at random (NMAR) in this study (IBM, 2011; Little & Rubin, 2002). Because there is no statistical procedure that validly differentiates between MAR and NMAR, it is critical to examine the possible reasons for missing data logically and with a solid understanding of the study design (McKnight, McKnight, Sidani, & Figueredo, 2007). After carefully examining the few cases with missing data, missing data were considered to be “ignorable” (McKnight et al., 2007), and missing data were diagnosed MAR. That is, patterns of missing data could be explained by study variables, but the relationship among the missing data would not be presumed to have a meaningful effect on missing data in the dependent variable, PFC (McKnight et al., 2007). When there are low instances of missing data (around less than 5% of the total number of cases), and those values can be considered to be missing at random, listwise deletion would be considered appropriate (IBM, 2011); therefore, this study used it.

Chapter Four: Results

H1: Among families of children with autism, there is a direct relationship between specific sample characteristics and the receipt of family-centered care

To test Hypothesis One (*H1*), intercorrelations were checked among the predictor variables (child's age, child's race or ethnicity, parent education, poverty status, adequacy of health insurance coverage, usual source of care, severity of ASD, stability of child's health care needs). Means, standard deviations, and intercorrelations are provided in Table 7. Results of the regression indicate that these eight sample characteristics are statistically significant predictors of the receipt of FCC, $F(8, 763) = 9.75, p < .001$, with race, adequacy of health insurance, severity of ASD, and stability of child's health care needs significantly correlating with FCC. The adjusted R^2 was .08, indicating that approximately 8% of the variance in receipt of FCC was predicted by sample characteristics. According to Cohen (1992), this is a small to medium effect. The beta coefficients, presented in Table 8, suggest that, for children with ASD, his or her race, having adequate health insurance, and the stability of his or her health care needs contribute most to predicting his or her receipt of FCC.

Cross-tabs analysis of FCC and race, adequate health insurance, and stability of health care needs suggest that being White, having adequate health insurance, and having health care needs that are stable or change only once in a while resulted in greater likelihood of receipt of FCC. In this study, 97% of parents of children who were White reported receiving FCC, compared to 90% of children who were non-White; 96% of parents of children with adequate health coverage reported receiving FCC, compared to 91% of children without adequate health coverage; and 96% of parents of children with

health care needs that were either stable or changed once in a while reported receipt of FCC, compared to 76% of children with health care needs that changed “all the time.”

H2: Among families of children with autism, receipt of family-centered care is inversely associated with perceived family challenges, controlling for sample characteristics

A Pearson Correlation was computed to determine the relationship between FCC and PFC, controlling for sample characteristics, $r = -.23, p < .001$. The direction of the correlation was negative, indicating that receipt of FCC was associated with fewer PFC. Results of the linear regression indicate the receipt of FCC statistically significantly predicted PFC, $F(9, 762) = 30.81, p = .000$. The adjusted R squared value was .26, indicating that approximately 26% of the variance in PFC was predicted by receipt of FCC, controlling for sample characteristics. According to Cohen (1992), this is a medium effect size. Therefore, the null hypothesis was rejected.

H3: Among families of children with autism, the relationship between receipt of family-centered care and perceived family challenges is mediated by unmet needs for child health services

To test the mediating impact of the effects of unmet needs on the relationship between FCC and PFC, a series of regression models was used. Step One tested the relationship between FCC and PFC, resulting in a statistically significant relationship, $r = -.23, p = .000$. In Step Two, a statistically significant relationship was found between FCC and unmet needs for child health services, $r = -.176, p = .000$. Step Three found that there was a statistically significant relationship between unmet needs for child health services and PFC, controlling for FCC, $r = .33, p = .000$. Finally, results from Step Four

indicated that unmet needs for child health services partially mediated the relationship between FCC and PFC, $r = -.17$, $p = .000$. Results from this mediation model indicate that the *total effect* of FCC on PFC is $r = -.20$, the *indirect effect* of FCC on PFC through unmet needs for child health services is $r = -0.04$, and the *direct effect* of FCC on PFC is $r = -.17$. See Figure 2 for results of regression analyses for Research Question 3.

Since the correlation between FCC and PFC in the final regression model did not equal zero, which would indicate complete mediation, partial mediation was established. Partial mediation occurs when the path from the predictor variable to the outcome variable is reduced, but is still different from zero when the mediator is included. Bootstrapping analysis found the confidence interval to be $-.230$ for the lower limit and $-.110$ for the upper limit, thereby confirming that the partial mediation was statistically significant and the null hypothesis of no association can be rejected.

Summary

Findings from the current study confirm that specific sample characteristics predict receipt of family-centered care for children with ASD, specifically race, adequacy of health insurance, and the stability of health care needs. Findings suggest that there is an inverse relationship between family-centered care and perceived family challenges, and that this relationship is partially mediated by unmet needs for child health services. Results can be generalized to families of children with ASD and other neurological disorders who utilize health care services for their child.

Chapter Five: Discussion

This is the first study to examine the relationships among family-centered care, unmet needs for child health services, and perceived family challenges for families of children with autism spectrum disorder (ASD). Findings from this study are consistent with Andersen's behavioral model of health services use (1995) which suggests that individuals' use of health services is based on their predisposition to use services, factors that enable or impede use, and their need for care (Andersen, 1995). In the current study, predisposing, enabling, and need characteristics from Andersen's model significantly predicted whether a child received family-centered care. Further, a child's receipt of family-centered care resulted in fewer perceived family challenges. The relationship between those two variables was partially mediated by a child's unmet needs for routine or specialty health services. Overall, two important findings can be gleaned from this study: (1) disparities exist in health care services for children with ASD and (2) family-centered care matters to families with children with ASD.

Disparities in Health Care Services

Disparities exist between those who get family-centered care. In the current study, children with ASD who were White, had adequate insurance, and whose health care needs were either stable or changed only once in awhile were most likely to receive family-centered care. The disparities in access to family-centered care based on race was also found by Coker et al. (2010) and Ngui and Flores (2006). Patient's ethnicity, or the ethnic and racial stereotypes surrounding it, can influence the decision-making of health care providers regarding treatment (Gance-Cleveland, 2005; Liptak et al., 2006a). This

may be due, in part, to a lack of training for health care providers in providing culturally relevant, family-centered care.

The Western medical model tends to focus on therapies and interventions for ASD; however, families from fatalistic cultures may not wish for interventions to “fix” their child and they may not view their child’s behavior or difficulties as problematic. Some families may prefer parent training that best helps their child become as independent as possible. Some cultures may perceive health care professionals as authority figures and place the utmost importance on professional’s opinions or suggestions, perhaps not feeling comfortable with interjecting their own ideas, needs, or preferences. The preponderance of the literature, including findings from the current study, suggest that it is critical for health care professionals to be aware of their own priorities, to not assume they know what families’ priorities may be, and to ask probing questions that will help families articulate their concerns and wishes (Gance-Cleveland, 2005; Liptak et al., 2006a).

In the current study, the researcher found that having health insurance that adequately covered a child’s needs for care, along with the stability of his or her health care needs, predicted a child’s receipt of family-centered care. Other studies on the broader population of children with special health care needs have found that those who have adequate health insurance are more likely to receive family-centered care (AAP, 2012; Tippy et al., 2005).

Currently, there is great variation among states in the rules and designations for health insurance coverage for individuals with ASD. For example, even in states that have enacted autism legislation reform, the amount of money insurance providers are

required to pay per year to cover particular therapies, such as behavioral therapy, varies from state to state. Many states have not yet enacted *any* autism reform legislation, meaning that although insurance companies in these states may be required to provide coverage for therapies, such as speech and occupational therapy, they are not required to pay for any behavioral therapies.

Behavioral therapy, however, is highly recommended by ASD professionals, and many families choose to engage their child with one or more models of behavioral intervention. Because insurance companies are currently not required to cover the cost of all or, in some states, any, behavior therapy, many families find themselves with difficult financial decisions and limited treatment options—all because their insurance does not adequately meet the needs of their child. Though the current study did not examine receipt of family-centered care based on geographic location, it is likely that the discrepancy in adequate health insurance coverage would be directly related to the state in which the child with ASD lives.

In the present study, families that reported their child's health care needs as stable also reported receiving family-centered care. Interpretation of this relationship is challenging; the analysis used in this study does not allow the determination of causal direction. Perhaps it is not a child's stable health care needs that result in his or her receipt of family-centered care, but rather that receiving family-centered care helps to stabilize the child's health care needs. When families feel like integral members on their child's health care team, they may feel better equipped to implement their children's treatment plans with fidelity and are more invested in doing so, thereby stabilizing their child's ASD-related health care needs.

Previous studies have found that a child's age, parent's educational level, poverty status, and presence of a usual source of care to be factors that significantly relate to the receipt of family-centered care (Coker et al., 2010; Kuo et al., 2011a). However, those findings were not replicated in this study, perhaps in part due to the specific focus on children with ASD. Perhaps not being White, lacking adequate health insurance, and having unstable health care needs are barriers of such significance to receiving family-centered care that other variables are not as difficult to surmount.

Findings based on studies that examine the broader population of children with special health care needs, and even research on children with IDD, cannot necessarily be applied to the sub-population of children with ASD. Continued research on barriers to health care service delivery, along with research on the needs that are specific to children with ASD and their families, will promote increased knowledge about this population.

Family-Centered Care Matters

Previous research has demonstrated the importance of family-centered care for children with special health care needs in general (Kuo et al., 2011a, Kuo et al., 2011b). When families receive this type of care, they experience fewer family challenges, ultimately contributing to a better quality of life. The present study confirmed that this is also true when looking specifically at families who have children with ASD. Family-centered health care service delivery can help families better manage the medical aspect of their child's ASD, thereby reducing some of the challenges they commonly experience.

When needs for health services go unmet, the family system is placed under a great deal of stress. This study contributed to a gap in the literature by examining how

these unmet needs influenced the relationship between family-centered care and perceived family challenges for families of children with ASD. Findings confirm that family-centered care has important implications on both the child and the family level; children who receive family-centered care have fewer unmet needs for health care services, which contribute to fewer perceived family challenges. This finding is important because at least one unmet need for routine or specialty health services was reported for almost a third (31%) of the children in this study. If these children had received family-centered care, their needs for health care services would have likely been met, alleviating these families of some of the perceived stressors related to having a child with ASD.

Implications

Findings from this study provide new information for policy, practice, and research related to health care service delivery for families of children with ASD.

Implications for Policy

Results from this study can be used to identify ways to improve current health care policies by making them more family-centered. The policy statement written by the AAP Committee on Hospital Care Institute for Family-Centered Care (2012) can inform efforts to make health care more family-centered. For example, Tenet 2 argues for flexibility in organizational policies, procedures, and provider practices so services can be modified for each family's needs, preferences, and cultural values. Tenet 5 emphasizes collaborating with patients and families at *all* levels of health care, including policymaking, program development, implementation, and evaluation. It is critical for families to be actively invited to participate on family advisory councils and committees. Parents, siblings, and other family members can offer important insights regarding

operational issues in health care facilities, ensuring that family members' voices are woven into the fabric of health care organization policies.

Findings from the current study suggest that children with ASD but without adequate health insurance will not receive family-centered care. Although by 2014 most health care plans will be required to cover behavior therapy due to the implementation of the federal Health Insurance Reform Bill, much more support is needed. National and state leaders can advocate for adequate insurance coverage for individuals with autism to ensure that individuals and families impacted by autism will get the services they need, with sufficient treatment options to fit their preferences and priorities.

Implications for Practice

The majority of insurance companies cover individual services, such as routine check-ups or occupational therapy, but do not cover family services like parent coaching or informal consultation. Consequently, health care providers must document their practice and bill services within these parameters. Based on findings from the current study, providers are encouraged to consider the "patient" as the family unit and partner with the family to develop a treatment plan that will meet both the child's and the family's needs. Although they will have to bill for services on an individual-level, healthcare providers are urged to reconsider the common conceptualization of service delivery and collaborate with the family to design and implement appropriate services and supports. Utilizing a family-centered approach serves to support entire families impacted by autism, not just diagnosed individuals.

Children with ASD often have complex health conditions that affect their health and quality of life (Barbaresi et al., 2006), thereby requiring a variety of services and

supports. Though the AAP's Committee on Hospital Care and Institute for Patient- and Family- Centered Care recently published a policy statement outlining the core tenets of a family-centered approach, a standardized, regulated practice has not been endorsed nor enforced. Some health care organizations may regard the AAP's position around family-centered care merely as suggested guidelines for best practice, therefore not developing appropriate policies and procedures to ensure a national workforce competent in providing family-centered care. Therefore, it is important to increase awareness among health care professionals on the importance of providing family-centered care to children with ASD as a standard way of providing services and supports.

It is time for health care providers to hold themselves and each other accountable for providing health care that is truly family-centered. One step towards mandating family-centered care as standard practice is to develop a specific checklist that describes what the core tenets of family-centered care "look" like, in practice. For example, Tenet 1 is defined as "listening to and respecting each child and his or her family" (AAP, 2012, p. 395). What does this really mean? What competencies would a health care provider need to demonstrate in order to be considered proficient in this area? Expertise in this core tenet may be evaluated by a checklist that includes a set of competency statements for each of the six core tenets of family-centered care outlined by the AAP (2012). Such a checklist could be used by individual providers and health care administrators as a self-assessment of their skills and success in providing family-centered care.

National rankings and funding decisions could include outside reviewers' scores of organizations' efforts and success with providing family-centered care, in addition to feedback from families receiving services and supports from the health care organization.

If all health care organizations would utilize a standard conceptualization of family-centered care, such as the most recent definition put forth by the AAP, and if a valid measure of assessing organizations' competencies in providing family-centered care were to be developed and practiced, experiences with the health care system would significantly be improved for families of children with ASD.

Implications for Future Research

Additional studies could expand knowledge in this area and develop comprehensive supports and programs to improve the family-level outcomes for children with ASD and their families. Consistent with other studies (e.g., Beatson, 2008), the current research found an important relationship between the receipt of family-centered care and perceived family challenges for families of children with ASD. Further, this study confirmed that research related to children with special health care needs in general might not apply to children with ASD. Future research could examine the differences in the relationship between family-centered care and perceived family outcomes for children with ASD versus children with other special health care needs, such as Down syndrome or Cerebral Palsy. Findings would inform family practitioners and health care professionals of gaps or inconsistencies in their service delivery systems.

Future research might identify which specific components of family-centered care might be more important than others. For example, given the unique manifestation of ASD and parents' common experiences of feelings of isolation (Glover-Graf, 2011), parents might wish to connect with other parents whose children have ASD-related characteristics similar to their own child, and might prioritize this component of family-centered care over that which a health care professional might directly provide. Knowing

families' priorities could help shape programs and services offered by health care organizations.

Limitations

Despite the contributions of this research, there are important limitations and weaknesses inherent to secondary data analysis. All data were self-reported from parents of children with ASD and other neurological disabilities and cannot be corroborated with other data sources, such as medical records or service claims, and may be subjected to recall bias. Participants may also have provided involuntary erroneous information, thereby affecting the quality of data obtained.

A second limitation is that this study did not include geographic information although it has been found to be an important factor regarding a child's receipt of family-centered care (e.g., Kuo et al., 2011a). Therefore, study findings must be interpreted in light of the potential discrepancy of resources and resulting access to family-centered care between urban and rural areas.

Conclusion

The key contribution of the present study has been to measure the impact of family-centered care on family-level outcomes for families of children with ASD. This study demonstrated that family-centered care matters for families of children with ASD. Parents of children with ASD commonly report high levels of stress, strained relationships, isolation, and periods of grief. Family-centered care is critical in reducing these challenges and improving families' quality of life.

Yet, discrepancies exist among those who receive family-centered care. Children who are non-White, who lack health insurance that adequately meets their needs, and

whose health care needs are unstable are less likely to receive care that is family-centered. This is not acceptable. *All* families should feel heard and respected and have access to services that fit their needs, beliefs, and cultural values. *All* families should receive honest and unbiased information and have opportunities to connect with other parents with similar experiences. And *all* families should be encouraged to be active members on their child's health care team. Though health care professionals have a bounty of medical knowledge and expertise, it is essential for practitioners to tap into families' strengths and effectively utilize parents', siblings', grandparents', and other family members' unique experiences and wisdom. Family-centered care can be a vehicle to bridge the expertise of health care professionals and families, and facilitate the ongoing partnerships that are critical to families' overall quality of life.

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Table 1

Frequencies of Other Health Conditions in Children Diagnosed with Autism Spectrum Disorder (N = 3,055)

Other health condition	<u>n</u>	%
ADD or ADHD (2-17 years)	1,242	35.1
Allergies	1,123	31.7
Anxiety problems (2-17 years)	1,285	32.6
Arthritis or other joint problems	97	7.4
Asthma	436	10.5
Behavioral or conduct problems (2-17 years)	835	30.5
Blood problems	28	1.5
Cerebral Palsy	65	5.8
Cystic Fibrosis	1	0.1
Depression (2-17 years)	404	12.5
Developmental delay (2-17 years)	1900	36.5
Diabetes	11	1.0
Down syndrome	24	2.4
Epilepsy or seizure disorder	199	11.3
Head injury, concussion, or traumatic brain injury	44	1.3
Heart problem	69	3.5
Intellectual disability or mental retardation (2-17 years)	620	30.9
Migraines or frequent headaches	230	11.5
Muscular Dystrophy	12	1.2

Note. ADD or ADHD = attention deficit disorder or attention deficit hyperactivity disorder.

Table 2

Frequencies of Health Conditions in Sample (N = 812)

Health condition	<u>n</u>	%
ASD only	132	16.3
ASD and (ADD or ADHD)	196	24.1
ASD and developmental delay	472	58.1
ASD and intellectual disability or mental retardation	93	11.5

Note. Some parents reported their child had more than one additional neurological health condition. ASD = autism spectrum disorder; ADD or ADHD = attention deficit disorder or attention deficit hyperactivity disorder.

Table 3

Demographic Characteristics of Sample (N = 812)

Characteristic	<u>n</u>	%
<i>Predisposing</i>		
Child's Age		
2 – 5	174	21.4
6 – 11	392	48.3
12 – 17	246	30.3
Child's Race/Ethnicity		
Hispanic	112	13.8
White, non-Hispanic	562	69.2
Black, non-Hispanic	76	9.4
Other, non-Hispanic	62	7.6
Parent Education		
Less than high school	28	3.4
High school graduate	91	11.2
More than high school	693	85.3
<i>Enabling</i>		
Poverty Status		
0% - 99% FPL	113	13.9
100% - 199% FPL	160	19.7
200% - 399% FPL	263	32.4
400% FPL or greater	276	34.0
Adequacy of Health Care Coverage		
Current insurance is not adequate	370	42.5
Current insurance is adequate	430	53.0
Usual Source of Care		
Child does not have usual source of sick and well care	85	10.5
Child does have usual source of sick and well	723	89.0
<i>Need</i>		
Severity of Autism		
Mild	492	60.6
Moderate	261	32.1
Severe	54	6.7

(Table 3 continues)

(Table 3 continued)

Characteristic	<u>n</u>	%
<hr/>		
Stability of Child's Health Care Needs		
Child's health care needs change all the time	42	5.2
Child's health care needs change once in awhile	221	27.2
Child's health care needs are usually stable	544	67.0

Note. FPL = Federal Poverty Guidelines.

Table 4

Frequencies of Receipt of Family-Centered Care (N = 793)

Receipt of Family-Centered Care	<u>n</u>	%
CSHCN never receives FCC	3	.4
CSHCN sometimes receives FCC	39	4.8
CSHCN usually receives FCC	114	14.0
CSHCN always receives FCC	637	78.4

Note. CSHCN = child with special health care needs; FCC = family-centered care.

Table 5

Counts of Perceived Family Challenges (N = 812)

Summed Score	<u>n</u>	%
0	0	0
1	15	1.8
2	136	16.7
3	185	22.8
4	112	13.8
5	134	16.5
6	82	10.1
7	66	8.1
8	39	4.8
9	26	3.2
10	12	1.5
11	4	.5
12	1	.1
13	0	0

Table 6

Counts of Unmet Needs for Child Health Services (N = 812)

Number of unmet needs	<u>n</u>	%
0	561	69.1
1	178	21.9
2	46	5.7
3	20	2.5
4	7	.9

Table 7

Means, Standard Deviations, and Intercorrelations for Receipt of Family-Centered Care and Predictor Variables

Variable	<u>M</u>	<u>SD</u>	1	2	3	4	5	6	7	8
FCC	2.75	.56	.00	.09**	.00	.00	.25***	.04	-.09**	.15***
Predictor variable										
<i>Predisposing</i>										
1. Child's age	2.09	.72	-	.08**	.04	.05	.09**	-.01	.03	.10**
2. Child's race	.70	.46	-	-	.16***	.21***	.03	-.03	-.01	.05
3. Parent education	2.82	.46	-	-	-	.38***	-.03	.01	-.10**	.04
<i>Enabling</i>										
4. Poverty status	2.87	1.04	-	-	-	-	-.08*	.04	-.09**	.08*
5. Adqcy of hlth cvrg	.54	.50	-	-	-	-	-	.04	-.05	.10*
6. Usual source of care	.90	.31	-	-	-	-	-	-	-.01	-.03
<i>Need</i>										
7. Severity of ASD	1.46	.62	-	-	-	-	-	-	-	-.17***
8. Stability of hc needs	2.62	.59	-	-	-	-	-	-	-	-

Note. FCC = family-centered care; Adqcy of hlth cvrg = adequacy of a child's health coverage; Stability of hc needs = stability of child's health care needs; ASD = autism spectrum disorder. * $p < .05$. ** $p < .01$. *** $p < .001$.

Table 8

Multiple Regression Analysis Summary for Sample Characteristics Predicting Receipt of Family-Centered Care

Variable	<u>B</u>	<u>SEB</u>	<u>β</u>
<i>Predisposing</i>			
Child's age	-.03	.03	-.03
Child's race or ethnicity	.11	.04	.09**
Parent education	-.01	.05	-.01
<i>Enabling</i>			
Poverty status	-.00	.02	-.01
Adequacy of health care coverage	.28	.04	.24***
Usual source of care	.06	.06	.03
<i>Need</i>			
Severity of ASD	-.06	.03	-.06
Stability of child's health care needs	.11	.03	.12***

Note. ASD = autism spectrum disorder. $R^2 = .09$; $F(8, 763) = 9.75$, $p < .001$.

** $p < .05$. *** $p < .001$.

Figure 1. Andersen's Behavioral Model of Health Services Use as a Conceptual Framework

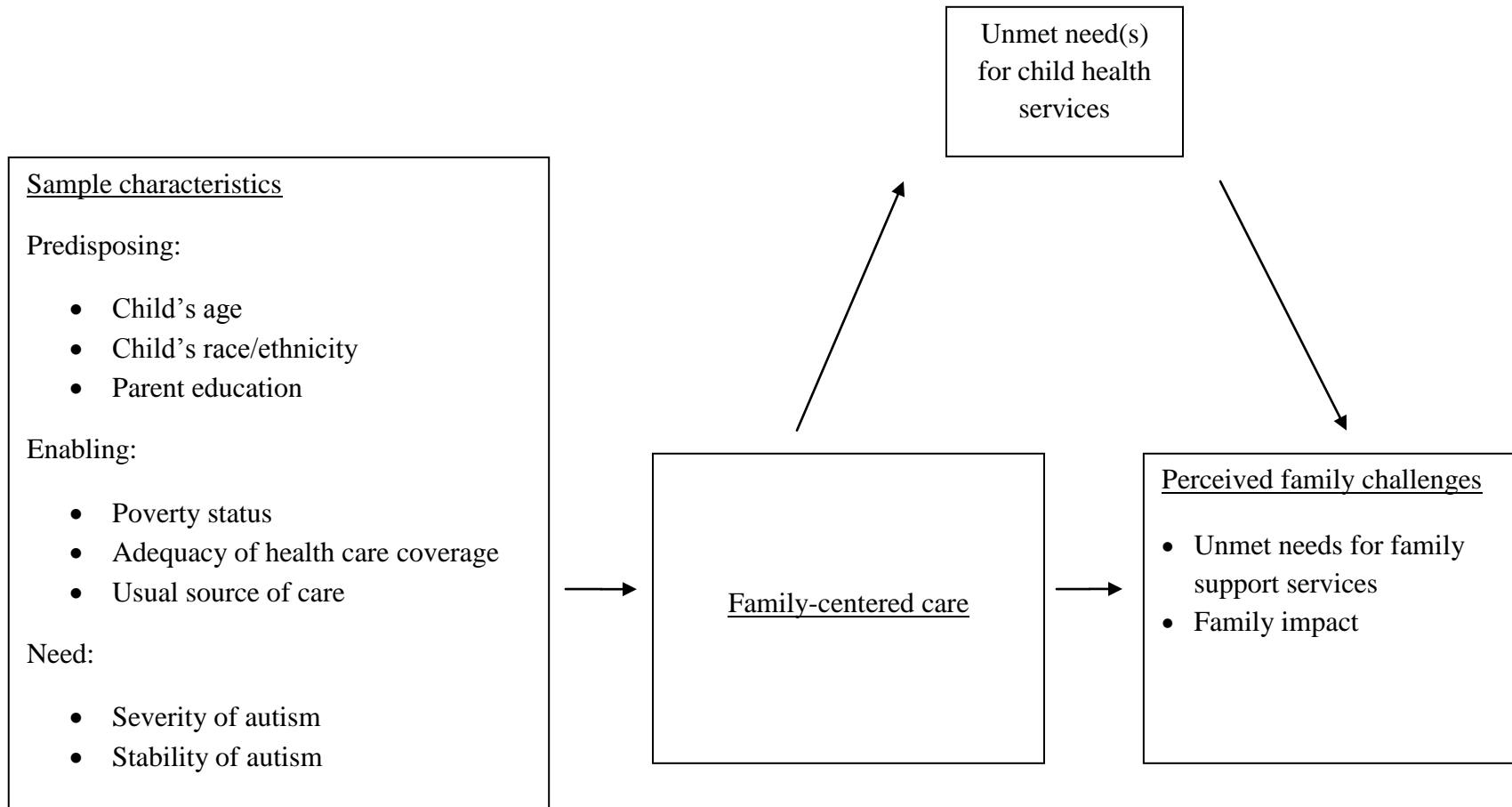
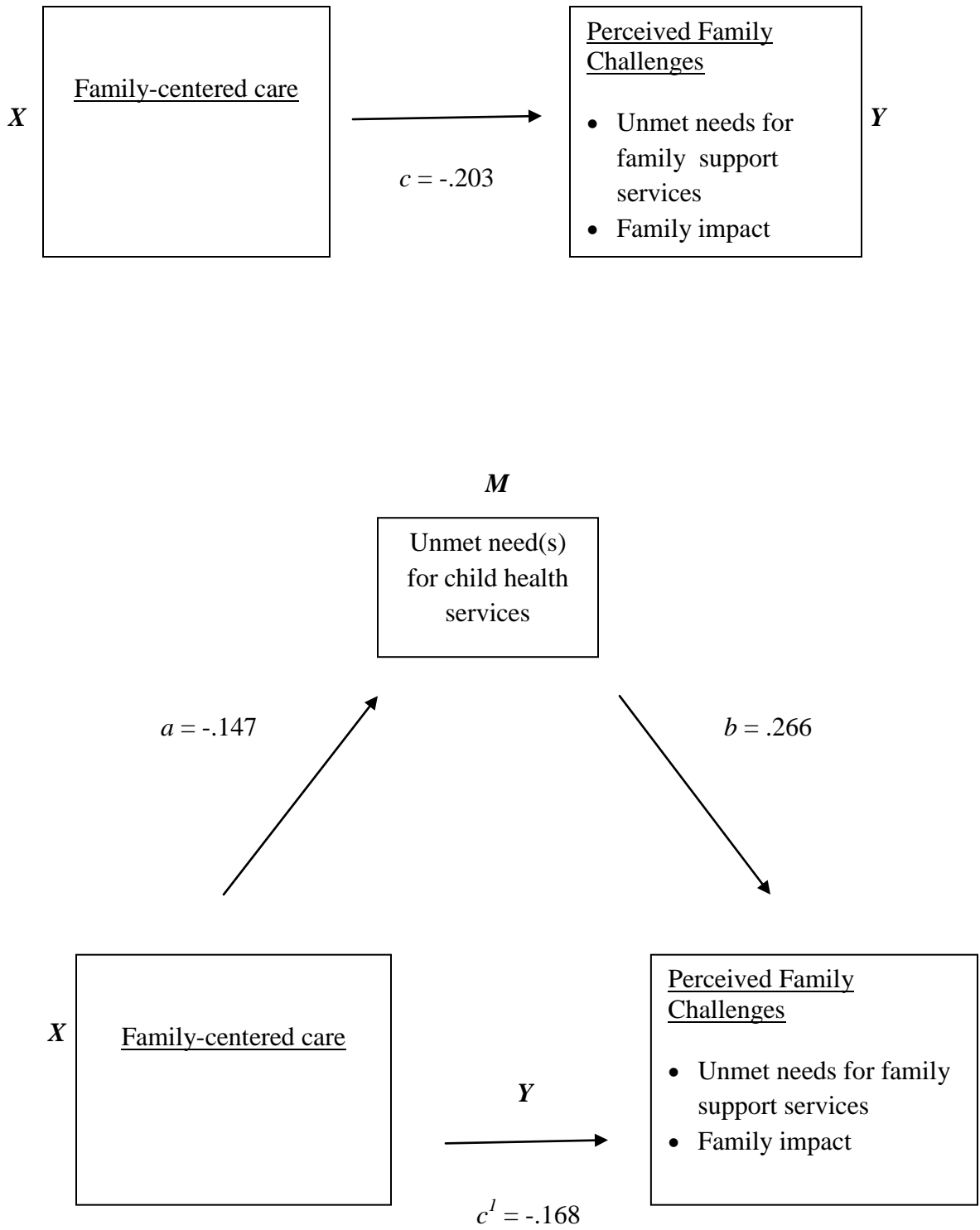


Figure 2. Results of Regression Analyses



Appendix A

Six Key Elements of Family-Centered Care

(Committee on Hospital Care and Institute for Patient- and Family- Centered Care, 2012)

- 1) *Listening to and respecting each child and his or her family**. Honoring racial, ethnic, cultural, and socioeconomic background and patient and family experiences and incorporating them in accordance with patient and family preference into the planning and delivery of health care.
- 2) Ensuring flexibility in organizational policies, procedures, and provider practices so services *can be tailored to the needs, beliefs, and cultural values of each child and family* and facilitating choice for the child and family about approaches to care.
- 3) *Sharing complete, honest, and unbiased information with patients and their families* on an ongoing basis and in ways they find useful and affirming, so that they may effectively participate in care and decision-making to the level they choose. Health information for children and families should be available in the range of cultural and linguistic diversity in the community and take into account health literacy. In hospitals, conducting physician rounds in the patients' rooms with nursing staff and family present can enhance the exchange of information and encourage the involvement of the family in decision-making.
- 4) *Providing and ensuring formal and informal support* (e.g., peer-to-peer support) for the child and family during each phase of the child's life. Such support is provided so that Health Insurance Portability and Accountability Act and other relevant ethical and legal guidelines are followed.

- 5) *Collaborating with patients and families at all levels of health care*: in the delivery of care to the individual child; in professional education, policymaking, program development, implementation, and evaluation; and in health care facility design. As part of this collaboration, patients and families can serve as members of child or family advisory councils, committees, and task forces dealing, for example, with operational issues in health care facilities; as collaborators in improving patient safety; as participants in quality-improvement initiatives; and as leaders or co-leaders of peer-support programs.
- 6) *Recognizing and building on the strengths* of individual children and families and empowering them to discover their own strengths, build confidence, and participate in making choices and decisions about their health care.

*Italics added for emphasis

Appendix B

Description of 2009-2010 NS-CSHCN Data Set

The 2009-2010 NS-CSHCN dataset is available to the public and can be accessed at the Data Resource Center for Child and Adolescent Health:

<http://www.childhealthdata.org/browse/survey>. Here, users can browse the data at both the national and state levels and conduct basic data analyses.

There are three files that comprise the 2009-2010 NS-CSHCN: Household File, Screener File, and Interview File. The Household File includes information for all households surveyed (n = 196,159); data includes geographic location, number of adults in household, number of children in household, sex of child, and household income. For each child in the household, the CSHCN Screener is conducted to determine CSHCN status (n = 371, 617). This file includes if and how a child met the CSHCN Screener. Children identified in the CSHCN Screener File as CSHCN are then given the full CSHCN Interview, but only one CSHCN per household (n = 40,242). This includes detailed information on the CSHCN population and data are representative of the CSHCN interviewed.

The Data Resource Center of the Oregon Health and Science University distributes the Interview File, with household and screener variables merged into the dataset; therefore, information on household demographics and CSHCN Screener are included. Data are provided in SPSS, SAS, and STATA formats. The dataset includes the original survey data and additional indicators developed by the DRC. This dataset is available to the public, but must be formally requested by filling a data use agreement form. This form requests information about the investigator, purpose of research, and

intended use. The DRC requires the investigator to reference the DRC in the final study write-up. Once the data use agreement form is approved, the database is released to the user.

Setting

The 2009-2010 NS-CSHCN was conducted using the State and Local Area Integrated Telephone Survey (SLAITS) methodology developed by the National Center for Health Statistics to quickly and consistently collect information on a variety of health topics at the local and state levels. Surveys conducted using SLAITS used the same sampling frame as the CDC's National Immunization Study (NIS) in order to efficiently identify households with age-eligible children (DRC, 2012). The NIS was conducted to monitor the immunizations of children across the country by estimating childhood vaccination rates (CDC, 2012c). The NIS used a random-digit dial sample and Computer-Aided Telephone Interviewing (CATI) to contact and select qualifying households. The NS-CSHCN used the same sampling frame to identify households with children and to implement a screening to identify CSHCN. At the time this paper was written, the 2009-2010 NS-CSHCN Survey Design and Operations Manual had not yet been released; further methodological details will be included as information becomes available.

Data Collection Methods

The sample in the 2009-2010 NS-CSHCN was selected by random digit dialing of landlines and cell phone numbers. Telephone numbers were randomly called to find households with children under 18-years old; about 3,100 to 5,500 households were contacted in each state (DRC, 2012). A detailed incentive plan was implemented to improve the likelihood that eligible households would participate in the survey.

Respondents eligible for an incentive were known to be age-eligible households that had not completed the CSHCN Screener or interview. The value of the incentive and the timing of the incentive offer were varied as part of an experiment on the use of incentives. The maximum total value offered to any household was \$15. Of all age-eligible households, 37% became eligible for an incentive. Of households that completed the CSHCN Screener, 50,312 received an incentive; 10,545 of the households that completed the detailed interview received an incentive (DRC, 2012).

Population

The 2009-2010 NS-CSHCN sample design was developed with the goal to obtain individual state samples and state and national CSHCN estimates. A total of 196,159 households, including 372,698 children, in the 50 states and the District of Columbia, were screened for special health care needs for the 2009-2010 NS-CSHCN. The number of children screened in each state ranged from 5,911 (KY) to 10,290 (CA). The number of households screened in each state ranged from 3,166 (OK) to 5,502 (CA). A total of 40,242 interviews with parents or guardians with CSHCN were completed. The number of CSHCN with detailed interviews ranged from 751 (DC) to 878 (TX). The target number of completed interviews (750) was achieved in every state and the District of Columbia. The interview completion rate was 80.8%, while the national response rate for special needs interviews was 25.5%. The NS-CSHCN questionnaire was professionally translated into Spanish, Mandarin, Cantonese, Vietnamese, and Korean. During data collection, 1,048 detailed interviews were completed by a Spanish-language interviewer and 25 detailed interviews were completed by an Asian-language interviewer (DRC, 2012).

Sampling Weights

Sampling weights were included in the public use data set in order to produce estimates representative of CSHCN households with CSHCN at the state and national levels. These sampling weights adjusted the survey responses to reflect the underlying child population. The weighting variable WEIGHT_I adjusted the survey responses to reflect the population of CSHCN age 0–17 years in each state and the District of Columbia based on the U.S. Census counts of children stratified by sex, age, and race or ethnicity (DRC, 2012). The DRC recommends this weight variable be applied to all work using the NS-CSHCN dataset (DRC, 2012).

Appendix C

Questions Used to Assess Receipt of Family-Centered Care

(and 2009-2010 NS-CSHCN reference)

C6Q02

(During the past 12 months), how often did [S.C.]’s doctors or other health care providers spend enough time with [him/her]? Would you say never, sometimes, usually, or always?

C6Q03

(During the past 12 months), how often did [S.C.]’s doctors or other health care providers listen carefully to you? Would you say never, sometimes, usually, or always?

C6Q04

When [S.C.] is seen by doctors or other health care providers, how often are they sensitive to your family’s values and customs? Would you say never, sometimes, usually, or always?

C6Q05

Information about a child’s health or health care can include things such as the causes of any health problems, how to care for a child now, and what changes to expect in the future. (During the past 12 months), how often did you get the specific information you needed from [S.C.]’s doctors and other health care providers? Would you say never, sometimes, usually, or always?

C6Q06

(During the past 12 months), how often did [S.C.]’s doctors or other health care providers help you feel like a partner in [his/her] care? Would you say never, sometimes, usually, or always?

*[S.C.] refers to Sampled Child

Appendix D

Questions Used to Assess Unmet Needs for Child Health Services

(and 2009-2010 NS-CSHCN reference)

C4Q05_1A

Did [S.C.] receive *all* the well-child check-ups that [he/she] needed?

C4Q05_31A

Did [S.C.] receive *all* the preventative dental care that [he/she] needed?

C4Q05_32A

Did [S.C.] receive *all* the other dental care that [he/she] needed?

C4Q05_2A

Did [S.C.] receive *all* the care from a specialty doctor that [he/she] needed?

C4Q05_4A

Did [S.C.] receive *all* the prescription medications that [he/she] needed?

C4Q05_5A

Did [S.C.] receive *all* the therapy that [he/she] needed?

C4Q05_6A

Did [S.C.] receive *all* the mental health care or counseling that [he/she] needed?

C4Q05_7A

Did [S.C.] receive *all* the substance abuse treatment or counseling that [he/she] needed?

C4Q05_8A

Did [S.C.] receive *all* the home health care that [he/she] needed?

C4Q05_9A

Did [S.C.] receive *all* the eyeglasses or vision care that [he/she] needed?

C4Q05_10A

Did [S.C.] receive *all* the hearing aids or hearing care that [he/she] needed?

C4Q05_11A

Did [S.C.] receive *all* the mobility aids or devices that [he/she] needed?

C4Q05_12A

Did [S.C.] receive *all* the communication aids or devices that [he/she] needed?

C4Q05_14A

Did [S.C.] receive *all* the durable medical equipment that [he/she] needed?

*[S.C.] refers to Sampled Child

Appendix E

Questions Used to Assess Perceived Family Challenges and Related Measurement of Variables (and 2009-2010 NS-CSHCN reference)

Burden on the Family individual item components	Recoded Response Categories
<p>C4Q06_1A (During the past 12 months), did you or your family receive <i>all</i> the respite care that was needed?</p>	<p>(0) Yes (1) No</p>
<p>C4Q06_2A (During the past 12 months), did you or your family receive <i>all</i> the genetic counseling that was needed?</p>	<p>(0) Yes (1) No</p>
<p>C4Q06_3A (During the past 12 months), did you or your family receive <i>all</i> the mental health care counseling that was needed?</p>	<p>(0) Yes (1) No</p>
<p>C9Q01_A* (During the past 12 months), would you say that the family paid more than \$5000, \$1000 to \$5000, or less than \$1000 for [S.C.]’s medical care?</p>	<p>(1) Less than \$1000 (2) \$1000 - \$5000 (3) More than \$5000</p>
<p>C9Q03/C9Q04 How many hours a week do you or other family members spend providing/ coordinating care?</p>	<p>(1) < 1 hour (2) 1-4 hours (3) 5-10 hours (4) 11 or more hours</p>
<p>C9Q05 Has [S.C.]’s health conditions caused financial problems for your family?</p>	<p>(1) Yes (0) No</p>

C9Q10

Have you or other family members
stopped working because of [S.C.]'s
health conditions?

(1) Yes
(0) No

C9Q06

Have you or other family members cut
down on the hours you work because of
[S.C.]'s health conditions?

(1) Yes
(0) No

* [S.C.] refers to Sampled Child