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# Shared decision-making and parental experiences with health services to meet their child's special health care needs: Racial and ethnic disparities

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### ABSTRACT

**Objectives:** Test the relationship between shared decision-making (SDM) and parental report of frustration with efforts to get services for their child and to address unmet health needs; assess SDM's influence on minority parents' service experiences.

**Methods:** Performed secondary analysis using the 2009–2010 National Survey of Children with Special Health Care Needs (n = 40,242). Used multivariate logistic regressions to test the association between SDM and parent-reported service experiences, and whether SDM influenced the association between minorities and negative service experiences. Propensity scores accounted for observed selection bias.

**Results:** Families engaged in SDM had lower odds of reporting service dissatisfaction. Fewer minority parents reported SDM engagement compared with Whites (between 62% and 66% versus 74%). Blacks engaged in SDM had higher odds of reporting negative service experiences compared with SDM-engaged Whites. This disparity was no longer significant after adjusting for covariates.

**Conclusion:** SDM is associated with lower reports of parental service dissatisfaction. Stratified analyses showed that SDM seems to be experienced differently across minority groups.

**Practice implications:** SDM may be a promising engagement strategy to improve parental service experiences. The role of SDM on increasing Black parents' reports of service dissatisfaction, perhaps due to increased awareness of service challenges, should be investigated.

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## 1. Introduction

Children with special health care needs (CSHCN) are a priority for the national health agenda given their need for timely and coordinated care that can improve health service experiences and outcomes. CSHCN are defined as those who are at increased risk for chronic physical, developmental, behavioral, and/or emotional conditions and who require physical, behavioral health, and related services (e.g., social services) of a type or amount beyond that required by children in the general population [1]. In the United States, one in five families has a child with a special health care needs [2]. In 2009–2010 and among racial and ethnic minorities (aka minorities), CSHCN represented 17.5% of Blacks, 11.2% of Hispanics and 13.6% of other racial or ethnic origin [3].

The Maternal and Child Health Bureau's mission for optimal health and quality of life for this patient population includes the provision of family partnership in decision-making, also known as shared decision-making (SDM), as a core component [2]. Yet, services for CSHCN are often hard to coordinate and deliver on the ground while also being informed by families' ongoing needs and preferences. Evidence supports this service gap as CSHCN, and particularly minorities, lack access to needed health care services [4]. The National Survey of Children with Special Healthcare Needs (NS-CSHCN) has reported that 10% of children lack any source of regular care and rely on the emergency room for care. The percentage is 15% for Black non-Hispanics and 12% for Hispanics. In addition, for 6% of the CSHCN population, including minorities, mental health needs have not been met in the past 12 months [3]. Furthermore, once minorities receive care, it is more likely to be poor in quality compared with similar care for Whites [5].

Given the complexity of the needs of this pediatric population, family input is critical to ensure that providers are gathering accurate information on each family's unique and evolving needs, resources, and service preferences. This information also reflects the families' values, cultural beliefs, and perceptions of health service

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experiences. SDM also places a strong emphasis on patient empowerment, a key aspect of improving services for minority patients [6]. Family input is especially critical for the CSHCN patient population because families can become frustrated navigating a complex labyrinth of service referrals and appointments.

Family-centered practices, including SDM [7], have received strong support from policy makers, professional associations, and service providers as a way to increase health care quality and reduce health disparities [4]. Those associations include the Substance Abuse and Mental Health Services Administration, the American Academy of Pediatrics, and the Institute of Medicine [8–10].

SDM is defined as two-way communication between a child's caregiver and the provider on medical and personal information related to treatment planning [11]. From the provider's perspective, SDM includes a discussion of treatment plans during which the provider encourages parents to ask questions and share concerns and listens to their preferences [12]. From the caregiver's (typically a parent) perspective, SDM refers to having the self-confidence and activation to ask questions and get what they want out of the clinical encounter [13,14].

This practice has been associated with increased health knowledge [15], patient satisfaction, treatment adherence, and positive health outcomes [16,17]. Despite shown benefits, access to SDM is lower among minorities than for Whites, in part due to provider-patient power differential, low patient self-efficacy, and cultural differences [18–20]. Altogether, this evidence suggests that SDM experiences among minority groups are a relevant area of research to address health equity. However, health disparities researchers still lack insight into whether SDM influences the negative association between minority group membership and health service satisfaction for this high-need patient population.

Several observational studies have examined the influence of SDM on increasing parental satisfaction with services among CSHCN [21–23]. This is a relevant area of research because higher parental satisfaction is expected to increase service engagement and ultimately improve child health outcomes [24–26]. Yet, these studies pose several limitations. First, aggregated SDM analyses may mask between-group differences, especially among minority groups. For example, one study that examined the role of SDM among racial and ethnic groups combined the groups of Black and Hispanic children when the researchers performed stratified analysis [27], despite observed socioeconomic and cultural differences [28]. Second, the role of SDM in increasing parental satisfaction with services has been assessed only on a single area of care such as mental health services [21], despite the fact that CSHCN often need a wide array of services spanning primary, behavioral, and developmental care. In addition, studies have not controlled for potential selection bias due to the lack of randomization and the fact that certain groups (i.e., Whites, highly impaired children, and those from higher resourced environments) are more likely to be engaged in SDM than others [12,29].

We overcame previous studies' limitations in several ways. Guided by the Andersen Behavioral Model of Health Care Use for Vulnerable Populations [30], we used a nationally representative sample of CSHCN to empirically examine whether SDM is associated with an array of health service experiences among parents, and further whether SDM modified the relationship between race/ethnicity and the outcome variables. In addition, we controlled for observed selection bias by implementing the group balancing technique of propensity scores on all regression analyses.

## 2. Methods

### 2.1. Data

This study uses cross-sectional data (2009–2010) from the NS-CSHCN, which was sponsored by the Maternal Child Health Bureau

(MCHB) of the Health Resources and Services Administration, U.S. Department of Health and Human Services [31]. This telephone/cell survey was conducted in English and Spanish using independent random samples from all 50 states and the District of Columbia. The NS-CSHCN data are publicly available [3]. The Institutional Review Board at the lead author's institution approved this study. This dataset is most suitable for this study because it provides a national sample of children, it includes rarely available parental reports on children's experiences and outcomes, and it focuses on CSHCN [32–34].

### 2.2. Sample

The 2009–2010 NS-CSHCN interview sample was achieved by screening 372,698 children 0–17 years of age living in 196,159 households nationwide, using the CSHCN Screener. The CSHCN Screener is a survey tool developed and validated specifically to identify children who meet the federal MCHB health consequences–based special health care needs definition [35]. The analytical sample ( $n = 40,242$ ) was restricted to children ages 0–17 and identified by the NS-CSHCN as having special health care needs and based on the screening tool.

### 2.3. Measures

#### 2.3.1. Dependent variables

**2.3.1.1. Health service experiences.** Based on survey questions assessing the level of parent dissatisfaction with the availability and quality of health services for their child, we constructed three binary dependent variables: 1) frustration in parents' efforts to get services for their child (usually or always versus never or sometimes), 2) unmet needs (versus got all needed care or did not need) for mental health care, and 3) unmet needs for occupational therapy, physical therapy, or speech therapy. The first variable was re-coded to reflect a negative health service experience to align with the other two variables that were phrased in that direction by the national survey.

#### 2.3.2. Independent variable

**2.3.2.1. Racial and ethnic group membership.** The NS-CSHCN publicly released race/ethnicity variable with four categories: Hispanic, non-Hispanic White, non-Hispanic Black, and non-Hispanic other. Each group was measured as a binary variable, and the non-Hispanic White was set as the reference group in between-group comparisons.

#### 2.3.3. Moderator

**2.3.3.1. Shared Decision Making (SDM).** MCHB has six core outcomes to assess progress in health care systems for CSHCN. The SDM measure assesses the first core outcome: CSHCN families are partners in decision-making around issues important to their child's health. This measure is already provided by the NS-CSHCN survey, and the SDM variable was constructed based on data for CSHCN whose families usually or always feel that they 1) discuss with providers a range of options to consider for their child's treatment; 2) are encouraged to ask questions or raise concerns; 3) find it easy to ask questions or raise concerns; and 4) believe that their health care providers consider and respect the treatment choices that the parent feels would be best for his or her child. The SDM variable was coded as one (1) if parents answered "usually/always" to all questions. Parents answering "don't know" or "refused" to any of the four questions were set to missing for this indicator, following recommendations from the NS-CSHCN survey.

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