Shared decision making (SDM) is a critical component of patient engagement and family-centered care. It is a national quality measurement priority recognized by the American Academy of Pediatrics and the US Department of Health & Human Services. 1 1 It is also specified as a national system performance measure for children with special health care needs (CSHCN) by the Federal Maternal & Child Health Bureau (MCHB). The measurement of shared decision making was redesigned for the 2009-10 National Survey of Children with Special Health Care Needs (NS-CSHCN). 1

**Background**

We had three objectives: (1) to evaluate the psychometric properties of the shared decision making (SDM) measure in the 2009-10 NS-CSHCN; (2) to estimate national prevalence, geographic disparities and sociodemographic variations in SDM among CSHCN; and (3) to assess the associations between SDM and the complexity of health needs, health and well-being and other measures of health care quality for CSHCN.

**Methods**

Data for this study come from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN) and were collected between July 2009 and March 2011. 1 The survey is directed and funded by the National Survey of Children with Special Health Care Needs and administered by the National Center for Health Statistics. The sample represented at least 750 children with special health care needs (CSHCN) from each state and DC (751-878 per state). 1 All estimates are adjusted for nonresponse bias and weight to represent the noninstitutionalized population of CSHCN age 0 to 17 years nationwide and in each state. Children with special health care needs were identified using the standardized CSHCN Screener. 1 The survey items used for the shared decision making measure were shown in Table 1.

**Objectives**

- No difficulties or delays accessing needed services
- A parent who is never frustrated in their efforts to get services for the child
- No problems getting needed referrals (SDM criteria)
- National: 70.3% of CSHCN met SDM criteria
- California and New York are the two only states that perform significantly worse than the national average
- Covariates: age, sex, race/ethnicity, household income and parental education

**Introduction:**

No problems getting needed referrals (SDM criteria)

**Results:**

- The four shared decision making items were iteratively specified after 12 rounds of cognitive interviews, where numerous candidate items were tested. Items were then presented with 132 households with children. Cognitive testing with parents and patients indicated a final version of the introduction and four questions had face validity, were understood as intended and reliable. Family focus groups before and during development confirmed the four items represented most essential components of shared decision making. Additional items were also relevant, but survey space limits prevented their inclusion. Cronbach’s Alpha for the four items was 0.68, indicating high internal consistency. Cronbach’s was lowest if any item was deleted, indicating that none should be removed from the measure. Item correlations demonstrated linked but differentiated information is provided by each item, with correlations ranging from 0.592 to 0.686. Factor analysis did not result in item groupings.

- Shared decision making is positively correlated with both having a medical home and receipt of family centered care (Pearson Correlation p-value <0.001). CSHCN who meet medical home criteria are 6.48 times more likely to meet SDM criteria than CSHCN who do not meet medical home criteria (AOR 95% CI: 5.52-7.22). CSHCN who receive family-centered care (FCC, a component of medical home) 1 also 6.06 times more likely to meet SDM criteria than CSHCN who do not receive FCC (AOR 95% CI: 9.05-10.95).

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