# Care Coordination, the Family-Centered Medical Home, and Functional Disability Among Children With Special Health Care Needs

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## ABSTRACT

**BACKGROUND:** Children with special health care needs (CSHCN) are at increased risk for functional disabilities. Care coordination has been shown to decrease unmet health service use but has yet been shown to improve functional status. We hypothesize that care coordination services lower the odds of functional disability for CSHCN and that this effect is greater within the context of a family-centered medical home. A secondary objective was to test the mediating effect of unmet care needs on functional disability.

**METHODS:** Our sample included children ages 0 to 17 years participating the 2009–2010 National Survey of Children with Special Health Care Needs. Care coordination, unmet needs, and disability were measured by parent report. We used logistic regression models with covariate adjustment for confounding and a mediation analysis approach for binary outcomes to assess the effect of unmet needs.

**RESULTS:** There were 34,459 children in our sample. Care coordination was associated with lower odds of having a func-

### WHAT'S NEW

Care coordination, an integral part of the familycentered medical home, has been shown to reduce unmet service needs. Our study demonstrates a positive association between care coordination and reduced functional disabilities among children with special health care needs.

CHILDREN WITH SPECIAL health care needs (CSHCN) face challenges in accessing needed medical services. Compared with children without special health care needs, CSHCN in the United States are less likely to attend routine well-child visits and receive preventive dental care in childhood and adolescence.<sup>1</sup> Unmet needs were greater for older children, those with multiple service needs, behavioral health problems, inconsistent health insurance coverage, more severe functional limitations, and unstable care needs.<sup>2,3</sup> Though there are many accepted definitions of care coordination, the Agency for Healthcare Quality and Safety has identified 5 common components: involvement of numerous participants, interdependence of participants

tional disability (adjusted odds ratio 0.82, 95% confidence interval 0.77, 0.88). This effect was greater for care coordination in the context of a medical home (adjusted odds ratio 0.71, 95% confidence interval 0.66, 0.76). The relationship between care coordination and functional disability was mediated by reducing unmet services.

**CONCLUSIONS:** Care coordination is associated with lower odds of functional disability among CSHCN, especially when delivered in the setting of a family-centered medical home. Reducing unmet service needs mediates this effect. Our findings support a central role for coordination services in improving outcomes for vulnerable children.

**Keywords:** care coordination; children with special health care needs; disability; medical home

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in carrying out different aspects of patient care, sharing of knowledge about roles and resources, reliance on information exchange, and facilitation of appropriate health care delivery.<sup>4</sup> However, a recent national study revealed that 41% of CSHCN were likely to have unmet care coordination needs.<sup>5</sup>

Care coordination is one of the core components of the family-centered medical home, a model of providing coordinated, compassionate, family-oriented care for children.<sup>6</sup> The importance of this component is supported by evidence of increased access to medical services<sup>7</sup> and reduced rates of hospitalization among CSHCN.<sup>8</sup> A national study of CHSCN found receiving adequate care coordination was associated with reduced risk of visiting the emergency department, having problems with referrals for specialty care, and missing days of school due to illness. Families reported lower out-ofpocket health care expenditures and lower likelihood of reducing or stopping work due to a child's special health care needs.9 A Massachusetts study revealed that CHSCN receiving care coordination services within a medical home setting have lower odds of having unmet



health care needs compared to those not receiving care coordination.<sup>2</sup>

The existing literature has focused on the impact of care coordination efforts on health service access and utilization. What is lacking is a clear linkage between these advantages of coordinated care and improved health outcomes,<sup>10</sup> particularly with respect to the burden of chronic conditions and associated functional disabilities. According to the Institute of Medicine, a "disability is the expression of a physical or mental limitation in a social context-the gap between a person's capabilities and the demands of the environment."<sup>11</sup> Though medical conditions may predispose an individual to becoming disabled, functional impairment is the result of a complex process involving biological, environmental, and social forces acting in a given place and time. Decreasing the risk of functional disability requires the prevention and early detection and treatment of potentially disabling conditions.<sup>11</sup>

Given current interest and investment in care coordination for children and families, we aimed to assess the relationship between care coordination and functional disability among CSHCN. We also aimed to determine the impact of receiving care coordination services in the setting of a family-centered medical home. A secondary aim was to assess whether unmet needs mediate the relationship between care coordination and functional disability. We hypothesized that receipt of care coordination services is associated with lower risk of having a functional disability and that this effect is greater in the setting of a family-centered medical home. We also hypothesized that impact of care coordination on functional disability status is mediated by a reduction in unmet service needs.

#### **METHODS**

#### DATA SOURCE, POPULATION, AND SAMPLE

We used data from the 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN). The survey is a national random-digit dial telephone survey sponsored by the US Department of Health and Human Services, Health Resources and Services Administration, and Maternal and Child Health Bureau and conducted by the National Center for Health Statistics and the Centers for Disease Control and Prevention. Eligible families were identified in all 50 states and the District of Columbia using the State and Local Area Integrated Telephone Survey approach. The methodology has been described in detail elsewhere.<sup>12</sup> A total of 372,698 children between birth and 18 years were screened using the validated CSHCN screener to identify a total of 40,242 children with special health care needs. The telephone survey completion rate for households with CSHCN was 80.8%. Public use data sets are available through the Data Resource Center for Child and Adolescent Health of the Child and Adolescent Health Measurement Initiative.<sup>13</sup>

According to the NS-CSHCN, the screening criteria included conditions lasting or expected to last at least 1 year: use of prescription medication other than vitamins, use of more services than a typical child, limitations in ability compared to a typical child, need of special therapy, or emotional or behavioral problems requiring treatment. The survey covered topics related to child health and functional status, health insurance and coverage, access to care and preventive services, care coordination, access to community-based services, impact of child's health on the family, and family social and demographic characteristics. Our study sample included all patients with complete information on key predictor and outcome variables.

#### VARIABLES

The primary predictor variable was receipt of effective care coordination. This was defined by affirmative answers to all 3 of the following survey items: family usually or always gets sufficient help coordinating care, doctor communicates with specialists, and family is very satisfied with physician communication with other physicians and service providers. The second predictor was receipt of care within a medical home, a composite measure designed by the NS-CSHCN to operationalize the core medical home components as outlined by the American Academy of Pediatrics.<sup>14</sup> The measure was created as a composite of the following 5 survey items: child has a personal doctor or nurse, child has a usual source for sick and well care, care is family-centered, family has no problems receiving needed referrals for the child, and child has effective care coordination. For the second part of our first aim, we constructed a variable to indicate the receipt of care coordination services in the absence of a medical home. We did so by identifying those individuals meeting all components of effective care coordination but not all components of the medical home composite variable.

The outcome measure, child functional status, was measured by 2 composite variables on the NS-CSHCN: in the last 12 months, child has a little or a lot of difficulty with activities or participation and child has a little or a lot of difficulty with 1 or more body functions. The variables were comprised of 14 items relating to child health status from the survey: difficulty with breathing, swallowing, circulation, chronic pain, vision impairment, hearing impairment, activities of daily living, movement, using his/her hands, learning, communicating, anxiety/depression, behavior, making and keeping friends. It should be noted that this measure reflects parental perception of child functional abilities and is not a validated measure of functional status. The mediator variable, unmet service need, was a composite measure of having an unmet need in 1 or more areas within the last 12 months: routine preventive care, specialist care, preventive dental care, other dental care, prescription medications, physical, occupational, or speech therapy, mental health, substance abuse services, home health, vision care, hearing aids, mobility aids, communication aids, and durable medical equipment.

We considered covariates for inclusion in the models that have been shown in the literature to be related to both access to care coordination services and functional outcomes. Among these was the number of CSHCN screener criteria met; we used this as a proxy measure of the extent of health care needs. Child-specific characteristics included age Download English Version:

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