

# Parental Limited English Proficiency and Health Outcomes for Children With Special Health Care Needs: A Systematic Review

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The authors declare that they have no conflict of interest.

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## ABSTRACT

**BACKGROUND:** One in 10 US adults of childbearing age has limited English proficiency (LEP). Parental LEP is associated with worse health outcomes among healthy children. The relationship of parental LEP to health outcomes for children with special health care needs (CSHCN) has not been systematically reviewed.

**OBJECTIVE:** To conduct a systematic review of peer-reviewed literature examining relationships between parental LEP and health outcomes for CSHCN.

**DATA SOURCES:** PubMed, Scopus, Cochrane Library, Social Science Abstracts, bibliographies of included studies. Key search term categories: language, child, special health care needs, and health outcomes.

**ELIGIBILITY CRITERIA:** US studies published between 1964 and 2012 were included if: 1) subjects were CSHCN; 2) studies included some measure of parental LEP; 3) at least 1 outcome measure of child health status, access, utilization, costs, or quality; and 4) primary or secondary data analysis.

**METHODS:** Three trained reviewers independently screened studies and extracted data. Two separate reviewers appraised studies for methodological rigor and quality.

**RESULTS:** From 2765 titles and abstracts, 31 studies met eligibility criteria. Five studies assessed child health status, 12 as-

essed access, 8 assessed utilization, 2 assessed costs, and 14 assessed quality. Nearly all (29 of 31) studies used only parent- or child-reported outcome measures, rather than objective measures. LEP parents were substantially more likely than English-proficient parents to report that their CSHCN were uninsured and had no usual source of care or medical home. LEP parents were also less likely to report family-centered care and satisfaction with care. Disparities persisted for children with LEP parents after adjustment for ethnicity and socioeconomic status.

**CONCLUSIONS AND IMPLICATIONS:** Parental LEP is independently associated with worse health care access and quality for CSHCN. Health care providers should recognize LEP as an independent risk factor for poor health outcomes among CSHCN. Emerging models of chronic disease care should integrate and evaluate interventions that target access and quality disparities for LEP families.

**KEYWORDS:** access; children with special health care needs; disabled children; health services accessibility; health services research; health care disparities; language; limited English proficiency; minority health; quality of health care

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## WHAT'S NEW

CSHCN with limited English proficient parents have significantly worse insurance and medical home access, family-centered care, and satisfaction with care than CSHCN with English-proficient parents. These disparities are independent of ethnicity and socioeconomic status.

## WHAT THIS SYSTEMATIC Review Adds

- Parental LEP—*independent of ethnicity and socioeconomic status*—is associated with worse insurance and medical home access for CSHCN.
- LEP families suffer worse quality of family-centered care.

- Little evidence is available to assess relationships between LEP and objective health outcomes.

## HOW TO USE This Systematic Review

- Understand how parental LEP is a risk factor for worse health care access and quality for CSHCN.
- Consider how these findings inform emerging models of chronic disease care within integrated health systems.
- Identify areas of solution-oriented research to reduce disparities.

IN 1964, TITLE VI of the Civil Rights Act mandated that federally funded programs, such as Medicaid, must avoid

discriminating on the basis of nationality by making all services accessible to individuals with limited English proficiency (LEP).<sup>1</sup> In the nearly 50 years since this landmark legislation, however, health care disparities related to LEP persist.<sup>2–5</sup> These LEP-related disparities may have far-reaching effects on child health because 10% of US adults of childbearing age report having LEP, defined by the US Census Bureau as speaking English less than very well.<sup>6</sup>

Although disparities in child health outcomes associated with race and ethnicity are well known, recent evidence suggests parental LEP may act as an independent determinant of health outcomes among racial and ethnic minority children. Healthy children whose parents have LEP are more likely to be uninsured, lack a medical home and specialty referrals, and experience serious medical errors compared to children whose parents are English proficient (EP).<sup>7–12</sup> LEP parents are also more likely to report poor communication with health care providers than EP parents.<sup>13–15</sup>

Health outcomes for children with special health care needs (CSHCN) may be especially sensitive to parental LEP. The Maternal and Child Health Bureau (MCHB) specifies that CSHCN are “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”<sup>16</sup> Health outcomes for CSHCN depend on use of specialized health services and their parents’ ability to understand and manage complicated medical and nutritional regimens, community and school-based resources, and other health information.<sup>17–19</sup> Because the volume, complexity, and potential health consequences of written and spoken health information are much greater for CSHCN than for children in the general population, parental LEP may be strongly associated with serious disparities in health outcomes for CSHCN. Conventional wisdom argues that other parental characteristics (eg, race, ethnicity, socioeconomic status, perceived discrimination) are covariates of LEP, and as such, may be the root causes of child health disparities. Yet, LEP itself is known to be an important proxy for acculturation and a modifiable factor for improving health care access.<sup>20–22</sup> Thus far there has been no systematic assessment to determine whether parental LEP is independently associated with health outcomes for CSHCN and is therefore an important social determinant of health for CSHCN. The aim of this systematic review of peer-reviewed literature was to assess our current understanding of parental LEP as it relates to health outcomes for CSHCN.

## METHODS

### ELIGIBILITY CRITERIA

Our review included only observational or experimental studies (cohort, case-control, cross-sectional, and randomized clinical trials) published in the US. Policy and opinion statements, case studies, and studies with only qualitative data were excluded. Studies were

included if: 1) subjects were children aged 0 to 18 years with any special health care needs based on the MCHB definition; 2) studies included some measure of parental LEP (such as level of English proficiency, primary household language, or preferred language of interview); 3) results included at least 1 outcome measure of child health status, access, utilization, costs, or quality; and 4) findings were based on primary or secondary data analysis.

### INFORMATION SOURCES

We searched 4 electronic databases of peer-reviewed literature, including PubMed, Scopus, Cochrane Library, and Social Services Abstracts, for articles that included these key search term categories: 1) language (eg, “language,” “communication barriers,” “English proficiency,” “non-English,” “multilingualism,” “minorities,” “cultural,” “ethnic”); 2) child (eg, “child,” “youth,” “adolescent,” “teen,” “family”); 3) special health care needs (eg, “disabilities,” “children with special health care needs,” “youth with special health care needs”); and 4) health outcomes (eg, “outcome,” “disparity,” “access,” “demand,” “insurance,” “uninsurance”) (Table 1). Searches were restricted to US English-language studies published from 1964 to September 4, 2012. Citations listed in bibliographies of articles that met eligibility criteria, including prior systematic reviews and meta-analyses, were also reviewed. An experienced librarian was consulted to develop search strategies.

### ARTICLE SELECTION

Studies were selected in a 2-step process. First, titles and abstracts derived from database searches were independently screened and flagged by 2 reviewers if potentially meeting eligibility criteria (AP and NF). Second, flagged studies were examined in full for inclusion by a third reviewer (MEW). Reviewers met regularly to discuss study classification and coding. Disagreements were resolved through discussion with the third reviewer (MEW), who reviewed full-text articles. Interrater reliability for title and abstract screening was moderate (kappa coefficient = 0.5228; range for moderate kappa = 0.41–0.60).<sup>23</sup> Data were then independently extracted from included studies by 2 reviewers (AP and MEW) using a structured tool<sup>24–27</sup> (Appendix) and reviewed together for completeness (AP and MEW).

### ANALYSIS

Data extracted from each study included: the type and number of subjects studied, study design type, covariates used to control for socioeconomic status, whether or not studies controlled for Hispanic ethnicity by language subgroup (English-speaking, Spanish-speaking), measure of parental LEP, objective primary outcome measures, parent- or child-reported primary outcome measures, and the magnitude and direction of associations between parental LEP and the primary outcome measures, including adjusted odds ratios with 95% confidence intervals.

Two senior reviewers (LS and DB) then independently assessed the methodological rigor of each study in these

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