



Children and Youth with Special Health  
Care Needs National Research Network

# Research Project Brief

## **PROJECT** | High Quality Health Care, IDEA Services, and Adverse Family Impact for US CSHCN: The Role of Prematurity in Early Childhood

- *Term: September 2018 to August 2019*
- *Grantee: CYSHCN*
- *Sub-recipient: Mass General Hospital for Children*
- *Funding Agency: Health Research Services Administration, MCH Research Networks Program*
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**Background** | Many children are born prematurely in the United States, yet little information exists on their healthcare access and negative family impact in the first five years of life. This study's purpose was to (1) understand differences in healthcare access and negative family impact among young children according to if they were born prematurely and (2) determine associations of healthcare access with negative family impact among young children born prematurely. We used 2016 and 2017 National Survey of Children's Health data on 19,482 children who were 0 to 5 years-old in the United States. This included 242 children born with very low birthweight (less than 1,500 grams at birth) and 2,205 children born with low birthweight (1,500 to 2,499 grams at birth) or preterm (born at less than 37 weeks). Healthcare access was measured by adequate health insurance, access to a medical home, and developmental screening. Negative family impact was measured by \$1,000 or more in annual out-of-pocket medical costs for the child, having a parent who cut-back or stopped work, parental aggravation, mother's health not being excellent, and father's health not being excellent. Very low birthweight children had higher risk of having a parent cut-back or stop work compared to other children. Adequate health insurance and medical home were each associated with lower risk of \$1,000 or more in annual out-of-pocket costs, having a parent cut-back or stop work, and parental aggravation among children born prematurely. Study findings show better healthcare access is linked to lower risk of negative family impact for young children born prematurely in the United States. To help increase healthcare access and decrease negative family impact for young children born prematurely, health initiatives should focus on this subgroup of children with special health care needs.

**Potential Impact** | Children born with prematurity often have special health care needs. They may benefit from additional health and educational services that can be difficult to access without a formal diagnosis. It is, therefore, important to better understand health care access and educational services receipt during the early childhood period for children born with prematurity in hopes of better optimizing their health across the lifespan.



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### **Publication**

Healthcare access and adverse family impact among U.S. children ages 0–5 years by prematurity status

<https://bmcpediatr.biomedcentral.com/articles/10.1186/s12887-020-02058-0>

### **Organizations Involved**

- MassGeneral Hospital for Children

