



Children and Youth with Special Health Care Needs National Research Network

# Research Project Brief

## PROJECT | Health System Research Priorities for Children and Youth With Special Health Care Needs – CYSHCN National Research Agenda

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**Background** | In this study, we sought to establish priorities for a national research agenda for children and youth with special health care needs (CYSHCN) through a structured, multistakeholder, mixed-methods approach. Using surveys, we solicited responses from >800 members of expert-nominated stakeholder organizations, including CYSHCN families, health care providers, researchers, and policymakers, to identify what research with or about CYSHCN they would like to see in a national research agenda. From 2835 individual free-text responses, 96 research topics were synthesized and combined. Using an adapted RAND/UCLA Appropriateness Method (a modified Delphi approach), an expert panel rated research topics across 3 domains: need and urgency, research impact, and family centeredness. Domains were rated on 9-point Likert scales. Panelist ratings were used to sort research topics into 4 relative-priority ranks. Rank 1 (highest priority) research topics had a median of \$7 in all domains. The RAND/UCLA Appropriateness Method was used to prioritize CYSHCN research topics and depict their varying levels of stakeholder-perceived need and urgency, research impact, and family centeredness. In the 15 topics that achieved rank 1, social determinants of health (disparities and rurality), caregiving (family resilience and care at home), clinical-model refinement (effective model elements, labor divisions, telemedicine, and system integration), value (stakeholder-centered value outcomes, return on investment, and alternative payment models), and youth-adult transitions (planning, insurance, and community supports) were emphasized.

**Potential Impact** | The consistency of our results, whether evaluated across the complete stakeholder group or among family stakeholders alone, suggests that they accurately reflect priorities of CYSHCN families. The synthesis of opinions of a national multidisciplinary group of CYSHCN experts, including family caregivers, represents a fundamental first step toward the development of a national research agenda to improve CYSHCN health systems. The work prioritizes the most important systems level questions, facilitates setting research goals related to these questions, and contributes to a blueprint to guide investigators to work cohesively toward achieving an idealized vision of comprehensive coordinated systems for CYSHCN.



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**Publication**  
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**Organizations Involved**  
CYSHCN



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