



Children & Youth with Special Health Care Needs National Research Network

FOR IMMEDIATE RELEASE

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National Research Agenda Highlights Priority Research Topics for Children with Special Health Care Needs

Aurora, Colo (March 2, 2022) – Nearly 20% of U.S. children have special health care needs. Because of their increased need for health care services, they tend to be the most vulnerable to problems with health systems, including quality and access to care. A national group of researchers aims to improve how health systems work for this vulnerable population through the establishment of a family-centered national research agenda for children and youth with special health care needs (CYSHCN).

In a [supplement to *Academic Pediatrics* released March 2, 2022](#), CYSHCNet provides a blueprint of research priorities aimed at improving health outcomes and the wellbeing of CYSHCN and their families/caregivers.

The supplement encompasses seven papers that explain each of the agenda’s priority topics plus an executive summary paper. The research topics were identified through a rigorous process known as the RAND/UCLA Appropriateness Method (RAM). Through this process, a diverse group of stakeholders, including youth and family caregivers, identified the following priorities:

- Child health and social determinants of health, to examine how the places people live, learn, work, and play impacts health
- Family health and how to support the adaptability of families with CYSHCN
- Caregiving and at-home support
- Telemedicine and supporting families living in rural areas
- Principles of care, to better understanding the keys to successful care management
- Health care financing, including payment models and value outcomes
- Youth-to-adult transitions and how gaps in support impact outcomes

“The agenda and the release of the supplement serves as a call to action for all stakeholders involved in the care of children and youth with special health care needs,” said CYSHCNet director, Christopher Stille, MD, MPH. “There are a lifetime of research possibilities within each topic identified by the agenda, and it’s our hope that researchers look to narrow the gaps that now exist between how health systems currently work and how they could work better for children, youth, and their families.”



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In addition to implications for researchers, the agenda and research gaps reported in the supplement are intended to influence policy and research funding decisions.

“We encourage those funding health systems research to make the most impact by establishing funding priorities aligned with the research agenda,” said Stille.

The supplement can be accessed here: <https://authors.elsevier.com/a/1egT06gdZRqPD9>

About CYSHCNet

[Children and Youth with Special Health Care Needs National Research Network \(CYSHCNet\)](#) is a national group of expert investigators, family leaders, and early-career researchers. Our vision is to improve the health, wellbeing, and quality of life of children and families by creating and promoting research excellence. The network partners with families and collaborates to share findings and train early-career investigators.

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