

Colorado and Boston Hospitals Lead National Network to Improve Health of Children and Youth with Special Needs

July 12, 2019 - A new research network for children and youth with special health care needs ([CYSHCN](#)), led by researchers at the [University of Colorado School of Medicine](#), [Children's Hospital Colorado](#) and [Boston Children's Hospital](#), will lead, promote and coordinate national research activities to improve their systems of care.

Funded through the U.S. Department of Health and Human Services, the Health Resources and Services Administration (HRSA), the Maternal and Child Health Bureau, the 11-site research network will lead, coordinate and promote health systems research for CYSHCN. The network's work will strengthen the base of evidence related to key components of a comprehensive, high-quality system of care for CYSHCN. It will respond to a need among CYSHCN and their families for evidence about how best to deliver and coordinate care for their conditions.

The new network is led by [Christopher Stille, MD, MPH](#), Professor of Pediatrics at the University of Colorado School of Medicine and Children's Hospital Colorado; [Jay Berry, MD, MPH](#), Assistant Professor of Pediatrics at Harvard Medical School and Boston Children's Hospital; and Charlene Shelton, RN, PhD, program manager at the University of Colorado Denver.

“We are very proud to lead the new network. It will be a ‘big tent’ for child health research across the United States, where researchers practice, and policy groups, and patient and family groups can work together,” said Dr. Stille. “We are kicking it off with 11 major institutions and partners, and eventually will include even more. The more diversity in the network, the better information we will get to help improve health care for children with special needs throughout the country.”

CYSHCN has relationships with Family Voices, Association of Maternal and Child Health Programs (AMCHP), American Academy of Pediatrics (AAP), state Medicaid programs, and the Children's Hospital Association (CHA), as well as research networks working in other areas of child and adolescent health. These stakeholders and others have collaborated to create a national research agenda for CYSHCN, which will be published later this year. In collaboration with CHA, the network hosts teams working on secondary database projects related to important health system topics for CYSHCN, including emergency and urgent care, transition to adulthood, disability and Social Security Income, multimorbidity, neonatal care, post-acute care, and chronic medication use.

The first of these secondary database projects, led by Dr. James Feinstein (University of Colorado) and Dr. Berry, focusing on opioid exposure in CYSHCN, has been published in the *Journal of Pediatrics*. Study findings will heighten parental and clinician awareness about choosing whether to prescribe opioids to CYSHCN and, if so, when and how follow-up should occur. Findings will also inform opioid prescribing guidelines and policies for CYSHCN at the hospital and governmental levels such as Medicaid Pharmacy and Therapeutics Committees to ensure the safety of opioid use in CYSHCN. A second completed study on polypharmacy in CYSHCN has also recently been published in the *Journal of Pediatrics*.

“The secondary data and analytics core of the network is thriving,” said Dr. Berry. “Over time, the core will fuel a portfolio of impactful health systems research on CYSHCN.”

Prospective network projects underway include assessing factors that boost parents’ confidence in caring for their children during times of stress; models of collaboration between academic medical centers and community clinicians for children with medical complexity; and a peer mentoring program to help youth with special health care needs transition from pediatric to adult health care.