

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 (CYSHCNet), 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."

CYSHCNet 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.

For more information on CYSHCNet, please visit the CYSHCNet website at www.cyshcnet.org, or the HRSA MCHB, Office of Epidemiology and Research, Division of Research website at <https://mchb.hrsa.gov/research/>.

About Boston Children's Hospital

[Boston Children's Hospital](#), the primary pediatric teaching affiliate of Harvard Medical School, is home to the world's largest research enterprise based at a pediatric medical center. Its discoveries have benefited both children and adults since 1869. Today, more than 3,000 scientists, including nine members of the National Academy of Sciences, 17 members of the National Academy of Medicine and 11 Howard Hughes Medical Investigators comprise Boston Children's research community. Founded as a 20-bed hospital for children, Boston Children's is now a 415-bed comprehensive center for pediatric and adolescent health care. For more, visit our [Vector](#) and [Thriving](#) blogs and follow us on social media [@BostonChildrens](#), [@BCH_Innovation](#), [Facebook](#) and [YouTube](#).

About Children's Hospital Colorado

Children's Hospital Colorado is one of the nation's leading and most expansive pediatric healthcare systems with a mission to improve the health of children through patient care, education, research and advocacy. Founded in 1908 and recognized as a top ten children's hospital by U.S. News & World Report, Children's Colorado has established itself as a pioneer in the discovery of innovative and groundbreaking treatments that are shaping the future of pediatric healthcare worldwide. Children's Colorado offers a full spectrum of family-centered care at its urgent, emergency and specialty care locations throughout Colorado, including its location on the Anschutz Medical Campus, and across the region. Scheduled to open in mid-2019, the new Children's Hospital Colorado, Colorado Springs will be the first pediatric-only hospital in southern Colorado. For more information, visit www.childrenscolorado.org, or connect with us on Facebook and Twitter.

About the University of Colorado School of Medicine

Faculty at the University of Colorado School of Medicine work to advance science and improve care. These faculty members include physicians, educators and scientists at UCHealth University of Colorado Hospital, Children's Hospital Colorado, Denver Health, National Jewish Health, and the Veterans Affairs Eastern Colorado Health Care System. The school is located on the Anschutz Medical Campus, one of four campuses in the University of Colorado system.

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