

For children with complex medical situations, a new roadmap for improving health

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Children with severe disabilities, serious cognitive impairments and medically complex situations require more specialized health care during their lifetimes. But establishing a consistent way to identify their overall health needs and measure progress in meeting those needs has been an elusive goal.

A team of UCLA researchers has developed a set of health outcome measures for such children using a software program that aggregates the latest research and expertise about how to treat their conditions. The team's work, published in the September issue of the journal *Pediatrics*, proposes a standard to shape the ideal model of care for children with medical complexity.

"What we hope to achieve is to not only reduce the amount of time these children spend in the hospital, but also to help improve their overall quality of life," said Dr. Elizabeth Barnert, first author of the study and an assistant professor of pediatrics at the David Geffen School of Medicine at UCLA and UCLA Mattel Children's Hospital. "For these children—and children in general—health also means improving how they're doing in areas like school, their family relationships and social situations."

Children with medical complexity refers to children with serious chronic conditions and functional limitations that often require dependence on technology and very frequent health care needs. Although only 3 percent of children in the United States are considered to fall into this category,

[health care spending](#) for the group makes up an estimated 40 percent of all spending for children's [health care](#) under Medicaid, the public insurance program that largely covers low-income people.

The researchers identified 10 key health outcome domains for children with medical complexity, including social integration, family support, community support, inclusive education and care centered on both patient and family.

In order to develop these health outcome areas, the researchers conducted a systematic literature review followed by a series of interviews with subject-matter experts on children with medical complexity, such as clinicians, researchers, caregivers and policymakers. The interviewees and other national experts then used online software to respond to a prompt asking about the elements for a healthy life for a child or youth with medical complexity.

Once the research team aggregated and categorized the responses, they applied the information to group concept mapping software, a process in which software produces a visual map representing how a group views a particular topic. In this case, the topic was characteristics of health for children with medical complexity.

In the future, the team would like to develop ways to set goals and measure improvements over time in each of the 10 areas, with some areas given higher priority, based on the child's needs. The researchers hope that the set of health outcome areas—and an array of metrics to measure progress across these areas—will enable health systems to better provide a comprehensive model of care for children with medical complexity.

Dr. Paul Chung, chief of general pediatrics at UCLA Mattel Children's Hospital, led the study. Other authors are Dr. Bergen Nelson, Lindsey

Thompson, Dr. Thomas Klitzner, Dr. Moira Szilagyi and Dr. Abigail Breck, all of the department of pediatrics at the David Geffen School of Medicine at UCLA, and Dr. Ryan Coller of the department of pediatrics at University of Wisconsin-Madison.

"Ultimately, our vision is to establish a standard for care that enables health systems to help these children succeed," Chung said. "There are great [health](#) benefits in improving [children](#)'s lives across all of these areas."

More information: Elizabeth S. Barnert et al, A Healthy Life for a Child With Medical Complexity: 10 Domains for Conceptualizing Health, *Pediatrics* (2018). [DOI: 10.1542/peds.2018-0779](https://doi.org/10.1542/peds.2018-0779)

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