

National database puts children with medically complex conditions at risk

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Credit: AI-generated image ([disclaimer](#))

A proposed national database that would serve as a centralized source of information on children with medically complex conditions puts those children and their families at risk for discrimination by making their health information public, and therefore accessible to employers and health insurers, according to experts at Rice University's Baker Institute

for Public Policy.

Quianta Moore, a scholar in [health](#) policy; Tara Blagg, a research associate in the institute's Center for Health and Biosciences; and Hannah Todd, an intern in the institute's Domestic Health Policy Program, outlined their insights in a new issue brief, "Ethical Considerations of a National Database for Children with Medical Complexity."

Introduced in Congress in 2015, the Advancing Care for Exceptional (ACE) Kids Act and its proposed database aims to improve treatment and care coordination.

"A national database for [children](#) with medical complexity has been lauded as an opportunity for researchers to improve treatments, families to receive coordinated care and physicians to provide higher quality care," the authors wrote. "However, the potential for discrimination against children with medical complexity and their families related to making their health [information](#) public creates concerns about the potential impact of passing the ACE Kids Act."

Children with [complex](#) medical condition make up approximately 0.5 percent of all U.S. children but account for almost one-third of all health care spending for children (about \$100 billion). Additionally, in children's hospitals, children with complex medical conditions account for more than half of hospital costs for all admissions and 85 percent of the costs for 30-day unplanned hospital readmissions. The complicated and multifaceted medical needs of these children require services from different specialties and, frequently, from different states. As a result, medical care for these children is often fragmented, the authors said. "Such fragmented care is problematic. Though children with medical complexity depend on comprehensive care, they have to navigate a health care system that struggles to effectively coordinate [health care](#)

services. This lack of coordination likely contributes to the high rates of adverse events (such as medical errors) that children with medical complexity experience compared to all other groups of children."

The 2015 ACE Kids Act proposes a national database in an effort to ameliorate this issue by providing a centralized source of information on children with complex medical conditions. This database would draw on state-level databases to create a single source of information to ensure that physicians would be able to provide care based on meaningful, evidence-based results.

"Although a national database for children with medical complexity is an enticing concept due to the potential improvements in research and medical care, there are ethical implications that make it more complicated," the authors wrote. "How might storing these children's medical records in a national database affect their lives and the lives of their families? Medical records that are widely available can be problematic, because there is a potential for discrimination."

The authors said the Genetic Information Nondiscrimination Act of 2008 (GINA) protects Americans from discrimination by [health insurance](#) providers and employers based on genetic information. Regarding health insurance, it specifically prohibits health insurance issuers from using genetic information to determine eligibility, coverage, underwriting or premiums. This includes information regarding family members. "Unfortunately, GINA only protects an individual with a genetic predisposition for the disease, but not an individual actively suffering from said disease," the authors wrote. "As such, if a child with muscular dystrophy is listed in a national database, the employer of the child's parent has the right to use this information to determine the cost of the parent's, and potentially even the family's, health insurance."

GINA specifically aims to prohibit discrimination based on "genetic

information," a diverse set of data that goes beyond mere genetic test results, the authors said. GINA categorizes family medical history, use of genetic services and participation in genetic research as "genetic information."

"For children with medical complexity, a national database containing medical information may not receive the same type of protection," the authors wrote. "Although many of these children have genetic conditions, protection under GINA would require that [health information](#) from children with medical complexity fall within the statute's definition of '[genetic information](#).' For instance, GINA would likely not provide protection for conditions that have already fully manifested. On the other hand, it is possible that medical information in the [database](#) could be considered family medical history and could be protected under GINA, but this is not guaranteed. Thus, there are risks associated with a [national database](#) for children with medical complexity that are not overcome by the potential benefit of improving care coordination."

More information: Ethical Considerations of a National Database for Children with Medical Complexity: [www.bakerinstitute.org/media/f ... CHB_Database_CMC.pdf](http://www.bakerinstitute.org/media/f...CHB_Database_CMC.pdf)

Provided by Rice University

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