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Ethical Considerations of a National Database for Children with Medical Complexity

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Children with medical complexity (CMC) 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).¹ Additionally, in children's hospitals, CMC 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 CMC require services from different specialties and, frequently, from different states. As a result, medical care for CMC is often fragmented. Such fragmented care is problematic—though CMC 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 CMC experience compared to all other groups of children. The Advancing Care for Exceptional Kids Act of 2015 (ACE Kids Act) proposes a national database in an effort to ameliorate this issue by providing a centralized source of information on CMC. 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. The ACE Kids Act states "Such data [on care for CMC] shall be reported in a

standardized format and made available to the public for purposes of establishing a national database on such claims."²

A national database sounds appealing and promising for improvements in research and care for CMC. It is positioned to optimize care coordination for CMC by holding the children's medical information in one central location that their numerous care providers can access. It would likely make tracking outcomes for CMC easier, allowing for best practices and improvements in care efficiency and efficacy. The existence of a national database would help to provide a more coordinated delivery of care system for CMC patients.

Although a national database for CMC is an enticing concept due to the potential improvements in research and medical care, there are ethical implications that make it more complicated. 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 Genetic Information Nondiscrimination Act of 2008 (GINA) protects Americans from discrimination by health insurance providers and employers based on genetic information.³ Regarding health insurance, it specifically prohibits health insurance issuers from using



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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.⁴ 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.

Additionally, GINA only prohibits genetic discrimination in the realms of health insurance and employment and fails to preclude discrimination based on conspicuous symptoms, or in other areas such as life insurance, disability insurance, and long-term care insurance. The American Medical Association (AMA) noted the risk of third-party access to genetic information in the "AMA Principles of Medical Ethics" by emphasizing how "the prospect of access to and use of such information [about individuals across a wide and growing spectrum of genetic variations associated with disease risk] by third parties who have a stake in an individual's health raises ethical concerns about confidentiality and potentially inappropriate use of genetic information."⁵ Some CMC have genetic conditions that are passed on from their parents, and the presence of this information in a national database could have a detrimental impact on how the parents are viewed and treated by their employers.

Finally, GINA specifically aims to prohibit discrimination based on "genetic information," a diverse set of data that goes beyond mere genetic test results. GINA categorizes family medical history, use of genetic services, and participation in genetic research as "genetic information."⁶ For CMC, a national database containing medical information may not receive the same type of protection. Although many of these children have genetic conditions, protection under GINA would require that all CMC health information 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 CMC that are not overcome by the potential benefit of improving care coordination. The risks specifically lie in the scope of the information protected, and that of protections afforded to patients and their families.

A national database for CMC has been lauded as an opportunity for researchers to improve treatments, families to receive coordinated care, and physicians to provide higher-quality care. However, the potential for discrimination against CMC and their families related to making their health information public creates concerns about the potential impact of passing the ACE Kids Act.

ENDNOTES

1. Jay G. Berry, *What Children with Medical Complexity, Their Families, and Healthcare Providers Deserve from an Ideal Healthcare System* (Palo Alto, California: Lucile Packard Foundation for Children's Health, December 1, 2015).

2. Advancing Care for Exceptional Kids Act, H.R. 546, 114th Congress, 2015.

3. See "Genetic Discrimination" page on the National Human Genome Research Institute website: <https://www.genome.gov/10002077/>.

4. Mark A. Rothstein, "GINA, the ADA, and Genetic Discrimination in Employment," *The Journal of Law, Medicine, and Ethics: A Journal of the American Society of Law, Medicine, and Ethics*, 36, no. 4 (2008): 837–840. doi:10.1111/j.1748–720X.2008.00341.x.

5. “Opinions on Genetics and Reproductive Medicine,” in *AMA Code of Medical Ethics* (Chicago: American Medical Association, 2016), <https://www.ama-assn.org/sites/default/files/media-browser/code-of-medical-ethics-chapter-4.pdf>.

6. Anya Prince and Myra Roche, “Genetic Information, Non-Discrimination, and Privacy Protections in Genetic Counseling Practice,” *National Society of Genetic Counselors*, 23, no. 6 (2014): 891–902. doi: 10.1007/s10897-014-9743-2.

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