# Journal of Health Care Law and Policy

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# Introduction

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# INTRODUCTION

This issue marks the Tenth Anniversary of the Journal of Health Care Law & Policy. The Journal was established in 1997 as a forum for publication of interdisciplinary scholarship on cutting edge issues in health care law and policy and it provides a journal experience for the growing number of students at the University of Maryland School of Law pursuing a specialization in health law. Since its founding, the Journal has fulfilled its mission by providing a space for the interdisciplinary discussion of leading issues in health law, policy, and bioethics, while providing students with an invaluable opportunity to work with leading health law and policy scholars. Recent issues of the Journal have included topics such as the legal and public health challenges of substance abuse, racial disparities in the American health care system, the legacy of tobacco litigation, access to genetic information, and the legal and regulatory obstacles to vaccine development. Journal contributors have included physicians, legal academics, health law practitioners, leaders in health policy, and experts in philosophy, public health, sociology, and other disciplines that consider issues related to health care.

Since its inception, the Journal has stimulated discussion about controversial health law and policy topics by state and federal legislators and been a resource for policy makers, the courts and health lawyers. For example, in the first issue, "Conducting Medical Research on the Decisionally Impaired," articles by Professor Jonathan Moreno and James Childress were cited by the National Bioethics Advisory Commission in its own report on the topic. In a subsequent issue, "Testing and Telling?: Implications for Genetic Privacy, Family Disclosure and the Law," articles by Professors Alta Charo, Ellen Wright Clayton, and National Human Genome Research Institute Director Francis Collins expanded the intellectual debate on the role law should play in governing the disclosure of genetic information by health care professionals to family members. In the issue entitled "The Crisis in Long Term Care," which included articles by Marie-Therese Connolly, Coordinator of the Justice Department's Nursing Home and Elder Justice Initiatives, and Professor Marshall Kapp, authors brought attention to the use of federal laws to improve quality of care in nursing homes. That Journal issue has been cited frequently in the long term care literature. A 2002 issue of the Journal touched on the topic of medical research as it relates to children. In that issue, entitled, "Research with Children: The New Legal and Policy Landscape," Duane Alexander, Director of the National Institute of Child Health and Human Development, wrote about the history of medical research using children as subjects in his article, "Regulation of Research with Children: The Evolution from Exclusion to Inclusion." In the same issue, we wrote about the implications for public health research of the *Kennedy Krieger* opinion in which the Maryland Court of Appeals ruled on two lawsuits alleging lead poisoning of children enrolled in a study conducted by the Kennedy Krieger Institute. (The table of contents for each of the prior issues of the *Journal* follows this Introduction.)

In large part, the *Journal* has been built on the success of our Law & Health Care Program's conferences, which focus on complex social issues ripe for legal and interdisciplinary analysis and for consideration by courts and legislatures. Most *Journal* issues have been based on these symposia and include more detailed versions of papers delivered at them. However, this anniversary issue of the *Journal of Health Care Law & Policy* is an open issue for which the *Journal* editors sought articles on "hot topics" in health law and policy over the past decade. The published pieces are wholly reflective of this goal, including papers on quarantine laws, genetic torts, cultural competence in health care delivery, regulation of assisted living facilities, and the establishment of an SEC for health care.

Health law has always been, at least in part, a response to new medical and other technologies. The rapid evolution over the last ten years of the internet, genetic science, and reproductive technologies has generated a number of laws and policy initiatives in the areas of electronic medical records, privacy, human subjects research, and assisted reproduction. Our new ability to detect changes in chromosomal structure is an example of a scientific advance that poses challenges for the legal system. In this issue, Daniel Goldberg, Research Professor in Health Law at the Health Law & Policy Institute at the University of Houston Law Center. addresses this challenge in his article, "Against Genetic Exceptionalism: An Argument in Favor of the Viability of Preconception Genetic Torts." A preconception genetic tort occurs when a person is exposed to a mutagen that results in structural changes to that person's DNA. These changes, in turn, can affect any offspring, and because they result in structural alterations to DNA, the offspring potentially carry those mutations in their own germline cells. While courts have confronted the issue of preconception torts for decades primarily through the diethylsulfidamide (DES) litigation, Goldberg asserts that the more recent phenomenon of preconception genetic torts have proved difficult for the judicial system to manage properly. Goldberg argues against genetic exceptionalism and contends that there are no policy considerations sufficient to justify categorically denying the viability of such torts.

During the last ten years we, as a nation, have faced a number of public health threats from the anthrax scare in the wake of 9/11 and the devastation of Hurricane Katrina to the potential spread of the SARS epidemic. The current threat of an avian flu pandemic has resulted in an unprecedented increase in disaster-preparedness research and policy-making. Much of the policy discussion surrounding this issue has focused on the intersection, or more accurately, collision, of individual rights and the government's interest in protecting the public health.

The clashes have been in response to mandatory vaccine initiatives, such as the effort to inoculate health care providers with the smallpox vaccine and laws expanding state ability to quarantine individuals exposed to infectious diseases. In this issue of the *Journal*, Professor Mark Rothstein, Director of the Institute for Bioethics, Health Policy & Law at the University of Louisville School of Medicine, and his Research Associate Meghan Talbott, discuss the impact of quarantine laws on workers in their article, "Job Security and Income Replacement for Individuals in Quarantine: The Need for Legislation." The article addresses the economic impact on quarantined workers, with Rothstein and Talbott proposing two legislative changes to protect quarantined workers during and after a disease outbreak.

The last ten years have also been remarkable in terms of the number of immigrants settling in the United States. The first half of this decade has been the highest five-year period of immigration in American history. Between January 2000 and March 2005, 7.9 million new immigrants settled within our borders. This change in the make-up of our population raises important issues of access to health care and culturally appropriate services, among other things. This issue of the *Journal* includes an article entitled "Legislation as Intervention: A Survey of Cultural Competence Policy in Health Care," in which four authors discuss the concept of cultural competence training in the health care context. The authors argue that cultural competence training plays an important role in addressing health and health care disparities and in helping providers offer services that are culturally and linguistically appropriate, allowing them to comply with related legislation. In the long run, they argue, such training in this area may allow services to be delivered more effectively, thereby saving money and increasing capacity.

Another important demographic trend that has influenced recent developments in health law is the continued "graying" of Americans. The number of Americans over sixty-five years old has grown from 31.2 million in 1990 to 35 million in 2000 and is predicted to reach 40.2 million in 2010. This trend has critical implications for the health care industry and policy-makers in the areas of Medicare and Medicaid coverage, end-of-life decision-making, and the quality of nursing homes and assisted living facilities. This issue of the *Journal* includes an article by Eric Carlson, Director of the Long-Term Care Project at the National Senior Citizens Law Center in Los Angeles, on the controversial topic: "Protecting Rights or Waiving Them? Why 'Negotiated Risk' Should Be Removed From Assisted Living Law." Carlson's article provides the first legal analysis of state negotiated risk laws, which are the laws that cover agreements limiting an assisted living facility's liability in certain circumstances. Carlson proposes that negotiated risk be abandoned and that all references to negotiated risk be eliminated from state law.

A final important development in health law over the last decade has been the growing emphasis on patient safety, quality of care, and the availability of

information about provider safety and quality for consumers. In 1999, the Institute of Medicine (IOM) issued its landmark report, *To Err is Human*, which alerted the health care industry and policy-makers to the large number of preventable patient injuries and deaths occurring in U.S. hospitals. Federal and state governments quickly realized that action was needed to address the recommendations in the IOM report. An integral part of the IOM report recommendations was the importance of making information available to consumers. This "market" concept—generating more informed consumers of health care services—is the subject of an article in this issue of the *Journal* by Keith Peters, a practicing attorney in Nebraska. His article, "What Have We Here? The Need for Transparent Pricing and Quality Information in Health Care: Creation of a SEC for Health Care," recommends a congressionally created health care provider commission, modeled on the SEC, to provide transparent pricing and quality information to all consumers.

We hope that the issue stimulates thought and further debate on these many issues. As the *Journal of Health Care Law & Policy* enters its second decade, it will continue to provide an opportunity for health care lawyers and policy-makers to share their research, scholarship, and recommendations on the issues that affect the fast-paced and evolving world of health care.

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