**ONLINE SUPPLEMENT**

**The Model State Public Health Privacy Act**

Developers of the Privacy Act (1999) sought to both make existing state law governing the protection of health information by public health agencies more consistent across states, as well as promote high standards for the protection of personal health data nation-wide (Interview 18; Interview 64; Interview 113). The CDC sponsored the model act, which was drafted by Georgetown Professor Lawrence Gostin and then-Adjunct Professor James Hodge with the input of a high-level, and very diverse, expert advisory board (Gostin and Hodge 1999). The Privacy Act was developed alongside federal health information privacy regulations, the Health Insurance Portability and Accountability Act, commonly known as “HIPAA” (Interview 149). However, HIPAA does not apply to health information collected by state public health departments (Gostin et al. 2001); therefore, states bear the responsibility for creating laws to govern the use and privacy of health information collected by public health agencies.

In the late 1990s there was considerable debate and controversy in the public health and HIV/AIDS activist communities about the sensitive data public health agencies were collecting on people with HIV/AIDS (Interview 124; Interview 149). The CDC and the academics involved were interested in creating a model law that would help states protect patients’ privacy while also allowing state public health departments to collect and share data. The advisory board included state legislators, HIV/AIDS advocacy organizations, the ACLU, representatives from federal agencies, a wide range of scholars (e.g. law professors, bioethicists, epidemiologists), and national organizations of public health practitioners (Gostin and Hodge 1999). The full board met to discuss an initial draft in Washington, D.C. in 1998. After serious objections were raised regarding the strength of the privacy protections by the self-named “Gang of Three” (the ACLU, AIDS Action Council, and Lambda Legal Defense and Education Fund), additional drafts were created and sent back to the advisory board (Fairchild, Bayer, and Colgrove 2007, 230–33). A final draft was completed in 1999 and disseminated to state legislatures and the larger public health community; however, it was considered too restrictive to gain the support of health officials like epidemiologists who valued the legal flexibility required for data sharing, analysis, and patient follow-up (Fairchild, Bayer, and Colgrove 2007, 233). Although bills based on the act were introduced in a few states, the model law was not ultimately adopted (Fairchild et al. 2007:233; Interview 56; Interview 113). However, the provisions included in the Act were incorporated into two of the subsequent model laws: the Emergency Powers Act and the Turning Point Act.

**The Model State Emergency Health Powers Act**

Shortly after the terrorist attacks of September 11, 2001, and the subsequent anthrax attacks in October, the CDC asked Gostin and CLPH (with whom it had previously entered into a multi-year cooperative agreement) to “drop everything” and draft the Emergency Powers Act (2001) (Interview 37; Interview 87). The Emergency Powers Act gives governors the ability to declare a “public health emergency” under certain conditions. The emergency declaration then triggers additional state emergency powers to share public health data, take control of private property, and treat and confine people thought to potentially pose a health risk to the public (Center for Law and the Public’s Health 2001). The Emergency Powers Act was drafted and promulgated in reaction to the events of 9/11, when developers knew that state legislatures were likely to take action on an emergency preparedness model act (Interview 36; Interview 119). However, in the months prior to 9/11, in partnership with CLPH, the CDC had already formulated plans to reform state public health law so as to broaden states’ ability to respond to public health emergencies, make state law more consistent, and raise the legal standards of due-process protections (Interview 119).

A small group of scholars affiliated with CLPH, put together the Emergency Powers Act in less than six weeks in consultation with the CDC (Interview 119). Gostin and Hodge were both primary drafters, although the work was divided up among a larger group of CLPH scholars, including Stephen Teret, who initially co-directed CLPH with Gostin, as well as CLPH Associate Directors Jon Vernick and Scott Burris (Interview 37, n.d.; Johns Hopkins Bloomberg School of Public Health 2000). CLPH produced a first draft of the law in late October, posted it on a public website to solicit comments, and sent it out to external scholars and organizations to obtain feedback (Interview 37; Interview 93). I characterize this drafting process as “expedited” because the law was created in an unusually short time period, and the mechanisms of expert review utilized were more “external” as compared with the other model laws.

The first draft of the Emergency Powers Act received an enormous amount of feedback—a considerable proportion of which was highly critical of the provisions from a civil liberties and bioethics standpoint (ACLU 2002; Annas 2002; 2003; Blevins 2002). The model act was revised again and released in its final form to the public in late December 2001. In stark contrast to the Privacy Act, as of August 2011, 40 states adopted the Emergency Powers Act in whole or in part (Hodge and White 2012). Since 2001, public health emergencies have been declared a number of times, including for H1N1 and Ebola, as well as for more routine health events, including substance abuse problems in Massachusetts (Interview 36; Interview 2014).

**The Turning Point Model State Public Health Act**

The Turning Point Act (2003) was the product of the Robert Wood Johnson Foundation (RWJF)-funded Public Health Statute Modernization National Excellence Collaborative. Developers of the Turning Point Act sought to help states assess and update their state public health laws to explicitly state the roles and responsibilities of state health departments, respond to public health emergencies (incorporating the Emergency Powers Act) and protect public health privacy (incorporating the Privacy Act) (Interview 174). The Turning Point Act had a particularly low emphasis on uniformity; it was marketed to states explicitly as a “tool” rather than something that should be adopted wholesale. The model act was just one piece of RWJF’s larger Turning Point Initiative, a nationwide, ten-year program to improve state and local public health systems. Gostin and Hodge of CLPH were paid consultants who advised and drafted the act.

The model act was the product of a three-year collaborative effort, where a large group of public health officials from five states came together with representatives of national associations and other academics to work on a comprehensive model public health law. The process by which the Turning Point Act was created can be clearly characterized by consensus—indeed it was often referred to as a “consensus process” (Interview 117). The act defines the role and responsibilities of public health agencies, and includes provisions for a wide range of issues including those found in Privacy Act and the Emergency Powers Act (Turning Point Public Health Statute Modernization Collaborative 2003). Thus, the Turning Point Act is the most comprehensive of the three acts and incorporates the earlier two. As of August 2007, the date of the last systematic adoption count, 26 states had adopted at least one part of model law (Center for Law and the Public’s Health 2007).

**The Uniform Emergency Volunteer Health Practitioners Act**

The Uniform Law Commission (ULC) drafted the Emergency Volunteers Act (2007) in response to Hurricane Katrina, which struck the Gulf Coast in 2005. That year, the Association of State and Territorial Health Officials (ASTHO) identified the “lack of national standards for the deployment and use of public health and emergency response personnel” as a key factor that impeded the emergency response to Hurricane Katrina (National Conference of Commissioners on Uniform State Laws 2007, 3). In 2006, the ULC appointed a study committee and convened a meeting hosted by the American Red Cross to determine if a uniform state law could ameliorate these problems (National Conference of Commissioners on Uniform State Laws 2007, 4). At that meeting, representatives of ULC, Red Cross, ASTHO, and a number of national associations representing health practitioners, e.g., the American Medical Association, agreed via “consensus” that the ULC should appoint a drafting committee for the uniform act (National Conference of Commissioners on Uniform State Laws 2007, 4). Developers of the Emergency Volunteers Act sought to establish a national registry system that would make it easier for volunteer health practitioners to practice out-of-state in the context of natural or man-made disasters. In addition, the Emergency Volunteers Act has provisions that limit the liability of volunteer health practitioners, as well as the organizations that host them, in emergency situations, and provisions relating to worker’s compensation for volunteers (Hodge, Pepe, and Henning 2007).

The ULC is made up of appointed volunteer lawyers, called commissioners, from all 50 states. The organization prides itself on being non-partisan, and taking great care with the drafting of uniform laws (i.e. making sure that the wording is correct) (Interview 14). They appoint a “reporter,” usually an academic—to handle the drafting (Interview 133). Hodge of CLPH served as the reporter for the Emergency Volunteers Act. In addition, the ULC appoints a drafting committee made up of commissioners to assist and vote on the final version of the law. Outside observers representing a broad base of stakeholders are invited to participate in committee meetings, review drafts and offer expertise and feedback; however, they cannot vote on drafts or the final act. As an institution, they emphasize a deliberative process (Interview 24). In this way, I have characterized the Emergency Volunteer Act drafting as “procedural.” Although the drafting of the Emergency Volunteers Act was marked by substantial internal disagreement, many involved cheer the uniform act as a success; the ULC reports that it has been adopted by 19 jurisdictions (including the U.S. Virgin Islands and D.C.) (Uniform Law Commission 2020).

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