



New England First Amendment Coalition

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SENT VIA ELECTRONIC MAIL

Department of Health and Human Services
Maine Center for Disease Control and Prevention
11 State House Station
Augusta, ME 04333-0011
c/o Bridget Bagley

RE: Proposed Changes to Data Release Rule, 10-144 CMR, Chapter 175

July 25, 2015

Dear Ms. Bagley,

On behalf of the New England First Amendment Coalition, I'm urging the Maine CDC to reconsider its recently proposed changes to the Data Release Rule. While these changes are intended to protect the privacy of individuals, they are neither necessary nor helpful to the public's response to infectious disease outbreaks. Worse, they may jeopardize the safety of those who would otherwise learn of potential risks to their health.

The type of information that could be withheld under your proposal — the names of schools, community centers and restaurants where outbreaks occur, for example — is crucial to the public's understanding of infectious diseases and necessary for a measured response to them. According to the American Public Health Association, "regular communications about the outbreak and risk of infection is one of the most important parts of an outbreak response." *See Communicable Diseases Manual (20th ed. 2015), American Public Health Association, pgs. A9-A10.* With a full understanding of how an outbreak is effecting their communities, residents can "avoid undue panic or concern, create an environment where additional cases can be identified," and perhaps most importantly, "help individuals and communities understand how transmission can be stopped." *Id.*

The Maine Freedom of Access Act already balances this need for health information with individual privacy protections. The statute allows for the release of "medical and epidemiological information" but "in such a manner that an individual cannot be identified." *See 22 M.R.S. § 42(5).* The statute makes no distinction between information that directly identifies an individual and the non-identifiable epidemiological data the center would make confidential. This is for good reason: There are few matters, if any, as important to Maine residents as public health and safety. Narrowing the scope of public information will make it more difficult — if not impossible — for residents to learn about disease outbreaks in their communities and take action to protect themselves and others.

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Consider the following scenarios that could occur under your proposal:

Five children are diagnosed with viral meningitis. Meningitis can be “very serious” and “it’s very important for anyone with symptoms of meningitis to see a healthcare provider right away.” See www.cdc.gov/meningitis/viral.html (last visited July 23, 2016). The children attend a school in a town-owned building with hundreds of other students. When the building isn’t being used for classes, it’s used for community functions that are open to the general public. Because of the number affected (less than six) and the number of children at the school (less than 2,000), the name of the facility is kept confidential. The parents of all other children at the school must now rely on the diligence of town officials to stay informed about preventative measures such as hand-washing and not sharing drinks. Extended family and friends who recently spent time with the afflicted children must rely on the forthcomingness of the parents to obtain information about possible symptoms. Community members using the building after hours have only town gossip, if anything, to explain why the door knobs in the facility were just scrubbed and the rooms thoroughly cleaned.

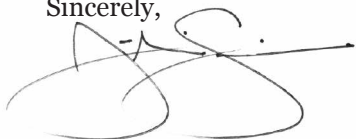
An employee at a new restaurant discovers she has Hepatitis A, a contagious liver disease that could result in “severe illness lasting several months.” See www.cdc.gov/hepatitis/hav/afaq.html (last visited July 23, 2015). Hepatitis often spreads when a person ingests fecal matter from contact with, among other things, food and drinks. *Id.* The employee worked in the restaurant’s kitchen and recently helped prepare food for about 100 dinner guests, exposing them all to some risk of contracting the virus. The restaurant didn’t keep a guest list and officials don’t know the names of all those who could be infected. Because only one person had hepatitis and fewer than 2,000 people ate dinner that night at the restaurant, the name of the establishment is withheld. Health officials notify those guests they could identify. Still, some number of unidentified restaurant patrons are back at home with their families, uninformed about the potential exposure and unaware that they have only a two-week window to receive vaccination.

These aren’t mere hypotheticals. A chicken pox outbreak occurred during the 2014-2015 school year, affecting several local schools. Two of them had less than six students with the illness. While chicken pox is not as serious a health concern as meningitis, it took a lawsuit by the Portland Press Herald to compel the disclosure of how many cases were found in each school. Under the new policy, withholding this information — whether for chicken pox, meningitis or a more serious illness — would become the norm. In 2013, a Durham church served a public dinner during which an employee with hepatitis helped prepare the food. Contrary to the policy now being proposed, the CDC at the time publicly named the church and helped educate the community about the risk of contracting the disease. With a change to the data release rule, it can be assumed that this type of much-needed disclosure would rarely occur.

The new policy would also allow the CDC to withhold the location of outbreaks when the number of infected individuals is larger and the pool of those potentially exposed is smaller. If 98 students in a school of 100, for example, were to contract an infectious disease, the center could withhold the name of that school and keep the public uninformed about where the outbreak occurred. It defies common sense to keep the location of an outbreak secret from the public when 98 percent of those at that location were infected.

For Maine residents, this policy change is of great concern considering the health risks involved and the relatively high percentage of residents that remain unvaccinated for various diseases such as the chicken pox. As the executive director of the National Academy for State Health Policy recently told the Press Herald, as much transparency as possible is preferred when promoting public health. Indeed, Maine residents have a right to know where outbreaks occur in their communities. The center’s proposed data release policy will severely curtail that right to know and put the safety of those residents at risk. While our organization understands the need to protect individual privacy in certain situations, this rule is neither a reasonable nor a safe way to do so.

Sincerely,



Justin Silverman
Executive Director



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