LeadingAge New York CONCERN

SENIOR HOUSING | ASSISTED LIVING | ADULT CARE FACILITIES | HOME CARE | RETIREMENT COMMUNITIES
ADULT DAY HEALTH CARE | PACE/MLTC | NURSING HOMES

MEMORANDUM

A.31 (Paulin)/S.5722 (Skoufis)

An act to amend the public health law, in relation to creating the health emergency response data system

LeadingAge New York has concerns with this legislation, which aims to create in statute the Health Emergency Response Data System (HERDS) and require the Department of Health (DOH) to disclose, within 7 days of its receipt, the aggregate data from HERDS reports to the entities reporting, government entities, and the public. First and foremost, LeadingAge NY supports the intent to increase transparency around public health emergencies (PHEs) and communicable diseases and the resources, needs and services of health care providers. However, this legislation requires clarification and an extended timeline for implementation and publication of data.

Although the legislation indicates that it would *create* the Health Emergency Response Data System (HERDS), a HERDS system is already in place -- the Health *Electronic* Response Data System (HERDS). The existing HERDS system is used for collection of a wide variety of provider data, not merely data pertaining to PHEs. This system is constantly evolving in response to changes in the health care and policy environment. Most recently, it was used to collect data concerning the impacts on providers of the Change Healthcare cyberattack.

With a broad-based HERDS system already in place, the system and the data to which this legislation would apply should be clarified. Although the intent of the legislation is to bring transparency to information gathered during PHEs, the use of the HERDS platform suggests a broader scope. Further, although the legislation would maintain the confidentiality of individually-identifiable information and refers to the disclosure of "aggregate" data, it does not define "individually-identifiable" – a term that typically refers to data about humans rather than about entities. The goals and content of the bill, however, suggest that it is intended to preserve the confidentiality of information identifying providers or other survey respondents. Aggregating data and protecting the identity of both responding providers and individuals would be important, given other issues presented by the bill that are discussed below. In addition, the bill requires the disclosure of details concerning geography and hospitals. The ability to effectively de-identify data, while maintaining this level of detail may be limited by the nature of the data. To the extent that data is sensitive in nature and difficult to de-identify, it should not be subject to disclosure.

It is important to recognize that, as we learned during the COVID emergency, data collection instruments (i.e., the survey questions) developed in an emergency are often created hastily and rolled out with little advance notice or training for providers. These instruments should evolve in response to changing conditions, although such revisions often lag behind changes in diagnostic techniques, therapeutics, and vaccines. Data submitters typically have little opportunity to establish systems and training for the collection and submission of the data elicited by the collection instruments. Those who are responsible for gathering and submitting the data may be operating under crisis conditions, protecting the health and safety of patients and residents. As a result,

inconsistent interpretations of data requests and errors in submissions are inevitable. Accordingly, if the posted data are to provide a valid picture of conditions in the field, it is critical that providers be given the opportunity to correct any errors made in their HERDS reporting.

The 7-day timeline for disclosure of the data collected under this new HERDS system will not allow for sufficient time to make corrections or to ensure de-identification prior to publication. We recommend that the deadline for publication be extended and that providers be permitted to correct data, even after publication.

In addition, it is important to recognize that much of the data collected by the current COVID-19 HERDS survey instrument is likely neither valid nor useful. Although the survey instrument has been revised over the course of the pandemic, the Department of Health has been reluctant to define terms or revise the phrasing of questions in response to feedback that the questions are subject to multiple interpretations or do not address current conditions.

For example, the survey questions on the nursing home and adult care facility survey concerning vaccinations are particularly puzzling and counterintuitive. They do not elicit information concerning the number of residents who are up-to-date in their COVID vaccination status. Instead, they are focused on eliciting information concerning the number of residents who have received a *complete* primary vaccine series (which could be the 2021 vaccine series) and any additional vaccine and the number of residents who have been vaccinated by the facility. When asking about the numbers who have declined the vaccine, the questions are intended to elicit the number of residents who have never been vaccinated against COVID. The survey does not elicit information about residents who were vaccinated against COVID in the past and are declining the current vaccine. We believe that these questions are subject to interpretation, and even if they are consistently interpreted as intended, the data collected are of little value. The important data point is the number of residents who are up-to-date in their vaccination status, not the number who were vaccinated early in the pandemic and received any additional vaccine.

For these reasons, we urge the Legislature to oppose A.31 (Paulin)/S.5722 (Skoufis) as it is currently written and make appropriate amendments to address these concerns.