December 4, 2024

The Honorable Kathy Hochul
Governor
NYS State Capitol
Albany, NY 12224

Re: A.5370 (Paulin)/S.5732 (Skoufis)

Dear Governor Hochul,

LeadingAge New York and its not-for-profit, mission-driven members write to you today in opposition to A.5370 (Paulin)/S.5732 (Skoufis). This legislation, while well-intended, seeks to create a statutory Health Emergency Response Data System (HERDS) and requires the Department of Health (DOH) to disclose aggregate data from HERDS reports within seven days of receipt. LeadingAge New York supports the goal of enhancing transparency surrounding public health emergencies (PHEs) and the resources, needs, and services of health care providers. However, several practical issues compel us to urge a veto of this bill, as well as the elimination of the existing, *daily* COVID-19 adult care facility (ACF) and nursing home COVID-19 HERDS reporting requirement.

Firstly, 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 the collection of a broad spectrum of provider data, not merely data pertaining to PHEs. This system is intended to evolve in response to changes in the health care and policy environment. For example, it was recently used to collect data concerning the impacts on providers of the Change Healthcare cyberattack. With a broad-based HERDS system already in place, the legislation lacks clarity regarding the specific system and data to which it would apply. 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 information that can be linked to a specific person, rather than to an entity. The goals and content of the bill suggest that it is *intended* to preserve the confidentiality of information identifying providers or other survey respondents. However, the bill requires the disclosure of details concerning geography and hospitals. It may be infeasible to effectively de-identify these data, while disclosing the information required by the bill. To the extent that data is sensitive in nature and difficult to de-identify, it should not be subject to disclosure.

The practical implications of the legislation's timeline for corrections should also be considered. The COVID-19 emergency revealed that data collection instruments developed hastily in response to a crisis can suffer from imprecise language that is subject to varying interpretations and can quickly become irrelevant as conditions evolve. Particularly during a PHE, providers operating under crisis conditions to protect residents would deserve an opportunity to correct any errors in submitted data to ensure validity and fair public representation.

Inspire Serve Advocate

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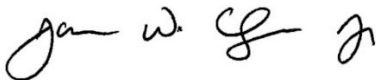p 518.867.8383 | f 518.867.8384 | www.leadingageny.org

The seven-day timeline for data publication proposed by this legislation is insufficient for making necessary corrections or ensuring de-identification before public disclosure.

The current daily HERDS survey submitted by all ACFs and nursing homes is an excellent example of the risks associated with publishing and relying upon data collected using a data collection instrument developed during an emergency. Due to flaws in its questions, the HERDS survey collects largely irrelevant and unreliable data. For example, instead of asking for the number of residents who have received the 2023-2024 vaccine doses (or now the 2024 updated vaccine), the HERDS survey requests the number of residents who have received "their complete COVID-19 vaccine series (either first and second dose of a two dose vaccine or a one dose vaccine)" and "at least one additional or booster dose." The survey's ongoing focus on the now obsolete 2020-22 vaccines is puzzling and confusing to data reporters. Ultimately, the data collected by the daily HERDS survey is of limited use to the public or public health authorities.

LeadingAge NY and our members understand the importance of data to inform public health decisions. However, the daily collection of granular information about COVID tests, infections and immunizations in long-term care facilities is no longer necessary. Even if such data were indeed needed and helpful to the public, the HERDS survey would be an inappropriate source, given the flaws in its drafting. Moreover, the types of data captured by the nursing home HERDS survey are also collected through the CDC's National Healthcare Safety Network (NHSN), which uses a clearly written, regularly updated collection instrument, supported by a data dictionary and online trainings. Not only is the HERDS survey largely useless and duplicative of NHSN data, it also imposes unnecessary burdens on our depleted workforce.

For these reasons, LeadingAge NY urges a veto of A.5370 (Paulin)/S.5732 (Skoufis). The legislation would require significant amendments to ensure that published data are valid and that transparency is enhanced without disclosing information that should remain confidential. Further, LeadingAge NY urges you to eliminate the current daily COVID-19 HERDs survey requirement, as New York State is no longer in a public health emergency, necessary data can be collected more efficiently, and staff resources are needed elsewhere.

Sincerely,

James W. Clyne, Jr.
President and CEO
LeadingAge New York