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MEMORANDUM

A.5370 (Paulin)/S.5732 (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 submitted during public health emergencies (PHEs) to the entities reporting, government entities, and the public. First and foremost, LeadingAge NY supports the intent to increase transparency around PHEs and the resources, needs and services of health care providers. However, this legislation requires clarification and an extended timeline for 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.

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 also 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.

Finally, it is important to recognize that, as we learned during the COVID emergency, data collection instruments (i.e., the survey questions) developed in a PHE are created hastily and evolve frequently. Data submitters 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 are operating under crisis conditions, protecting the health and safety of patients and residents. As a result, errors and inconsistent interpretations of data requests are inevitable. Accordingly, 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.

For these reasons, we urge the Legislature to oppose A.5370 (Paulin)/S.5732 (Skoufis) as it is currently written and make appropriate amendments to address these concerns.