



November 7, 2024

Valerie Deetz, Deputy Director
New York State Department of Health
Office of Aging & Long-Term Care
New York State Department of Health
875 Central Avenue
Albany, NY 12206

Dear Ms. Deetz,

LeadingAge New York, the Empire State Association of Assisted Living, and the New York State Center for Assisted Living, together representing most of all licensed adult care facilities (ACFs) and assisted living communities in the state, are writing with regard to concerns regarding new adult home regulations. Specifically, we were concerned to see in the Sept. 25th *State Register* the finalized new adult home regulation, a new paragraph is added section 487.10(e):

(5) For all facilities, a roster of all residents shall be submitted to the department on a quarterly basis in the manner prescribed by the department.

This change was made in the context of changes to the transitional adult home regulatory changes, however only this change applies to *all adult homes*. Despite concerns raised during the public comment period, the regulation was finalized, reportedly for the purpose of assisting with program development and improved data integrity. We are unclear of the nature and scope of the data required for the rosters, how the Department plans to use this data, and for what specific purpose. We are concerned about resident privacy and that the data collected through this new roster requirement may mirror the extensive data submissions currently required of transitional adult homes.

To the extent that the new rosters are similar to those currently required of transitional adult homes, the collection and transmission of this voluminous data raises privacy and data security concerns for the residents of adult homes and will require a significant investment of resources by the adult homes.

New York State Privacy Protection Law

We question what purpose would justify the exchange of personally-identifiable information and protected health information for the over 26,000 adult home residents in the state. If you

are looking for data, why does it have to be resident-specific? Our members are understandably particularly attentive to ensuring the protection of sensitive and identifiable information regarding their residents.

New York State's Personal Privacy Protection Law (Public Officers Law, Article 6-A, sections 91-99), which governs the collection and retention of personal information by state agencies, provides that a state agency may "maintain in its records only such personal information which is relevant and necessary to accomplish a purpose of the agency required to be accomplished by statute or executive order to implement a program specifically authorized by law." (POL §94) The Department has not indicated any statutory authority for this broad collection of information, nor has it indicated why the collection of this protected personal information is necessary for the Department to meet a particular purpose.

The state law also indicates that agencies must collect personal information directly from the data subject whenever practicable, except when collected for the purpose of making quasi-judicial determinations. In addition, data collections must be accompanied by detailed notices to the data subject, which include the authority granted by law for the collection and maintenance of the information and the purpose for which the information is collected. Further, the new rosters appear to be a "system of records" under the law, which must be accompanied by the submission of a privacy impact statement to the Committee on Open Government.

The Department has not articulated to our associations the legal authority or purpose of this data collection, nor has it communicated any determination that the collection of the information from the data subject is impracticable or that a privacy impact statement has been filed.

Using Scarce Resources Wisely

In addition to the significant privacy concerns outlined above, the associations would like to bring to the Department's attention the onerous administrative burdens this data collection will impose, with no apparent benefit to residents. The aging services field is experiencing a workforce crisis. ACFs and assisted living programs that serve low-income seniors are struggling to keep their doors open, and we see an ongoing trend of closures. The ongoing incremental administrative burdens that are added year after year have cumulative effects, and ultimately pull scarce resources away from being able to provide services and supports to residents and from training, developing and supporting staff. We also note that the Department's data reporting requirements typically include a "no tolerance" approach to even the slightest instance of noncompliance or late filing that regularly results in regulatory violations, which will even further stress and deplete facility resources and staff. The Department should be considering the impact of any new requirement, to ensure that the benefit of the requirement merits the administrative burden and cost. Further, the Department should be seeking to simplify or streamline requirements when the burden outweighs the benefit.

Collaborating on a More Targeted Approach

While we are unclear what specifically the Department is attempting to achieve in this endeavor, nor what data will be required, we expect that together we may be able to determine a more targeted solution to improve data integrity or develop a program.

To comply with both the spirit and letter of the Privacy Protection Law and to ensure that adult home resources are focused on resident care, we urge the Department to limit the data collected to the minimum necessary to achieve the Department's goal. The roster that is currently required for transitional adult homes has 22 individual fields to be completed for each resident, including sensitive information such as mental health diagnoses and Medicaid CIN number. And, while all ACF and assisted living providers collect the data requested in the roster, they don't do so in this format. The data exists in various documents that are completed in the admission process, some of which is already provided in the Quarterly Statistical Information Report (QSIR). The provider would have to set up an additional, duplicative process to capture these data points in a way that can be submitted to the Department. If the Department insists that this information is necessary, it is critical that the fields be limited to only those data points truly necessary.

Lastly, we urge the Department to entertain waiver requests for those providers whose circumstances may not relate to whatever problem DOH is trying to solve. Again, this would limit the data exchange to only that information that is truly necessary should be shared.

Conclusion

We share the Department's commitment to work collaboratively to continue to ensure the quality of services provided to ensure the highest quality of life for the people our members serve. We hope that together we can work to address any policy or program issues collaboratively in the future, before they reach a point of proposed regulations.

Sincerely,



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cc:

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