March 5, 2021

Allison Beam, Acting Secretary
Pennsylvania Department of Health
Health and Welfare Building
8th Floor West
625 Forster Street
Harrisburg, PA 17120

Sent via E-mail: abeam@pa.gov

Dear Acting Secretary Beam,

The undersigned aging and disabilities advocacy organizations have joined together in a workgroup to seek solutions to the racial and ethnic disparities which exist within the Commonwealth in access to and quality of long term services and supports. We are writing today to make recommendations to the Department concerning the collection and utilization of data to address these disparities, particularly as they relate to the COVID-19 pandemic.

The August 2020 Governor’s Task Force Report on Racial Disparities and the January 2021 DHS Racial Equity Report recognize the imperative to immediately develop strategies to address long-standing racial, societal, cultural, and institutional inequities that COVID-19 has exposed. Additionally, we understand from a recent presentation by Brian Lentes that the Department of Health will soon be releasing its own Racial Disparities report with approximately 69 recommendations. We applaud the Wolf Administration for its commitment to addressing this important topic. Nowhere have these disparities had more devastating effects than in Pennsylvania’s Long-Term Care (LTC) facilities.

To address racial, ethnic, and language disparities, PA must collect accurate and meaningful data on where disparities exist. This requires the accurate collection of race, ethnicity, and language data, along with the resources to analyze it. We write with recommendations for improving racial, ethnic, and spoken language disparity data collection, analysis, and utilization as relates to COVID-19 and long-term care facilities. We also believe the state should also expand its data collection to capture sexual orientation and gender identity (SOGI) data, however, this is not the focus of this set of LTC facility COVID data recommendations.
We cannot collectively address racial and ethnic disparities if we are not fully informed about the scope of the problem or the impact of our efforts. Accordingly, we have six major data recommendations to address racial and ethnic disparities in long-term care. We believe the state must: 1) improve and expand data collection; 2) share data collected; 3) analyze data and share analysis; 4) probe root causes of disparities reflected in data collected; 5) use data to accomplish meaningful changes in policy and practice; and 6) assess interventions and impact.

Below, we detail each of these six areas of recommendation.

1. **Recommendation #1: Improve and Expand Data Collection**

   We have recommendations that generally apply to data collection on race, ethnicity, and language and recommendations that are specific to race, ethnicity, and language within the LTC facility and COVID-19 context.

   a. Generally, data collection must be broad and inclusive enough to capture the full extent of racial, ethnic, and language diversity in the Commonwealth. Accordingly, we recommend:

   i. Collect race data by 1) African American or Black, 2) American Indian or Alaska Native, 3) Asian, 4) Native Hawaiian or Other Pacific Islander, 5) Other Race, 6) Multiple Race, and 7) White.

   ii. Collect disaggregated ethnicity data –

   1) Currently, the state collects ethnicity by Hispanic, non-Hispanic, or unknown. More precise, disaggregated ethnic data could be collected as subgroups of these categories.

   2) We must further disaggregate Asian health data¹ because disaggregated analyses typically identified differences in access to care for Asian American subgroups. State policies to collect disaggregated health data for Asian Americans may reveal heterogeneity in experiences of care and inform specific policies to reduce disparities in access to care.²

   iii. Collect spoken and written language data for residents and staff.

   iv. Report both raw numbers and rates per 100,000 people. Raw case and mortality numbers do not show the whole picture.

   v. Missing data should continue to be reported as “not reported” yet every effort should be made to enforce reporting requirements and collect required data.

   vi. Search out and employ best practices in data collection.

   vii. Streamline data collection to ensure consistency within DHS and among state agencies. Complete a full inventory of data currently available

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¹ “Institute a statewide standard around racial/ethnic data collection that mirrors the standards in the Affordable Care Act, moving the commonwealth towards disaggregating Asian health data.” – Governor’s task force

across all state agencies to eliminate any duplication of reporting by providers.

b. Specific to Long-Term Care Facilities and COVID-19, the state must:
   i. Collect race, ethnicity, and language data for nursing facilities residents.
   ii. Collect COVID-19-specific data by race, ethnicity, and language data for all nursing facility residents and staff on tests, cases, hospitalizations, ICU bed use, deaths, and other measurable outcomes (as they are identified)
   iii. Collect data in a manner such that COVID-19, LTC Facility, and race, ethnicity, and language data can be compared by zip code, by pre-existing co-morbidities, by payor, by age, and other factors.
   iv. Use multiple sources, including public data, to compile and collect data that includes data derived from individuals’ (MDS) data, facility reporting, CHC-MCOs, Medicaid applications, and any other accessible source.
   v. Make any needed changes to CHC-MCO and LIFE program contract requirements to facilitate data collection.
   vi. Collect data that will support analyzing the racial, ethnic, and language disparities data against other data and across other factors that may have an impact.

2. **Recommendation #2: Share Data Collected**
   Transparency is essential. All data on racial and ethnic disparities must be made public and readily available. Accordingly, we recommend that the state:
   a. Report race, ethnicity, and language (REL) data for each of the following COVID-19 categories: tests, cases, deaths, hospitalizations, ICU admissions, and other outcomes for nursing facility residents
   b. Report weekly, disaggregated totals in addition to cumulative aggregates.
   c. Provide a report in an easily understandable, accessible format.
   d. Make any needed changes to CHC MCO and LIFE program contracts to require CHC-MCO and LIFE Program collection and publication/transparency of data collected.
   e. Create a CHC LTSS disparities dashboard that includes quality and quantitative data to ensure there is equitable access to quality LTSS. Provide details from satisfaction surveys by race and ethnicity and include in dashboard.

3. **Recommendation #3: Analyze Data and Share Analysis**
   The purpose of data collection is to be able to use it to analyze where disparities exist and whether interventions are necessary. Accordingly, it is imperative that the state devote the resources to analyze the data and share the analysis. We recommend that the state:
   a. Utilize the University of Pittsburgh and similar experts to assist with data analysis.
   b. Analyze racial, ethnic, and language data against existing data sources.
   c. Compare nursing facility quality data, including Medicare star ratings, by racial, ethnic, and language makeup of the resident populations.
   d. Monitor health disparities on an on-going basis and produce annual reports on racial and ethnic health disparities in LTC.
   e. Share data analysis publicly through annual reports and more frequent stakeholder
presentations of quarterly data analysis.

4. **Recommendation #4: Probe Root Causes of Disparities Reflected in Data Collected**

National studies are beginning to uncover the causation behind the disparate impact COVID-19 has had on people of color. Pennsylvania must take a hard look at these studies and determine how it can directly and expeditiously conquer the factors causing these disparate outcomes, developing both essential immediate steps to “plug the dam” and prevent inequity as well as long-term strategies for addressing systemic issues. Multiple layers of analysis are necessary to truly understand the disparities using various data sources. The Department of Health should work in partnership with the Governor’s Task Force on Racial Disparities and the Departments of Human Services and Aging to probe the root causes of the disparities identified in the data.

To do this, the state must:

a. Evaluate data across income levels, payment source, geographic location, by facility, across comorbidities.

b. Evaluate facility quality, staffing levels, and compliance data against racial, ethnic, and language disparity data.

c. Correlate disparate outcomes and performance problem areas.

d. Determine causes and correlations for disparities identified.

5. **Recommendation #5: Use Data to Accomplish Meaningful Changes in Policy and Practice**

Collecting and analyzing data is just a first step to achieve meaningful results by making changes to policy and practice. Attention should be paid to the urgently needed interventions for COVID-19 first, with more lasting focus on the broader systemic changes.

a. Innovate immediate COVID-19 interventions to correct for outcomes and performance problem areas in facilities where disparities have been identified.

b. Identify health disparity reduction target(s) and select an intervention(s).

c. Measure impact of interventions and modify or expand over time, using continued data collection.

d. Develop ongoing process for evaluating data and adjusting policies and practices in response.

e. Develop long-term interventions to correct for identified racial and ethnic disparities.

f. Use performance reviews and performance measures to ensure that providers understand and are actively addressing disparities.

g. Engage community-based organizations and stakeholder groups to discuss data and gather input into strategies to address disparities.

h. Utilize focus groups with LTSS participants, including LTC facility residents, that represent historically marginalized communities to understand what they value, want, and see as barriers. Local LTC Ombudsman programs may be a good source to identify residents for this effort.

i. Utilize focus groups with LTSS providers: nursing facility, home and community based, Area Agencies on Aging and other CBOs as appropriate.
j. Survey and engage non-English speaking adults and LGBT communities of all ages and backgrounds to evaluate needs and identify goals.

k. Engage community-based organizations, experts, and stakeholder groups in outreach around strategies to address disparities.

6. **Recommendation #6: Assess Interventions and Impact**

   Evaluating how interventions have impacted disparities is the final step in the data cycle. We recommend that the state:
   
   a. Determine and implement a measurement approach.
   
   b. Assess performance and reassess program design.
   
   c. Use data over time to assess impact and change in health disparities.

Along with the Department, we are dedicated to helping improve the lives of nursing facility residents, and appreciate the dedication the Department has shown, particularly during this difficult time. We would appreciate the opportunity to meet with your staff in the weeks ahead to further discuss how the Department can adopt our recommendations. You can reach us by emailing Pamela Walz at pwalz@clsphila.org and/or Diane Menio at menio@carie.org.

Sincerely,

Diane A. Menio, Executive Director  
Center for Advocacy for the Rights and Interests of the Elderly  
menio@carie.org

Pamela Walz, Supervising Attorney  
Community Legal Services  
pwalz@clsphila.org

Peri Jude Radecic, Chief Executive Officer  
Disability Rights Pennsylvania  
pradecic@disabilityrightspa.org

Michael Grier, Executive Director  
Pennsylvania Council on Independent Living  
mike.grier@thepcil.org

Laval Miller-Wilson, Executive Director  
Pennsylvania Health Law Project  
imillerwilson@phlp.org

Karen C. Buck, Executive Director  
SeniorLAW Center  
KBuck@SeniorLAWCenter.org

cc: Andrew Sharp, Deputy Secretary of Intergovernmental Affairs, Office of the Governor - andsharp@pa.gov  
Secretary Teresa Miller, Department of Human Services – teresamill@pa.gov  
Secretary Robert Torres, Department of Aging - rotorres@pa.gov