TESTIMONY IN SUPPORT OF A MODIFIED VERSION OF SB359 PROHIBITING THE DISAGGREGATION OF STUDENT DATA BY ETHNIC OR RACIAL SUBGROUPS IN THE PUBLIC SCHOOL INFORMATION SYSTEM

March 8, 2018

Honorable Members of Education Committee:

My name is Shaolei Lu, a physician and assistant professor at Brown University and a director of Rhode Island Asian American Alliance Group. I am writing to testify in regard of bill No. SB359 “Prohibiting the Disaggregation of Student Data by Ethnic or Racial Subgroups in the Public School Information System”.

One may wonder why a Rhode Island organization wants to testify to a Connecticut bill. Here is why. Last year, Rhode Island quietly passed an Asian student data disaggregation bill without being noticed by most Asian communities. We did not even have a chance to express our objection before it was signed into law in July 2017. We have organized a big protest since and are still fighting against it. Rhode Island Asian communities have been late at the table, but we must support neighboring Asian communities prohibiting any similar unfair legislations.

I support the original concept of “prohibiting educational institutions or other state agencies from mandatory collection and separation of data from students by subpopulations of national origin or ethnicity”. However, we are very concerned in regard of this portion of the current bill language “unless ... collected uniformly across the entire population of students”. I believe the entire population shall not be subject to registry of ancestry immigration nation of origin or ethnicity origin.

I am supporting the original concept because any government support must be need-based. Each race or subpopulation of national origin has students who need extra help at school. If the goal is to identify these students, we should use school grades, standard exam scores, language spoken at home and other parameters that are already available in the system. Even if we have the most detailed racial information, we still need to allocate resources based on each student’s academic performance. How can collecting racial data be helpful for that purpose?

Please modify the bill language as to “No population of students shall be subject to data collection of ancestry nation of origin and ethnicity origin”. Please then vote for the modified version of bill SB359.

The language of a bill can be misconceived to the opposite direction. Besides collecting ethnic or racial subgroup data in the school system, special interest groups ask government to collect similar data for medical purposes. I am strongly against such request being added to any legislation. I have been a practicing allopathic physician and a medical researcher for over 20 years and have published over 30 peer-reviewed papers most of which involved genetics and epidemiology. I agree that there are some weak and evolving correlations between racial subgroup and specific disease. But I am more certain that most individuals of each racial group do not have the most popular disease of his/her group. Again, we should directly target the disease, not racial subgroups. Even if we have the most detailed racial information, we still need to follow specific medical procedures to identify patients. Therefore, the key is to let all the individuals gain proper medical access, enforcing it as a general policy (since it is already in place), and then let the medical professionals work on the medical issues. Useful information
collected from racial subgrouping is very limited. Personalized precision medicine has been the mainstream. Physicians are currently using very detailed genetic information to treat patient and guide prevention. Racial correlation as a primitive tool is rarely used in every day practice especially for citizens born on the US land.

Second, even if we still wanted to collect disaggregated racial data despite of its limited medical use, the best data that have already been collected are in the patient’s medical chart. If someone had a chance to look at the demographic part of patient’s medical record, he/she could see detailed information about race, ethnicity, country of origin, and religion. Such data are placed side by side with the medical data for readily correlation. These data are trustable. They are collected by health care providers who have appropriate professional training to collect the data accurately and completely. If we really need to do research about race and disease, this is the most useful and readily available data. In contrast, the government employees and subcontractors who would collect the subgrouping data without any medical training; the data would not be collected in the medical context; answers to the question would be optional and subjective. The data finally collected would be incomplete, prone to error and misleading.

Third, Health Insurance Portability and Accountability Act (HIPAA) prevents unauthorized access of patient’s health information. Since the racial data collected by the government are placed out of medical environment, any correlation study between race and disease would need access to the medical record, which would have to let each individual sign agreements to allow government to access to his/her own medical information. It is obviously unrealistic.

To sum up, there is absolute no need to collect data of any ancestry nation of origin or any ethnicity for both education and health purposes.

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