STATE OF NEW YORK

2051

2021-2022 Regular Sessions

IN SENATE

January 19, 2021

Introduced by Sen. SANDERS -- read twice and ordered printed, and when printed to be committed to the Committee on Health

AN ACT in relation to requiring the New York state department of health to collect and report certain data concerning COVID-19

The People of the State of New York, represented in Senate and Assembly, do enact as follows:

Section 1. Short title. This act shall be known and may be cited as the "equitable data collection and disclosure on COVID-19 act".

§ 2. Findings. (a) The World Health Organization (WHO) declared COVID-19 a "public health emergency of international concern" on January 30, 2020. By late March 2020, there have been over 470,000 confirmed cases of, and 20,000 deaths associated with, COVID-19 worldwide.

(b) In the United States, cases of COVID-19 have quickly surpassed those across the world, and as of April 12, 2020, over 500,000 cases and 20,000 deaths have been reported in the United States alone.

(c) Reports have shown racial inequities in COVID-19 testing and treatment, specifically in communities of color and in Limited English Proficient (LEP) communities.

(d) The burden of morbidity and mortality in the United States has historically fallen disproportionately on marginalized communities, those who suffer the most from great public health needs and are the most medically underserved.

(e) Historically, structures and systems, such as racism, ableism and class oppression, have rendered affected individuals more vulnerable to inequities and have prevented people from achieving their optimal health even when there is not a crisis of pandemic proportions.

(f) Significant differences in access to health care, specifically to primary health care providers, health care information, and greater perceived discrimination in health care place communities of color, individuals with disabilities, and LEP individuals at greater risk of receiving delayed, and perhaps poorer, health care.

EXPLANATION--Matter in *italics* (underscored) is new; matter in brackets [-] is old law to be omitted.

LBD06222-01-1

(g) Communities of color experience higher rates of chronic disease and disabilities, such as diabetes, hypertension, and asthma, than non-Hispanic White communities, which predisposes them to greater risk of complications and mortality should they contract COVID-19.

(h) Such communities are made even more vulnerable to the uncertainty of the preparation, response, and events surrounding the pandemic public health crisis, COVID-19. For instance, in the recent past, multiple epidemiologic studies and reviews have reported higher rates of hospitalization due to the 2009 H1N1 pandemic among the poor, individuals with disabilities and preexisting conditions, those living in impoverished neighborhoods, and individuals of color and ethnic backgrounds in the United States. These findings highlight the urgency to adapt the COVID-19 response to monitor and act on these inequities via data collection and research by race and ethnicity.

(i) Research experts recognize that there are underlying differences in illness and death when each of these factors are examined through socioeconomic and racial or ethnic lenses. These socially determinant factors of health accelerate disease and degradation.

(j) Without clear understanding of how COVID-19 impacts marginalized racial and ethnic communities, there will be exacerbated risk of endangering the most historically vulnerable of our nation.

(k) The consequences of misunderstanding the racial and ethnic impact of COVID-19 extends beyond communities of color such that it would impact all.

(l) Race and ethnicity are valuable research and practice variables when used and interpreted appropriately. Health data collected on patients by race and ethnicity will boost and more efficiently direct critical resources and inform risk communication development in languages and at appropriate health literacy levels, which resonate with historically vulnerable communities of color.

(m) The dearth of racially and ethnically disaggregated data reflecting the health of communities of color underlies the challenges of a fully informed public health response.

(n) Without collecting race and ethnicity data associated with COVID-19 testing, hospitalizations, morbidities, and mortalities, as well as publicly disclosing it, communities of color will remain at greater risk of disease and death.

§ 3. Emergency funding for state data collection on the racial, ethnic, and other demographic disparities of COVID-19. Funding shall be appropriated from the general fund to conduct or support data collection on the racial, ethnic, and other demographic implications of COVID-19 in New York state, including support to assist in the capacity building for state and local public health departments to collect and transmit racial, ethnic, and other demographic data to the relevant state department of health agencies.

§ 4. COVID-19 data collection and disclosure. (a) Data collection. The commissioner of health, shall make publicly available on the department's website of the data collected across all surveillance systems relating to COVID-19, disaggregated by race, ethnicity, sex, age, primary language, socioeconomic status, disability status, and county, including the following:

(1) data related to all COVID-19 testing, including the number of individuals tested and the number of tests that were positive;

(2) data related to treatment for COVID-19, including hospitalizations and intensive care unit admissions; and

(3) data related to COVID-19 outcomes, including total fatalities and case fatality rates, expressed as the proportion of individuals who were infected with COVID-19 and died from the virus.

(b) Timeline. The data made available under this section shall be updated daily throughout the public health emergency.

(c) Privacy. In publishing data under this section, the commissioner of health shall take all necessary steps to protect the privacy of individuals whose information is included in such data, including, but not limited to:

(1) complying with privacy protections provided under the regulations promulgated under the federal Health Insurance Portability and Accountability Act of 1996; and

(2) protections from all inappropriate internal use by an entity that collects, stores, or receives data, including use of such data in determinations of eligibility or continued eligibility in health plans, and from inappropriate uses.

(d) Consultation with Indian tribes. The department of health shall consult with Indian tribes and confer with urban Indian organizations on data collection and reporting.

(f) Report; public. No later than 60 days after the date on which the commissioner of health certifies that the public health emergency related to COVID-19 has ended, a summary of the final statistics related to COVID-19 shall be made public.

(g) Report; legislature. No later than 60 days after the date on which the commissioner certifies that the public health emergency related to COVID-19 has ended, the department of health shall compile and submit to the senate committee on health, the senate committee on finance, the assembly committee on ways and means and the assembly committee on health a preliminary report:

(1) describing the testing, hospitalization, mortality rates, and preferred language of patients associated with COVID-19 by race and ethnicity; and

(2) proposing evidenced-based response strategies to safeguard the health of such communities in future pandemics.

§ 5. Commission on ensuring health equity during the COVID-19 public health emergency. (a) Establishment. No later than 30 days after the effective date of this act, the commissioner of health shall establish a commission, to be known as the "Commission on Ensuring Health Equity During the COVID-19 Public Health Emergency" (referred to in this section as the "Commission") to provide clear and robust guidance on how to improve the collection, analysis, and use of demographic data in responding to future waves of the coronavirus.

(b) Membership and chairperson. (1) The Commission shall have 17 members which shall consist of:

(A) the commissioner of the department of health;

(B) the secretary of state;

(C) the commissioner of homeland security and emergency services;

(D) the director of the office of minority health and health disparities prevention;

(E) the director of the office of emergency management;

(F) the director of the office of mental health;

(G) three members appointed by the temporary president of the senate; one member appointed by the senate minority leader; three members appointed by the speaker of the assembly and one member appointed by the assembly minority leader; and

(H) racially and ethnically diverse representation from at least three independent experts with knowledge or field experience with racial and ethnic disparities in public health appointed by the commissioner of health.

(2) The commissioner of the department of health shall serve as the chairperson of the Commission.

(c) Duties. The Commission shall:

(1) examine barriers to collecting, analyzing, and using demographic data;

(2) determine how to best use such data to promote health equity across the state and reduce racial, Tribal, and other demographic disparities in COVID-19 prevalence and outcomes;

(3) gather available data related to COVID-19 treatment of individuals with disabilities, including denial of treatment for pre-existing conditions, removal or denial of disability related equipment, including ventilators and CPAP, and data on completion of DNR orders, and identify barriers in obtaining accurate and timely data related to COVID-19 treatment of such individuals;

(4) solicit input from public health officials, community-connected organizations, health care providers, state and local agency officials, and other experts on barriers to, and best practices for, collecting demographic data; and

(5) recommend policy changes that the data indicates are necessary to reduce disparities.

(d) Report. No later than 60 days after the effective date of this act, and every 180 days thereafter until the commissioner certifies that the public health emergency related to COVID-19 has ended, the Commission shall submit a written report of its findings and recommendations to the governor and the legislature and post such report on the department of health's website. Such reports shall contain information concerning:

(1) how to enhance state, local, and Tribal capacity to conduct public health research on COVID-19, with a focus on expanded capacity to analyze data on disparities correlated with race, ethnicity, income, sex, age, disability status, specific geographic areas, and other relevant demographic characteristics, and an analysis of what demographic data is currently being collected about COVID-19, the accuracy of that data and any gaps, how this data is currently being used to inform efforts to combat COVID-19, and what resources are needed to supplement existing public health data collection;

(2) how to collect, process, and disclose to the public the data described in paragraph one of this subdivision in a way that maintains individual privacy while helping direct the state and local response to the virus;

(3) how to improve demographic data collection related to COVID-19 in the short- and long-term, including how to continue to grow and value the Tribal sovereignty of data and information concerning Tribal communities;

(4) to the extent possible, a preliminary analysis of racial and other demographic disparities in COVID-19 mortality, including an analysis of comorbidities and case fatality rates;

(5) to the extent possible, a preliminary analysis of sex, gender, sexual orientation, and gender identity disparities in COVID-19 treatment and mortality;

(6) an analysis of COVID-19 treatment of individuals with disabilities, including equity of access to treatment and equipment and inter-

sections of disability status with other demographic factors, including race, and recommendations for how to improve transparency and equity of treatment for such individuals during the COVID-19 public health emergency and future emergencies;

(7) how to support the state, local, and Tribal communities in order to eliminate barriers to COVID-19 testing and treatment; and

(8) to the extent possible, a preliminary analysis of state policies that disparately exacerbate the COVID-19 impact, and recommendations to improve racial and other demographic disparities in health outcomes.

§ 6. This act shall take effect immediately.