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POLICY RESEARCH CENTER

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## Research Policy Update

### *COVID-19 and State Data Disaggregation*

The purpose of this research policy update is to review the current status of data disaggregation of cases and death counts for the novel coronavirus (COVID-19) for American Indians and Alaska Natives (AI/ANs) in the 50 U.S. states and the District of Columbia (DC). Despite requirements in legislation and calls from the public, not all states provide data to the public on COVID-19 cases and deaths for AI/ANs. AI/ANs and tribal nations have a right to accurate and accessible disaggregated data in order to better combat the ongoing pandemic with current, accurate COVID-19 case and death counts. After some background information, this update provides a comparison of public reporting of state data on COVID-19 cases and deaths for AI/ANs in May, June, and August 2020, as well as recommendations for improving data reporting moving forward.

### Data Disaggregation and AI/ANs

**What is Data Disaggregation?** Data disaggregation refers to the breakdown of data by smaller subcategories or groupings. Often these subcategories are demographic in nature, including race/ethnicity, gender, age, and/or nationality or tribe. Disaggregating data can be the reporting of data by any number of smaller, more detailed subcategories.

**Why is disaggregating AI/AN data necessary?** Accurate data for AI/ANs continues to be reported publicly in limited states for COVID-19 case and death counts.<sup>1</sup> Often, the smaller size of the AI/AN population, lower counts, and privacy concerns are cited as the reason for lack of public reporting,<sup>2</sup> but access to quality, disaggregated data is necessary for the development of public policy, strategic planning, health intervention implementation, community empowerment, and for tribal governance.<sup>3</sup> In addition, laboratories are now required to report race/ethnicity data for COVID-19.

<sup>1</sup> Conger, K., Gebeloff, R., Oppel Jr., R. A. (2020, July 30). Native Americans Feel Devastated by the Virus Yet Overlooked in the Data. *The New York Times*. Retrieved from <https://www.nytimes.com/2020/07/30/us/native-americans-coronavirus-data.html>

<sup>2</sup> NCAI Policy Research Center. (n.d.). The Asterisk Nation. Retrieved from <http://www.ncai.org/policy-research-center/research-data/data>

<sup>3</sup> NCAI Policy Research Center. (2016). Disaggregating American Indian & Alaska Native data: A review of literature. Washington DC: National Congress of American Indians. Retrieved from [http://www.ncai.org/DataDisaggregationAIAN-report\\_5\\_2018.pdf](http://www.ncai.org/DataDisaggregationAIAN-report_5_2018.pdf)

**Federal Mandate on COVID-19 Testing Data Disaggregation:** The Coronavirus Aid, Relief, and Economic Security (CARES) Act requires that all laboratories conducting COVID-19 testing report race/ethnicity of the testing recipient to states or the appropriate health agency and comply to do so “no later than” August 1, 2020.<sup>4</sup> While this requirement was not specifically to report publicly on their website, if the laboratories were required to report race/ethnicity data officially, it is reasonable to assume that states would include it in their public COVID-19 reporting.

**State COVID-19 Data:** While every state provides COVID-19 case and death count data on their websites, not all states consistently report COVID-19 data for all races/ethnicities, as defined by the Federal Office of Management and Budget (OMB) categories.<sup>5</sup> In practice, this means that states report data publicly for a variety of differing race/ethnicity groups, as well as various combinations of race/ethnicity groups, making public comparisons across state lines challenging or even impossible.

Media outlets have taken note of this shortcoming in state reporting and have outlined the lack of data for racial/ethnic minorities at the state level, in particular for smaller minority groups, despite the COVID-19 pandemic disproportionately impacting communities of color and the need for accurate, accessible data to combat these disparities.<sup>6, 7, 8</sup> The National Academy for State Health Policy also began tracking state COVID-19 data disaggregation by race/ethnicity.<sup>9</sup> At present, all 50 states and DC report data on racial/ethnic groups for COVID-19 in some manner on their websites, but the reporting is not consistent or complete across states.

## Review of State COVID-19 Data Disaggregation for AI/ANs

In light of the increased visibility of racial/ethnic disparities in cases and deaths from COVID-19 as well as the criticism of states for lack of publishing data disaggregated by race/ethnicity, we hypothesized that states might improve public reporting of race/ethnicity for COVID-19 cases and deaths for AI/ANs over time given the new requirements and all the attention in the media and by advocates to the need for this data disaggregation. Therefore, we reviewed and compared state COVID-19 data disaggregation for AI/ANs in May 2020, June 2020, and again

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<sup>4</sup> U.S. Department of Health and Human Services. (2020). *COVID-19 Pandemic Response, Laboratory Data Reporting: CARES Act Section 18115*. Accessed on July 15, 2020 at: <https://www.hhs.gov/sites/default/files/covid-19-laboratory-data-reporting-guidance.pdf>

<sup>5</sup> U.S. Census Bureau. (2020). *Race: About*. Accessed on July 15, 2020 at: <https://www.census.gov/topics/population/race/about.html>

<sup>6</sup> Vann, M., Kim, S. R. (2020, April 30). Minority groups at risk as states withhold, provide partial COVID-19 racial data. *ABC News*. Retrieved from <https://abcnews.go.com/Politics/states-missing-covid-19-racial-ethnic-data-creates/story?id=70338255>

<sup>7</sup> Kim, S. R., Vann, M. (2020, May 7). Many States Are Reporting Race Data For Only *Some* COVID-19 Cases and Deaths. *Five Thirty Eight*. Retrieved from <https://fivethirtyeight.com/features/many-states-are-reporting-race-data-for-only-some-covid-19-cases-and-deaths/>

<sup>8</sup> Hellmann, J. (2020, May 18). Frustrations grow over incomplete racial data on COVID-19 cases, deaths. *The Hill*. Retrieved from <https://thehill.com/homenews/state-watch/498395-frustrations-grow-over-incomplete-racial-data-on-covid-19-cases-deaths>

<sup>9</sup> National Academy for State Health Policy. (2020). *How States Report COVID-19 by Race and Ethnicity*. Retrieved from <https://www.nashp.org/how-states-report-covid-19-data-by-race-and-ethnicity/>

in August 2020, which was after the required deadline for laboratory reporting, to measure any changes in state data disaggregation public reporting practices.<sup>10</sup>

**Table 1** compares May and June 2020 practices of reporting AI/AN COVID-19 data publicly among the 50 U.S. states and DC. Initially in May 2020, we found that a total of 29 states (57%) publicly reported COVID-19 data for AI/ANs, “Native Americans,” or some other combination of those terms alone or in combination with another race and ethnicity, and in our review in June 2020, that number had only increased by two states to 31 (61%). Eight states (16%) did not report on AI/AN COVID-19 data in any manner in May 2020, and in June 2020, that number had decreased by half, with only 4 states (8%) not publicly reporting COVID-19 in AI/ANs at all. In May, 14 (27%) of states only included AI/ANs in the “other” category, and that number increased by one state to 15 (29%) in June 2020.

**Table 1: State Public Reporting on AI/ANs within COVID-19 Data – May and June 2020**

State AI/AN Reporting Method	Terminology Used	May	June
<b>States That Report AI/AN or Native American, Alone or in Combination with Another Race/Ethnicity</b>		29 (57%)	31 (61%)
	<b>American Indian Only</b>	4 (8%)	5 (10%)
	<b>Alaska Native Only</b>	0 (0%)	0 (0%)
	<b>AI/AN</b>	20 (39%)	21 (41%)
	<b>Native American</b>	2 (4%)	3 (6%)
	<b>AI/AN, Native American in Some Combination of the Terms</b>	1 (2%)	1 (2%)
	<b>AI/AN, Native American in Combination with Other Racial Groups</b>	2 (4%)	2 (4%)
<b>“Other” Category used for AI/ANs</b>		14 (27%)	15 (29%)
<b>No Reporting of AI/AN data (N/A)</b>		8 (16%)	4 (8%)

Significant variance occurs among the states and DC on how data for AI/ANs is reported. Terms include American Indian, Alaska Native, and Native American, as well as combinations thereof, as well as combinations with other, unrelated racial/ethnic groups, including Asian, make interpretation of the data challenging. States also continued to fail to report AI/AN data (“N/A”) or combine many racial/ethnic groups into an “Other” category.

<sup>10</sup> Data was collected by the NCAI Policy Research Center on May 11, June 26, and August 25 of 2020.

For our second comparison, we expected that states would improve public reporting of COVID-19 data by racial/ethnic groups by the deadline for laboratories and testing facilities to report additional race information to states and health agencies. However, we found limited improvement between June and August 2020.

**Table 2** shows the June to August 2020 comparison of state reporting for AI/AN COVID-19 data. For August 2020, we found that the total number of states publicly reporting data for AI/ANs, “Native Americans,” or some combination of those terms, alone or in combination with another race/ethnicity, had only increased from 31 (61%) in June 2020 to 34 (67%) in August 2020. We had expected this increase to be larger due to the deadline for race/ethnicity reporting requirements on August 1, 2020. However, in August 2020, no states failed to publicly report AI/AN data in any way, but 15 (29%) still counted AI/ANs as part of an “Other” category. Finally, we did see an increase in adherence to OMB racial/ethnic categories with 24 (47%) states reporting AI/AN data as the OMB term “American Indian/Alaska Native,” which is an increase from 21 (41%) in June and 20 (39%) in May.

**Table 2: State Public Reporting on AI/ANs within COVID-19 Data – June and August 2020**

State AI/AN Reporting Method	Terminology Used	June	August
<b>States That Report AI/AN or Native American, Alone or in Combination with Another Race/Ethnicity</b>		31 (61%)	34 (67%)
	<b>American Indian Only</b>	5 (10%)	4 (8%)
	<b>Alaska Native Only</b>	0 (0%)	0 (0%)
	<b>AI/AN</b>	21 (41%)	24 (47%)
	<b>Native American</b>	3 (6%)	4 (8%)
	<b>AI/AN, Native American in Some Combination of the Terms</b>	1 (2%)	0 (0%)
	<b>AI/AN, Native American in Combination with Other Racial Groups</b>	2 (4%)	2 (4%)
<b>“Other” Category used for AI/ANs</b>		15 (29%)	17 (33%)
<b>No Reporting of AI/AN data (N/A)</b>		4 (8%)	0 (0%)

In June 2020, a single state, North Dakota, had yet to publicly release any racial/ethnic data for COVID-19, which was particularly concerning due to the relatively high proportion of the AI/AN population in the state. In August 2020, North Dakota now reports disaggregated data that includes AI/ANs.

## AI/AN COVID-19 Case and Death Count Reporting

States also varied in terms of whether they reported COVID-19 case counts or percentages of counts among the total reported number of cases and deaths. Even among states that report data for AI/ANs, some states reported only cases or only deaths. **Tables 2 and 3** examine the differences between May, June, and August 2020 among the 50 states and DC in terms of how they report COVID-19 case counts (**Table 3**) and COVID-19 death counts (**Table 4**) for AI/ANs and calculates estimates of the counts when provided as percentages by the states.

**Table 3: State Public Reporting of COVID-19 Case Counts and Approximate Counts for AI/ANs – May, June and August 2020**

State AI/AN COVID-19 Reporting Method	COVID-19 Case Counts and Approximate Counts	May	June	August
States That Report Number of AI/AN Cases as Counts		17 (33%)	22 (43%)	28 (55%)
	For State Reporting Cases as Counts, Total Number of Case Counts	3,940	13,322	30,152
States That Report Number of AI/AN Cases as a Percentage of Total Cases		11 (22%)	9 (18%)	6 (12%)
	For States Reporting Cases as Percentages, Total Number of Approximate Cases	4,173	8,803	10,963
Total number Combined AI/AN Case Counts and Approximate Case Counts from Percentages		8,111	22,125	41,115
States That Report N/A for AI/AN Case Counts		23 (45%)	20 (39%)	17 (33%)

Between May 2020 and August 2020, 11 additional states began releasing COVID-19 AI/AN cases as counts, either as a new development or a transition from percentages to counts, for a total of 28 (55%) states. Among the 50 states and DC, when combining both data reported as AI/AN case counts and approximate AI/AN cases calculated from reported percentage of AI/AN cases among the total cases in a given state, the total for AI/AN cases was 41,115 on August 25.

However, for the same time frame, the Indian Health Service, reported a total of 38,215 cases, since March 23, 2020.<sup>11</sup> Both of these are likely to be undercounts, but these numbers point to how important it is for states to publicly report their COVID-19 case numbers to see the additional cases reported outside of the Indian Health Service. In addition, 17 (33%) states still do not publicly report AI/AN COVID-19 case counts.

In **Table 4**, the combined COVID-19 death counts and approximate death counts for AI/ANs in August 2020 were 1,037, however, for the same time frame, the Centers for Disease Control and Prevention (CDC) reported COVID-19 deaths for AI/ANs at 1,518.<sup>11</sup> This difference is likely due to the lack of public reporting of some of these deaths by states on their own websites. Again, both counts are likely to be underestimating the total COVID-19 deaths among all AI/ANs (**Table 4**), especially since the number of states that do not publicly report AI/AN death counts is still 24 (47%). In some cases, it is not clear whether this is due to lack of reporting, putting AI/AN deaths in an “other” category, or no AI/AN COVID-19 deaths in those states.

**Table 4: State Public Reporting of COVID-19 Death Counts and Approximate Counts for AI/ANs – May, June, and August 2020**

State AI/AN COVID-19 Reporting Method	COVID-19 Death Counts and Approximate Counts	May	June	August
<b>States That Report Number of AI/AN Deaths as Counts</b>		10 (20%)	15 (29%)	22 (43%)
	<b>For States Reporting Deaths as Counts, Total Number of Deaths</b>	122	423	981
<b>States That Report Number of AI/AN Deaths as Percentages</b>		7 (14%)	8 (16%)	5 (10%)
	<b>For States Reporting Deaths as Percentages, Total Number of Approximate Deaths</b>	93	90	56
<b>Total Number of Combined AI/AN Death Counts and Approximate Deaths from Percentages</b>		215	513	1,037
<b>States That Report N/A for AI/AN Deaths</b>		34 (67%)	28 (55%)	24 (47%)

<sup>11</sup> NCAI Policy Research Center (2020). Research Policy Update: COVID-19 Data – Situation Summary. Washington DC: National Congress of American Indians, August 20, 2020. Retrieved from [http://www.ncai.org/policy-research-center/research-data/prc-publications/NCAI\\_COVID19\\_Data\\_Situation\\_Summary\\_FINAL\\_8\\_20\\_2020.pdf](http://www.ncai.org/policy-research-center/research-data/prc-publications/NCAI_COVID19_Data_Situation_Summary_FINAL_8_20_2020.pdf)

These COVID-19 death counts for AI/ANs are particularly concerning given the recent spike in COVID-19 in rural reservations throughout the southwestern United States, as well as the general disproportionate impact of the pandemic on AI/ANs. The CDC recently published a report that found that COVID-19 cases among AI/ANs were 3.5 times higher than among non-Hispanic whites, and data was only available from 23 states during the first six months of the pandemic, which is similar to our findings for publicly reported state data in May 2020.<sup>12</sup> The CDC report highlights how the lack of available COVID-19 data on AI/ANs is a significant public health challenge in a pandemic.

**Conclusion:** While there were some minor improvements to public reporting of COVID-19 data for AI/ANs among the 50 states and DC across May, June and August 2020, there remains a need for more states to improve their public reporting and data disaggregation. While we expected to see additional improvements after the required deadline for laboratory reporting on race/ethnicity on August 1, 2020, our review found only minor improvements in public reporting for AI/ANs by states, even with our review being towards the end of August. States continue to vary in the terminology they use to report race/ethnicity which makes comparisons across states difficult, and combining AI/AN data with other races/ethnicities or putting AI/AN data in the “other” category makes comparisons and interpreting trends even more difficult.

These differences among state reporting of COVID-19 cases and deaths for AI/ANs present significant barriers to efforts by tribal nations, states, and other public health entities to protect AI/AN communities and tribal nations during the COVID-19 pandemic. Ensuring public reporting by all states that consistently uses the same terms (American Indians and Alaska Natives) across states would be a step in the right direction, but data must be further disaggregated in ways that help tribal nations in those states better understand the impact of COVID-19 on their communities. States have a responsibility to report data in an accurate and accessible manner for all racial/ethnic groups, especially during the ongoing COVID-19 pandemic, which is having a disproportionate impact on racial/ethnic groups compared to the general U.S. population. With about one third of states not publicly reporting AI/AN COVID-19 cases and almost half not publicly reporting AI/AN COVID-19 deaths, improvements in COVID-19 case and death reporting by states with consistent and complete data disaggregation by race and ethnicity are urgently needed.

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<sup>12</sup> Hatcher, S. M. (2020). COVID-19 Among American Indian and Alaska Native Persons—23 States, January 31–July 3, 2020. *MMWR. Morbidity and Mortality Weekly Report*, 69.