



COMMONWEALTH OF VIRGINIA
Virginia Board for People with Disabilities

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June 10, 2020

Dr. Norman Oliver
Commissioner
Virginia Department of Health
P.O. Box 2448
Richmond, VA 23218

RE: Collection and Analysis of COVID-19 Data Regarding People with Disabilities

The Virginia Board for People with Disabilities (the Board) appreciates the immense efforts that the Virginia Department of Health (VDH) has made in response to the COVID-19 pandemic. We also appreciate being included in VDH's Health Equity Working Group, which has provided a forum for vital conversations about how to best support underserved populations during this crisis. One of the group's discussion topics, which we would like to bring to your attention in this letter, has been the need for additional data on the impact of COVID-19 among these underserved populations.

Pandemics exacerbate already existing health inequities, including health inequities between people with and without disabilities. Even in normal times, people with disabilities experience unique challenges regarding employment, communication, transportation, mobility, and discrimination that can substantially limit their access to health care and other vital services.ⁱ These challenges have been compounded by the need for social distancing during this crisis, as well as people with disabilities' particular vulnerability to COVID-19. Their vulnerability stems from their underlying health conditions,ⁱⁱ the continued reliance of the disability services system on institutional and congregate living settings, which accounted for over half of the state's COVID-19 deaths as of June 5, and the reliance of many who live independently on direct support professionals who have had difficulty obtaining personal protective equipment and testing.

While people with disabilities have borne the brunt of the pandemic, data needed to assess and mitigate the impact of COVID-19 on this population has been largely unavailable to the public. VDH has been reporting the number of cases and deaths in long-term care facilities and congregate living settings, but many people with disabilities also live in home- and community-based settings. The Department of Behavioral Health and Developmental Services (DBHDS) recently began reporting cases and deaths among recipients of DBHDS-licensed services, and among residents and staff at DBHDS-run facilities, but there are also people with disabilities who do not receive services from DBHDS-licensed providers. Furthermore, both of these data populations likely include at least some individuals who do not have a disability. More data is also needed to assess their outcomes, including recovery rates and rates of transfer from home- and community-based settings to institutional settings as a result of COVID-19.

In recent years, policymakers, researchers, and nonprofit organizations around the country have repeatedly recognized the need to collect more health-related data on people with disabilities. For example,

- The 2010 Affordable Care Act recognized the prevalence of health disparities among people with disabilities and required “federally conducted or supported health care or public health program, activity or surveys” to collect and report data on disability status;
- The U.S. Department of Health and Human Services’ blueprint for the nation, *Healthy People 2020*, includes objectives to “increase the number of population-based data systems...that include in their core a standardized set of questions that identify people with disabilities” and “increase the number of state...health departments that have at least one health promotion program aimed at improving the health and well-being of people with disabilities;”
- Key agencies within the U.S. Department of Health and Human Services collaborated with disability experts during 2018 to review existing health surveillance data on people with disabilities and recommend needed improvements;ⁱⁱⁱ
- The Centers for Disease Control and Prevention’s COVID-19 case report form asks for disability status;^{iv}
- Several academics have called for more data on people with disabilities, both in general and during the COVID-19 pandemic;^v
- The Robert Wood Johnson Foundation has called on states to collect detailed COVID-19 data regarding marginalized groups, including people with disabilities, saying the following: “Data disaggregation should follow best practices and extend not only to public health data on COVID cases, hospitalizations, and fatalities, but also to: measures of access to testing, treatment, personal protective equipment (PPE), and safe places to isolate when sick; receipt of social and economic supports; and the downstream consequences of COVID on well-being, ranging from housing instability to food insecurity;”^{vi} and
- The Consortium for Citizens with Disabilities urged the federal government to consider disability status as a relevant factor in the Paycheck Protection and Health Care Enhancement Act’s requirement that the U.S. Department of Health and Human

Services report on COVID-19 testing and diagnosis data by “race, ethnicity, age, sex, geographic region and other relevant factors.”^{vii}

We understand that VDH is constantly striving to improve its health surveillance data, and we respectfully request that future improvements consider people with disabilities. We also request that you consider additional improvements regarding race, ethnicity, sexual orientation, and occupation that have been recommended by other members of the Health Equity Working Group. Thank you for your consideration, and please do not hesitate to reach out to us for further discussion or assistance.

Sincerely,



Teri Morgan
Executive Director
Virginia Board for People with Disabilities

Cc: Dr. Daniel Carey
Dr. Janice Underwood
Sable K. Nelson

ⁱ National Council on Disability (2009). *The current state of health care for people with disabilities*. https://ncd.gov/rawmedia_repository/Od7c848f_3d97_43b3_bea5_36e1d97f973d.pdf; Krahn, G., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health, 105*(S2), S198-206. <https://ajph.aphapublications.org/doi/pdf/10.2105/AJPH.2014.302182>

ⁱⁱ Turk, M., Landes, S., Formica, M., & Goss, K. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disability and Health Journal*. https://www.sciencedirect.com/science/article/pii/S1936657420300674?dgcid=raven_sd_aip_email; Centers for Disease Control and Prevention (2020, April 7). *People with Disabilities*. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>; Landes, S., Stevens, D., & Turk, M. (2020). COVID-19 and pneumonia: Increased risk for individuals with intellectual and developmental disabilities during the pandemic. Lerner Center for Public Health Promotion, Syracuse University. <https://lernercenter.syr.edu/2020/04/27/covid-19-and-pneumonia-increased-risk-for-individuals-with-intellectual-and-developmental-disabilities-during-the-pandemic/>

ⁱⁱⁱ Bonardi, A., Krahn, G., Morris, A., & the National Workgroup on State and Local Health Data (2019). *Enriching our knowledge: State and local data to inform health surveillance of the population with intellectual and developmental disabilities*. https://aclprdep01.azureedge.net/cdn/ff/OATVJImFLs5gbVqdM6iUN0xHELxw4o-ogEah3HlsULA/1569854246/public/Aging%20and%20Disability%20in%20America/Final_State_Data_Paper_09.25.2019%20word%20master%20508%20compliant.pdf

^{iv} Centers for Disease Control and Prevention (2020, May 5). *Information for health departments on reporting cases of COVID-19*. <https://www.cdc.gov/coronavirus/2019-ncov/php/reporting-pui.html>

^v Boyle, C., Fox, M., Havercamp, S., & Zubler, J. (2020, May 24). The public health response to the COVID-19 pandemic for people with disabilities. *Disability and Health Journal*. https://www.sciencedirect.com/science/article/pii/S1936657420300686?dgcid=raven_sd_aip_email; Turk, M., & McDermott, S. (2020, May 28). The Covid-19 pandemic and people with disability. *Disability and Health Journal*. https://www.sciencedirect.com/science/article/pii/S1936657420300698?dgcid=raven_sd_aip_email; Krahn, G., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4902165/pdf/nihms790838.pdf>

^{vi} Robert Wood Johnson Foundation (2020). *Health equity principles for state and local leaders in responding to, reopening, and recovering from COVID-19*. https://www.rwjf.org/en/library/research/2020/05/health-equity-principles-for-state-and-local-leaders-in-responding-to-reopening-and-recovering-from-covid-19.html?cid=xsh_rwjf_fb

^{vii} Consortium for Citizens with Disabilities (2020, April 27). *COVID-19 data collection and reporting concerning people with disabilities* [Letter]. <http://c-c-d.org/fichiers/COVID-disability-data-collection-letter-2020-4-27.pdf>