March 20, 2020

Robert Kadlec
Assistant Secretary for Preparedness and Response
Assistant Secretary for Health
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: Need for Critical Information to Investigate Possible Abuse and Neglect of Persons with Disabilities in the COVID-19 Response

Dear Assistant Secretary Kadlec,

We, the foregoing designated Protection and Advocacy (P&A) systems established under federal law to protect the rights and well-being of persons with disabilities, need your immediate assistance to ensure the safety of persons with disabilities against the COVID-19 virus. We write collectively through our national membership association, the National Disability Rights Network.

The federal laws which authorize our work mandate that we monitor and investigate for possible abuse and neglect of people with disabilities, and advocate to protect the rights of those who have been or continue to be abused or neglected. The COVID-19 crisis creates numerous opportunities for persons with disabilities to be subjected to abuse or neglect in the identification and treatment of the virus, especially those who reside in institutions. Our P&A agencies are monitoring facilities which serve persons with disabilities, and will need to investigate abuse and neglect of persons with disabilities in the response to the COVID-19 pandemic. Individuals with disabilities have been some of the most significantly impacted by the outbreak.

In this time of national crisis, the P&A system needs to work collaboratively with our federal partners to ensure persons with disabilities are not lost in the response, especially in regard to testing. To accomplish this task, we seek access to information and data from you, our federal partners, to ensure that we can continue to respond to allegations of abuse and neglect. In the early stages of our states’ responses of this virus, P&As need information and data of COVID-19 testing necessary to respond to
any discriminatory treatment and rights violations in how these tests are administered. P&As seek the following information,

1. The number of COVID-19 tests that have been distributed in each state, where those tests were distributed within the state, and when those test were made available to test recipients;
2. All known formal or informal policies and practices used by the CDC, states and localities, that reflect the criteria being used to determine who receives the tests, when they receive the tests, and whether there are differences among providers, regions, states, and more local geographic or service provision areas;
3. The number of tests requested by each state;
4. The number of tests completed to date for each state, the number still in process, and any backlog in processing;
5. All available demographic statistical information, especially the known disability of persons who have been tested, or if disability is not asked.
6. The number of testing kits scheduled to be provided to each state, where those tests will be distributed within the state, and when will those testing kits be made available to test recipients;
7. The peak number of tests that can be processed at a given time, and any backlog in processing;
8. The number of tests that are believed to be optimal to make available and process each day as this pandemic continues based on current understanding of the virus.

As this virus progresses, P&As will be seeking other information from you to continue to protect the rights of people with disabilities. For now your cooperation to quickly provide this information to the P&As is necessary to facilitate timely investigations and advocacy that may be necessary to bring a quick end to any harm that may have occurred to people with disabilities related to testing. A timely response is critical to allow us to fulfill our federal mandate to protect and advocate for people with disabilities. We also understand that information is rapidly changing so are amenable to receiving additional information as it comes in.

We appreciate your cooperation and hope we can work collaboratively in this matter to address this national health crisis. We look forward to your swift production of the information and data requested.

Sincerely,

Alabama - Alabama Disabilities Advocacy Program
Alaska - Disability Law Center of Alaska
Arizona – Arizona Center for Disability Law
Arkansas - Disability Rights Arkansas
Florida - Disability Rights Florida
Indiana - Indiana Disability Rights
Kansas - Disability Rights Center of Kansas
Kentucky - Kentucky Protection and Advocacy
Maine - Disability Rights Maine
Massachusetts - Disability Law Center
Mississippi - Disability Rights Mississippi
Montana - Disability Rights Montana
Native American - Native American Disability Law Center
Nebraska - Disability Rights Nebraska
New Hampshire - Disability Rights Center of New Hampshire
New Jersey - Disability Rights New Jersey
New York - Disability Rights New York
North Carolina - Disability Rights North Carolina
North Dakota - Disability Rights North Dakota
Oklahoma - Oklahoma Disability Law Center
Oregon - Disability Rights Oregon
Rhode Island – Disability Rights Rhode Island
South Carolina - Protection & Advocacy for People with Disabilities
Tennessee - Disability Rights Tennessee
Utah - Disability Law Center
Vermont - Disability Rights Vermont
Washington - Disability Rights Washington
Wisconsin - Disability Rights Wisconsin

Cc: Anita Everett, Director, Center for Mental Health Services
Julie Hocker, Commissioner, Administration on Disabilities
Elinore McCane-Katz, Assistant Secretary for Mental Health and Substance Use
Lance Robertson, Administrator and Assistant Secretary for Aging
Mark Schultz, Assistant Secretary, Office of Special Education and Rehabilitative Services