NATIONAL DISABILITY RIGHTS NETWORK
Protection & Advocacy for Individuals with Disabilities

Senator Lamar Alexander
Chairman
U.S. Senate Committee on Health,
Education, Labor and Pensions
428 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Alexander:

Thank you for the opportunity to provide comments on the white paper "Preparing for the Next Pandemic". The National Disability Rights Network (NDRN) strongly agrees that preparation for the next pandemic should begin now especially in light of the deficiencies that have come to light as a result of the COVID-19 pandemic. We appreciate the Committee's prudent decision to plan now and solicit feedback from stakeholders as Congress looks toward preparing for future pandemics.

NDRN is the non-profit membership association of Protection and Advocacy (P&A) agencies and Client Assistance Programs (CAP) that are located in all 50 States, the District of Columbia, Puerto Rico, and the United States Territories. In addition, there is a P&A affiliated with the Native American Consortium which includes the Hopi, Navajo and San Juan Southern Paiute Nations in the Four Corners region of the Southwest. P&A agencies are authorized under various federal statutes to provide legal representation and related advocacy services, and to investigate abuse and neglect of individuals with disabilities in a variety of settings. The P&A Network comprises the nation's largest provider of legally-based advocacy services for persons with disabilities.

As our nation looks to prepare for subsequent pandemics, we urge the Committee and Congress to consider the following comments and recommendations in response to the white paper:

Economic Stabilization

The introduction of the paper states, "The federal government is also responsible for helping to stabilize the economy and work with foreign countries associated with a global event". It is indisputable that the COVID-19 pandemic has inflicted severe economic distress for many Americans not seen since the Great Recession.[1] Some prognostications suggest sustained double digit unemployment for the foreseeable future. This troubling economic outlook is particularly concerning for people with

1 Kochhar, R. (2020, June 11). Unemployment rose higher in three months of COVID-19 than it did in two years of the Great Recession. Retrieved from https://www.pewresearch.org/fact-tank/2020/06/11/unemployment-rose-higher-in-three-months-of-covid-19-than-it-did-in-two-years-of-the-great-recession/

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disabilities who already faced a serious gap in the Labor Force Participation Rate going into the pandemic when compared to people without disabilities.[2] We urge the Committee and Congress to consider programs that will provide sustained federal support for all Americans, including people with disabilities who face particular hardships given the economic fallout associated with pandemics. While we commend Congress for its passage of the Paycheck Protection Program and Health Care Enhancement Act ; the Coronavirus Aid, Relief, and Economic Security (CARES) Act,; the Families First Coronavirus Response Act; and the Coronavirus Preparedness and Response Supplemental Appropriations Act, we believe Congress should consider the inclusion of automatic fiscal stabilizers so that much needed assistance programs do not arbitrarily end.

Automatic fiscal stabilizers would tie fiscal policy action to data based on the health of the economy.[3] This would reduce the need for frequent fiscal Congressional action during and after the pandemic and allow for quick policy activation, faster implementation facilitated by pre-planning, and sustained policy support that lasts as long as needed.[3] The implementation of automatic fiscal stabilizers during a pandemic could greatly alleviate the strain on assistance programs such as the Supplemental Nutrition Assistance Program, Temporary Assistance for Needy Families, and Unemployment Insurance which are relied upon in an economic downturn and benefit people with disabilities.[4]

Responses to Recommendations

In response to the five recommendations outlined in the paper, we offer the following comments and which we urge the Committee and Congress to take into consideration:

1.) Tests, Treatments and Vaccines

a.) There should be no "rationing" of treatment or hospital care based on perceived "quality of life" measures, which frequently exclude people with disabilities, especially older people with disabilities, as well as communities of color including individuals with underlying heath conditions, from care. We know from media reports and reports from the P&As of "Do Not Resuscitate" orders placed on patient files without consent as well as encouragement of "Do Not Hospitalize" orders for nursing home residents. Similar reports provide evidence of "dumping" by nursing homes.[5] These policies are related to the rationing of care. Some

2 Pauli, P. (2020, February 25). Ten-Fold Decrease in Job Gains for People with Disabilities. Retrieved from https://www.respectability.org/2020/02/best-states-2020/

3 Shambaugh, J. (2020, April 20). We need to let economic data guide further economic policy responses to COVID-19. Retrieved from https://www.brookings.edu/blog/up-front/2020/04/20/we-need-to-let-economic-data-guide-further-economic-policy-responses-to-covid-19/

4 SNAP Provides Needed Food Assistance to Millions of People with. (2017, October 11). Retrieved from https://www.cbpp.org/research/food-assistance/snap-provides-needed-food-assistance-to-millions-of-people-with

5 Silver-Greenberg, J. (2020, June 23). 'They Just Dumped Him Like Trash': Nursing Homes Evict Vulnerable Residents. Retrieved from https://www.nytimes.com/2020/06/21/business/nursing-homes-evictions-discharges-coronavirus.html?auth=login-google

high-profile figures have endorsed rationing care based on age, or prioritizing "life years."[6]

b.) The P&As have been on the frontline helping ensure that if the pandemic results in government decisions to ration treatment, decisions about how medical treatment should be allocated are made without discriminating based on disability. P&As across the country have written letters and filed complaints which have resulted in state governments and the federal government clearly conveying that any protocols that may be implemented for rationing treatment comply with federal laws.

c.) We need expanded capacity to monitor, report and remedy conditions where Covid-19 has caused the most harm: nursing homes and assisted living centers, psychiatric hospitals, state institutions for people with developmental disabilities, group homes for people with disabilities, and communities of color. P&As have the skills and legal access to perform this work, but lack sufficient funding to perform these duties robustly without additional funding during a pandemic.

d.) We need to build up hospital capacity. During this relative "lull" in hospitalizations nationally, there should be a priority on **expansion of hospital capacity and treatment capacity**, particularly in areas now underserved (poor urban communities, rural areas). Despite the widely perceived scarcity of hospital (particularly ICU) beds, 42 hospitals have closed already this year.[7] Additionally**, we need to make sure that planning and services exist** and are well funded to ensure that individuals have the ability to transition back into their community following hospitalization.

e.) Expanded transparency and safety protocols for the testing of any potential vaccines prior to production and distribution, despite "Operation Warp Speed." Human trials should be done with informed consent about the risks of participation to both the test recipient and close contacts. Typically, vaccines are tested on lower income communities, and communities of color where test subjects are paid to participate. Prior experiences with similar vaccine developments have resulted in serious injuries to test trial participants and (in the case of the H1N1 vaccine and even the 1976 swine flu outbreak) release of dangerous vaccines that can cause serious harm to test recipients and their close associates.

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6 Emanuel, E M.D., Ph.D et.al (2020, June 25). Fair Allocation of Scarce Medical Resources in the Time of Covid-19. Retrieved from https://www.nejm.org/doi/pdf/10.1056/NEJMsb2005114

7 Ellison, A. (2020, June 22). 42 hospitals closed, filed for bankruptcy this year: From reimbursement landscape challenges to dwindling patient volumes, many factors lead hospitals to shut down or file for bankruptcy. At least 42 hospitals across the U.S. have closed or entered bankruptcy this year, and the financial challenges caused by the COVID-19 pandemic may force more hospitals to do the same in coming months. . Retrieved from https://www.beckershospitalreview.com/finance/42-hospitals-closed-filed-for-bankruptcy-this-year.html

2.) Disease Surveillance

a.) Testing improvements and standardization of testing protocols: Some states are doing (and reporting) antibody testing, others do Polymerase Chain Reaction (PCR) infection testing and some do both, without accurate reporting on the types of tests done and differentiating the results. Different states are doing different tests, often produced by local labs. This does not provide uniform data about viral spread, etc. nor useful information for test subjects. This underscores the need for the Committee and Congress to seriously consider testing improvements and standardization of testing protocols in order to avoid a patchwork of testing procedures.

b.) Systematic epidemiological testing of U.S. population: There should be massive epidemiological testing of a large subset of the U.S. population, done by the U.S. government. This has not been done although there have been several smaller private studies. This would be a good utilization of the call for expanded public health resources.

3.) Stockpiles, Distribution and Surges

Immediate procurement of respirator masks and expanded manufacturing capacity: More than three months into the Covid-19 crisis, there are still insufficient NP95 masks for hospital use, much less for vulnerable community members. There is still major scarcity, forcing priority distribution to hospital workers, but no priority is given for nursing homes, group homes, psychiatric facilities, low-income communities, etc. where most deaths have occurred. This problem has persisted throughout the years and should be meaningfully addressed now to address this and future pandemics.

4.) Public Health Capabilities

Contact tracing: Contact tracing has been used historically for tuberculosis outbreaks, sexually transmitted diseases and Ebola, but not for a virus where upwards of 20% of the population has been infected. There are many implications for people with disabilities and for people of color, who bear the brunt of government surveillance which requires more thoughtful consideration going forward. Any steps to implement expansive contact tracing must be done with transparency and with protections for those who wish to opt out, in particular people with disabilities and people of color who have historically faced prejudicial treatment and racial discrimination which warrant heightened levels of skepticism around government surveillance initiatives.

5.) Who Is On the Flagpole?

Federal and local cooperation: Certain federal activities could greatly impact the course of Covid-19 and support local efforts: (1) development and manufacture of uniform Covid-19 test kits; (2) manufacture and

distribution of stockpiles of personal protective equipment (PPE) and medical equipment; (3) collection of national epidemiological data collection.

Additional Considerations for Congregate Settings

The paper touches on the disproportionate impact COVID-19 has had on people in congregate settings but we urge the Committee and Congress to more seriously take into account the devastation seen within these facilities. Numerous media reports have indicated a disproportionate impact on individuals living in institutions and congregate facilities which include many people with disabilities. Additionally, since the beginning of April, NDRN has called for the release of prisoners and other detainees with disabilities who are vulnerable to COVID-19. It has been well documented in the media that it is almost impossible to socially distance while in detention, which has resulted in large COVID-19 outbreaks in these facilities. Advocates have been warning of overcrowding for many years and believe now is the time to address this issue in anticipation of a future pandemic.[8]

In addition to urging the Committee and Congress to increase funding for community based resources which will allow individuals to transition out of institutions and protect them in the event of a pandemic, we urge Congress to increase funding for the P&As during pandemics. Rights violations will happen, as they have during the COVID-19 pandemic, under the emergency declarations as many policies do not take people with disabilities into consideration. Only the P&As will be there to advise and protect people with disabilities both during and after pandemics as evidenced by the fact that the P&As have been part of the catalyst that resulted in state and federal guidance on medical rationing during this pandemic. We also urge the Committee and Congress to consider the Justice Roundtable's recommendations and the pieces of legislation included in the recommendations as models for addressing large scale infection outbreaks in detention facilities during a pandemic.

Thank you for the opportunity to comment and provide recommendations. Please contact Cyrus Huncharek, Public Policy Analyst, at cyrus.huncharek@ndrn.org should you have any questions or concerns with these comments.

Sincerely,

Curtis L. Decker
Executive Director

8 ProPublica. (2020, June 18). The Prison Was Built to Hold 1,500 Inmates. It Had Over 2,000 Coronavirus Cases. Retrieved from https://www.propublica.org/article/the-prison-was-built-to-hold-1500-inmates-it-had-over-2000-coronavirus-cases