UNITED STATES of CARE

June 25, 2020

Hon. Lamar Alexander
455 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Alexander:

Thank you for the opportunity to offer feedback on your white paper outlining recommendations and asking critical questions regarding pandemic preparedness for current and future crises. United States of Care believes federal leadership is essential to both preparing for a pandemic before it occurs and also managing the development and implementation of a national response.

United States of Care is a nonprofit, nonpartisan organization founded in early 2018 with an ambitious mission: to ensure that every single American has access to quality, affordable health care regardless of health status, social need or income. We believe there is no one-size-fits-all approach to solving our health care challenges. That is why our Board and Founder's Council includes leaders from business, government, and other experts from across the health care ecosystem. The feedback we provide below was developed in consultation with selected members of our Board and Founder's Council, including our Board Member, former US Senator Bill Frist, M.D., as well as the knowledge of our in-house health policy experts.

The Necessity of a Coordinated National Response to Fight a National Pandemic

From the outset, the nation's pandemic response has been compared to putting our country on 'war footing.' However, just as when the President orders our brave men and women in uniform into war, we would never respond with 50 separate armies. In the same vein, threats to public health cannot be faced with fifty unique, uncoordinated strategies. While we are indeed a constitutional republic of fifty states, each of which should be afforded maximum flexibility to implement a local response, the federal government is the only organization capable of establishing proactive boundaries and baselines to promote the general welfare, as our Constitution requires.

The Critical National Role of the Centers for Disease Control and Prevention

Our nation's first line of defense during a pandemic is the Centers for Disease Control and Prevention (CDC). The CDC, however, could benefit from greater examination of its mission and authorizing statutes to align their work to be as effective as possible. The agency's response to COVID-19 may, in part, have been hindered by statutory limitations on its operations or inflexible and directed funding which could have hurt the agency's capacity to either quickly respond to a crisis and/or coordinate with local, state and federal agencies and non-governmental organizations. Ideally, to the greatest extent achievable, the CDC should empower the trusted professional expertise of its career staff and Congress should facilitate this paradigm as much as possible. Given the depth of concern regarding its operational difficulties, the CDC would also benefit from an internal review of its mission, priorities, resource allocations, and operational structure. When it comes to COVID-19, we need to know what broke down inside and outside the CDC so we can be prepared for the next crisis. Congress can also provide funding for an outside entity to complete a review or require the General Accounting Office (GAO) to undertake one.

Balancing Privacy & Protection of Personal Data with Public Health Information Needs

We agree with the white paper's recommendations that there must be increased efforts to ensure timely communication, coordination, and data sharing across federal agencies, states, and health professionals to expand our nation's ability to track infectious diseases. In addition, we commend the Chairman for asking questions regarding the privacy concerns many Americans have about disease surveillance and data collection. This is a particularly pressing issue requiring the Committee's immediate attention given the current need for contact tracing in response to the coronavirus.

Any legislation aimed at improving disease surveillance must establish **clear privacy standards** balancing the protection of people's personal information while also providing public health professionals with usable information. This standard does not need to be defined by existing Health Insurance Portability and Accountability Act (HIPAA) requirements. At the same time, however, the Committee would be remiss to waive HIPAA protections without establishing a new, clear set of privacy protections reflecting our contemporary technological reality and the benefit such technology may provide within a pandemic response. In particular, we encourage the Committee to develop new privacy standards explicitly ensuring any data collected for disease surveillance efforts are used exclusively for public health purposes. Any legislation the Committee considers should prohibit use of this data for any other purposes other than public health, including potential commercial uses. Fortunately, there are provisions in current bipartisan legislation, the Exposure Notification Privacy Act, which would address many of these privacy concerns. Congress also has similar precedent for protecting sensitive data as they did in 2015 via the Internal Revenue Service's (IRS) Taxpayer Bill of Rights, and may want

to consider a similar paradigm for pandemic testing, contact tracing and other necessary public health surveillance.

While it is critical for individual data shared with public health entities to be protected and for people to have confidence they can safely provide information, there is also a necessary balance surrounding this data so that public health professionals both inside and outside of government can utilize information to make sound decisions and conduct appropriate research. For instance, the U.S. Census bureau shares tremendous amounts of data in specific ways down even to the block level. Congress should require the appropriate federal agency to develop standards for public health data sharing which strike the vital balance between personal privacy, anonymity and the ability of public health professionals and researchers to engage in their work.

Eliminating & Addressing Disparities

Any discussion of pandemic preparedness must reflect the undeniable reality that our current and future crises will disproportionately impact people of color and those with disabilities and chronic illnesses. These populations will always have greater needs during an emergency. As such, in order to appropriately target interventions and reduce both cost and mortality rates, each component of pandemic preparedness must be driven by a commitment to ensuring access and inclusion for vulnerable populations. This includes, but is not limited to, communities of color, native and indigenious populations, rural and underserved areas, those with disabilities, individuals with chronic illnesses, and the elderly.

We are pleased the Department of Health and Human Services (HHS) Office of Minority Health has directed $40 million to minority, rural, and socially vulnerable communities. However, more needs to be done, particularly for the key aspects of any pandemic response: testing, treatment, and surveillance. Efforts to ensure access and inclusion for vulnerable populations and communities of color, especially in the areas of testing and treatment covered by Medicaid, must also be flexible enough and conveniently located so people without transportation or who are unable to travel even short distances can be treated appropriately. This requires building an infrastructure for vaccine research enrollment, and eventually treatment, with non-traditional partners that already are trusted in these communities. There are currently no requirements that research trials take into account the vast diversity of the people who live in the United States; Congress should require such endeavors reflect the demographic compositions of our nation's residents. Side by side with an effort such as this, the federal government should seek and include representatives from communities of color, advocates for the disabled and those with chronic diseases to inform current and future pandemic responses.

We encourage the Chairman to direct federal agencies to leverage existing data to identify our most vulnerable communities and develop strategies to prioritize these populations for increased allocation and distribution of medical supplies, treatments, and vaccines in future crises. Unfortunately, the disproportionate impact of COVID-19 on vulnerable populations and

communities of color was largely predictable based on existing public health research. Federal agencies, such as the CDC, already collect vast amounts of data through their routine surveillance and monitoring responsibilities. Agencies should make use of the data they already collect to proactively identify the populations that are at the highest risk in public health crises, and incorporate this information into future pandemic response strategies. This analysis and preparation will not only help minimize the mortality rates among the most vulnerable, but also allow for increased efficiencies in cost and also in response timeliness. Prioritizing the allocation of resources to the areas of highest need will generate cost savings in the long term as lives are saved while also encouraging lower-risk communities to draw from local resources before relying on federal assistance.

Development and Distribution of Treatments, Vaccines & Permanent Testing Infrastructure

The Chairman's white paper rightly points out COVID-19 has demonstrated the need to consider how the country can better prepare to rapidly develop tests, treatments and vaccines for future pandemics. Similarly, we appreciate the Chairman's *Recommendation 1.3* that the National Institutes of Health's (NIH) existing Medical Countermeasure Innovation Partner program should be better leveraged in addition to replicating the successes of the NIH's Accelerating COVID-19 Therapeutic Interventions and Vaccines (ACTIV) partnerships and the Rapid Acceleration of Diagnostics (RADx) initiative during the current pandemic. We also recognize and commend the numerous private entities continuing to develop diagnostic technologies and vaccines for the coronavirus. However, we caution against overreliance on the private sector alone to lead the development and provision of tests and treatments in response to an emergent pandemic.

The price and ability to pay for necessary therapeutics, which is part of a larger debate about the cost and availability of prescription drugs, should not impede the ability of people to receive treatment or a vaccine during a pandemic; we believe this is a matter of national security. Going forward, Congress should establish a not-for-profit or government partnership similar to the Vaccines for Children Program to ensure a fair and uniform price for a cure. Our nation remains one of the world's leading innovators because of the risks taken by entrepreneurs and great American companies. United States of Care is proud to have an Entrepreneurs Council, which offers advice to us and those we serve regarding innovation and the needs of the private sector. Nevertheless, when it comes to a pandemic and our nation's response, while the private sector should be incentivized for research, similar to a Federal Emergency Management Administration (FEMA) disaster response, the federal government should take the lead in both surge capacity and delivery infrastructure. Simply stated, private sector incentives should not dictate or delay our ability to produce and administer a vaccine to all people who live in the United States with priority given to populations most affected and at risk.

We also believe Congress should provide funding and direction for the federal government to put in place a permanent system of testing infrastructure which would include training, continuing education and requirements for health care providers, hospitals and state and local public health departments to maintain coordination and readiness in order to immediately scale up these activities when a pandemic occurs.

Being Ready for an Outbreak 365 Days Per Year

The Crimson Contagion After-Action Report stated global supply chains for critical medical supplies are unlikely to meet global demand during a pandemic. Accordingly, the federal government must invest in infrastructure for manufacturing and delivery systems that can meet the surge need created by a pandemic or any public health crisis. For example, the government could purchase, lease or maintain idled manufacturing plants for the sole purpose of national emergency activation to meet surge demand. Outside of a crisis, the government could lease or partner with non-profit entities to maintain and utilize these facilities. By investing in this infrastructure before the next crisis, the federal government will have the ability to act quickly and prevent delays caused by negotiating with private sector actors when time is of the essence.

Federal agencies must also **update their disaster preparedness strategies** to specifically include plans for exercising the authorities under Title I of the Defense Production Act (DPA). By proactively planning to leverage DPA authority, the government can rapidly activate existing manufacturing infrastructure to respond to the surge needs of a public health crisis. In addition, Congress should make clear that during a national emergency, medical supplies will be purchased close to their cost of development, whether the DPA is enacted or not. This would be in line with existing public health programs such as the CDC's Vaccines for Children Program, which we previously mentioned above. This program requires federal agencies to secure vaccines at a discount so all children can receive necessary medications to ensure the public's well being. We can and should replicate this dynamic during a pandemic.

The coronavirus pandemic has demonstrated a critical national security need for a **well-maintained and monitored stockpile** of medical equipment and supplies. Although the federal Strategic National Stockpile has proved crucial in providing personal protective equipment (PPE) and ventilators during the early COVID-19 response, neither the stockpile nor the supply chain were sufficiently equipped to meet the full extent of the medical surge. In addition, numerous reports from providers and local responders suggest resources received from the stockpile were frequently expired, malfunctioning, or outdated.

Congress should write legislation providing HHS and the Assistant Secretary for Preparedness and Response with the funding to ensure the national stockpile not only effectively serves as a centralized repository supplementing the resources of states and localities, but is also actively monitored and maintained. Specifically, the federal government must have the ability to monitor the location of every item in the nation's medical inventory at any given time, as well as

establish a process to replace and replenish obsolete items. HHS must concurrently establish new supply chains in anticipation of the next public health crisis so states and hospital systems are not competing with - or bidding against - the federal government to secure medical supplies.

Investment in Our Public Health Infrastructure

The pandemic is proving that **long-term investment in public health infrastructure** is essential at the federal, state, and local levels. It is a matter of national security that the United States commit to prioritizing long-term public health efforts ranging from combating infectious diseases to addressing disparities in access to care. For all these reasons, the creation and funding of a new public health workforce would be valuable. In the short term, such a program will be useful for contact tracing and community testing. In the long term, these workers will be essential in connecting vulnerable communities to care, particularly if they are recruited from the communities in which they will work; the nation stands to benefit if public health education and navigation services can be offered in relevant languages and delivered by those with trusted local relationships, such as community health workers. It may also be useful to direct HHS to research the gaps in our public health system and report to Congress on their recommendations to address the most critical needs, both in the context of pandemic response as well as for ongoing public health infrastructure, education, and safety recommendations outside of periods of crises. For instance, at a minimum, when a national contagion occurs within our borders, all workers should immediately have access to paid sick leave.

Educating the Public About Public Health

Finally, Congress should appropriate funding for **a national public information campaign** to educate those living in the United States about the critical nature of public health preparedness. These efforts would be wise to include funding for a more permanent public education campaign as well as provide flexibility so government agencies can quickly communicate public health instructions in a sustained emergency situation such as COVID-19. In our current fractured media environment, many people are susceptible to disinformation campaigns. This is a dangerous reality Congress must confront, especially when the health of one's neighbor and the economic vitality of the nation are inextricably linked to every individual's personal choices and behavior. A vibrant public education effort would also combat the frightening political attacks we have seen inflicted upon public health professionals across the country. Unfortunately, our nation finds itself in a precarious moment of deep public mistrust of government. Any campaign to educate people regarding public health issues should demonstrate public health is a public good, explain how contact tracing happens every day in every community in America, and how testing and pandemic response is implemented and why it is safe.

On behalf of our entire organization, we commend Chairman Alexander for undertaking this critical national work and providing an opportunity for expert feedback and collaboration. If you

or your staff have further questions, please contact Andrew Schwab, our Director of Policy, Federal Affairs & Partnerships, at aschwab@usofcare.org.

Sincerely,

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