

February 4, 2022

The Honorable Patty Murray
Chair, U.S. Senate Committee on
Health, Education, Labor and Pensions
428 Senate Dirksen Office Building
Washington, D.C. 20510

The Honorable Richard Burr
Ranking Member, U.S. Senate Committee on
Health, Education, Labor and Pensions
648 Hart Senate Office Building
Washington, D.C. 20510

Dear Chair Murray and Ranking Member Burr:

Thank you for the opportunity to provide input on the discussion draft of the PREVENT Pandemics Act. We, the undersigned disability, aging, and chronic condition groups, appreciate your work to ensure that the United States is prepared for the next pandemic. We know that the next pandemic will come, and we hope that we can work together to use what we have learned in the last two years to save lives when the next pandemic occurs.

We are concerned that the current discussion draft does very little to address the disproportionate impact that the COVID-19 pandemic has had on older adults and people with disabilities and chronic conditions. In fact, the draft does not include any references to disability or older adults.

It is well known that people in congregate settings, older people, and people with certain disabilities and conditions are at higher risk of severe COVID-19 and death, and that this risk is also higher among racial and ethnic minority groups. As of January 2022, 23% of all COVID-19 deaths occurred among long-term care facility residents.¹ There is also evidence that the COVID-19 cases and deaths in nursing homes are underreported.² Since the beginning of the pandemic, CDC has consistently reported that some people – older people, people with certain chronic conditions and disabilities – were more likely to become severely ill, be hospitalized, and die from COVID-19.³ The CDC currently reports that more than 81% of COVID-19 deaths occur in people over age 65, that people from racial and ethnic minority groups are dying from COVID-19 at younger ages, people from minority groups are younger when they develop chronic conditions, and that people with disabilities are more likely to have chronic health conditions, live in congregate settings, and face barriers in accessing health care.⁴ Of the conditions listed by the CDC,⁵ many if not all, disproportionately impact racial and ethnic minority groups.

The PREVENT Act must center the needs of those most at risk for severe disease and death from future pandemics. Toward this end, we offer the following suggestions.

¹ <https://www.kff.org/coronavirus-covid-19/issue-brief/key-questions-about-nursing-home-cases-deaths-and-vaccinations-as-omicron-spreads-in-the-united-states/>

² <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2784031>

³ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

⁴ <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html>

⁵ Cancer, chronic kidney disease, chronic liver disease, chronic lung disease, dementia, diabetes, heart conditions, HIV infection, immunocompromised state, mental health conditions, overweight or obesity, sickle cell disease or thalassemia, smoking, stroke, substance use disorders, tuberculosis.

Section 101: Comprehensive Review of the COVID-19 Response

The task force purposes (page 4, line 13), its functions (page 9, line 7), and reports (page 20, line 4) must include an analysis of the impact on people with disabilities, chronic conditions, living in congregate settings, and racial and ethnic minorities. The analysis should look at intersections of these and other demographics including age. The analysis of communication to the public (page 10, line 22) should ensure accessible and understandable information provided by the Federal government to the people, including language translation and alternative formats. The assessments of the capacity of health care facilities and workforce (page 11, line 14) to respond to COVID-19 must include an analysis of how to divert and care for recovering or infectious individuals **outside** of long-term care facilities or other congregate settings with high infection risk; this analysis should encompass the capacity to support and equip community-based services for people with disabilities and the direct support workforce.

Section 102: Appointment and Authority of the Director of the Centers for Disease Control and Prevention

The CDC Strategic Plan (page 25, line 13) should include efforts to address health disparities in all centers and offices. This work should involve, but not be limited to, the Office of Minority Health and Health Equity, and should include improvements to CDC data collection. The strategic plan should also include plans for communicating to the public, in accessible and plain language, information on risks and mitigation strategies during public health emergencies.

Section 104: Strengthening Public Health Communication

The Public Health Information and Communications Advisory Committee (page 40, line 22) should include efforts to communicate with marginalized communities likely to be disproportionately impacted by public health emergencies, including people with disabilities, chronic conditions, living in congregate settings, older adults, and racial and ethnic minorities.

Section 112: Supporting Access to Mental Health and Substance Use Disorder Services During Public Health Emergencies

This section addresses continued access to mental health and substance use disorder services during public health emergencies (page 46, line 3). This section should take into consideration the increased mental health and substance use disorder needs during public health emergencies. Continued access to services is crucial, but so is a plan for addressing the increased need.

There should be a similar section, under the Administration for Community Living (ACL) and Centers for Medicare and Medicaid Services (CMS) regarding continued safe access to disability and aging services during public health emergencies. From the provider relief funds to the distribution of personal protective equipment (PPE), providers of home and community-based services were left out of efforts to support health care services, harming the direct support workers in the field and the people with disabilities that rely on these services. Preparing for the next pandemic must include learning from these mistakes and ensuring that people with disabilities and older people can continue to access as safely as possible the community services they need.

Section 114: Assessment of Containment and Mitigation of Infectious Diseases

While we appreciate that isolation and quarantine are primary considerations during an infectious disease public health emergency, the civil rights and accommodation needs of persons with disabilities and older persons who cannot receive effective health services without personal assistance also need to be explicitly considered and balanced within state, tribal, and territorial preparedness and response plans. We strongly recommend that the GAO report include a component evaluating the degree to which these recognize, or fail to recognize, that civil rights laws are not automatically suspended during a public health emergency, whether the state or territory's plans concern isolation and quarantine, hospital visitation, or crisis standards of care.

Section 201: Addressing Social Determinants of Health and Improving Health Outcomes

We agree that addressing health disparities in pandemics must include addressing social determinants of health and health disparities before the next pandemic begins. The entities envisioned in this section should also demonstrate the capacity to address health disparities among people with disabilities and older adults, which necessarily imports a commitment to collect demographic data on disability status such as functional limitations among underserved populations and communities. We recommend the committee add people with disabilities and older adults to the populations described on page 63 lines 10-11.

Section 202: National Academies of Sciences Report

We support the requirement for this study to build on previous studies and recommendations, including reports on racial and ethnic health disparities. This analysis should include health disparities faced by people with disabilities and chronic conditions how disparities intersect with age and sexual orientation and gender identification.⁶

Section 232: Vaccine Distribution Plans

We agree that the Public Health Service Act should be amended to recognize the existence of non-influenza pandemics. We urge the committee to go further regarding vaccine distribution plans beyond the distribution to states and localities currently addressed. The committee should address not only distribution of vaccines, but the accessibility of vaccines to the public and the enforcement of relevant civil rights laws and regulations. This would include, but is not limited to, accessibility of vaccine information, accessibility of vaccination sites, and distribution of vaccines to high risk groups and underserved groups. These provisions may belong in this section or any other relevant section.

Section 301: Research and Activities Related to Long-term Health Effects of SARS-CoV2 Infection

We support the committee's efforts to address the long-term effects of COVID-19 infection, also known as Long COVID or Post-Acute Sequelae of SARS-CoV2 (PASC). We urge the committee to include in this work related and similar post-viral illnesses, such as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. Much like PASC, ME/CFS is known to frequently follow a viral infection. PASC and ME/CFS both have no diagnostic test, no FDA-approved treatment, and no yet known biomedical cause. Both conditions are based solely on patient reporting. The recent rise in PASC, thought to affect more than

⁶ Swenor BK. Including disability in all health equity efforts: an urgent call to action. *Lancet Public Health*. 2021 Jun;6(6):e359-e360. doi: 10.1016/S2468-2667(21)00115-8. PMID: 34051160.

half of individuals infected with COVID-19⁷ has brought attention to post-viral illnesses. These new efforts must not leave behind the millions of people with other post-viral illnesses that currently have little epidemiology or research and no treatment. The committee should insert “and other post-viral conditions, including but not limited to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome,” after “SARS-CoV-2 infection” on page 119 line 1-2 and line 8.

Title IV: Modernizing and Strengthening the Supply Chain for Vital Medical Products

Throughout this section, we urge the committee to take into account people with higher than average need for medical products. The strategic national stockpile must take into account the number of people who rely on medical products every day and those whose need for medical products may increase during a public health emergency.

Section 404: Improving Transparency and Predictability of Processes of the Strategic National Stockpile

In this section, the “other applicable entities” (page 136, line 19) and “other appropriate stakeholders” (page 137, line 13) should include disability service providers, geriatricians, and other medical professionals working in congregate care settings, and representatives of communities that rely on medical countermeasures.

Section 310: Grants for State Strategic Stockpiles

In this section, grant applications from states are required to include how the awardee will coordinate with relevant entities under section 319C-1 of the Public Health Service Act (page 149, lines 17-19). Section 319C-1 requires an All-Hazards public health Emergency and Response Plan, which includes “preparedness and response strategies and capabilities that take into account the medical and public health needs of at risk individuals in the event of a public health emergency.” The committee should make clear that the awardees under this section must also take into account the needs of people with high risk in public health emergencies when developing their plan. The needs of high-risk people should also be included in exercise and drills (page 153, line 1), the guidance from the Secretary (paragraph 6, page 153 beginning on line 21), state reports (paragraph 8, page 155, beginning on line 4), and the GAO report (page 156, beginning on line 12), especially the impact of such stockpiles on the ability of the State to prepare for and respond to the needs of people at high risk during a public health emergency.

Section 508: Improving FDA Communication

We appreciate that this section includes consultation with patient groups (page 184, line 19). We urge the committee to add representatives from disability organizations and aging organizations.

Additional Provisions

In addition to the changes outlined above, we urge the committee to include measures to help older people, people with disabilities and people with chronic conditions to respond to public health emergencies. These include assistance to individually prepare for emergencies and ensuring that they can continue to access daily living support, assistive and durable medical devices, and health care safely.

⁷ <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2784918>

Several organizations have communicated to the committee on the need for this legislation to address access to medications in public health emergencies.⁸ Both CDC and the Federal Emergency Management Agency (FEMA) urge people to obtain extra supplies of medications and medical supplies as a part of everyday preparedness. The committee should use its jurisdiction over ERISA-regulated plans to require plans to ensure that people who take regular medications or need regular supplies can have extra supply on hand, at least to CDC and FEMA recommendations. The committee should also require that plans, at the declaration of an emergency, allow early refills, longer refill periods, medication synchronization, home delivery, and waive utilization management. These changes should apply to medications and supplies. We also urge the committee to address access to daily living support, assistive technology, and durable medical equipment in public health emergencies to the extent of its jurisdiction.

Thank you for the opportunity to comment on this discussion draft. For more information contact Rachel Patterson, Senior Director of Federal Relations & Policy, Epilepsy Foundation at rpatterson@efa.org.

Sincerely,

Alpha-1 Foundation
American Academy of Physical Medicine & Rehabilitation
American Association on Health and Disability
American Network of Community Options and Resources (ANCOR)
Association of University Centers on Disabilities
Autistic Self Advocacy Network
Be a Hero
Cystic Fibrosis Foundation
Disability Rights Education and Defense Fund (DREDF)
Epilepsy Foundation
Justice in Aging
Lakeshore Foundation
Little Lobbyists
Muscular Dystrophy Association
National Health Council
National Multiple Sclerosis Society
The AIDS Institute
The Arc of the United States

⁸ <https://www.epilepsy.com/sites/core/files/atoms/files/Coalition%20letter%20-%20medications%20in%20emergencies.pdf>