

**Human Rights & the Centrality of Care & Support for Ongoing COVID-19 Impacts in the United States: Submission to the Office of the UN High Commissioner for Human Rights. April 2024.**

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**EXECUTIVE SUMMARY, *Hannah Lipstein***

**UN Resolution 54/6 affirmed the integral role of care within a human rights framework.[[1]](#footnote-1) This report offers a contribution to the upcoming UN expert workshop and thematic study specific to the *intersections of the COVID-19 pandemic and the human rights of care.***

In the United States, the COVID-19 pandemic strained a care infrastructure already beset with inequalities and precarities. In acute stages of illness, many individuals found few resources to support them or their dependents. Many more went on to develop long COVID and, to this day, rely on ongoing care from a constellation of family members, loved ones, or professionals.

The U.S. passed several measures aiming to ease the burdens of the pandemic. Direct financial payments, for example, provided economic relief to citizens but also highlighted inequities of access to government support. Further, even though the need remains high to this day, much of the early influx of government assistance expired. Very few systemic issues were addressed during this flurry of attention.

The pandemic took a disproportionate toll on long-term care facilities. With many sites underfunded, understaffed, and isolated, a communicable disease like COVID-19 was able to wreak havoc both on residents and staffers. Here, the pandemic caused significant mental, physical, and emotional suffering.

COVID-19 also exposed significant systemic care inequities. While many white and wealthier Americans work safely from home and arrange for private child- or eldercare, other multiply-marginalized Americans face significantly higher rates of acute infection and death, disease exposure on the job, unemployment, inadequate healthcare, a dearth of childcare options, and illness or loss of primary caregivers—all of which complicate or make impossible the tasks of care.

Our report closes with suggestions. We advocate for: (1) development of a system of support for caregivers; (2) dedicating significant resources to research on acute and long COVID; (3) and establishing an international standard for informal caregiver fund provisions.

**1. COVID CARE AND SUPPORT, *Matilda Olufunke Ajibola & Sharit Cardenas Lopez***

**Medical Impacts:** Long COVID is when SARS-CoV-2 symptoms like chronic pain, chest pain, shortness of breath, brain fog, and intense fatigue resurface and linger for weeks, months, or years.[[2]](#footnote-2) It can lead to developing new conditions like diabetes, blood clots, and heart and neurological conditions.[[3]](#footnote-3) It is estimated that 65 million people worldwide suffer from long COVID.[[4]](#footnote-4)

Research suggests individuals who experienced severe COVID-19 illness, had pre-existing health conditions, did not get the vaccine, and marginalized populations experiencing negative social determinants of health have a higher risk of developing long COVID.[[5]](#footnote-5)[[6]](#footnote-6) Surveys have found long COVID significantly harmed people’s lives; 43 percent of people with long COVID reported a worse quality of life, 45.2 percent required a reduced work schedule, and 22.3 percent could not work.[[7]](#footnote-7)

The COVID-19 pandemic dramatically impacted healthcare workers.[[8]](#footnote-8) Research suggests stress related to the pandemic left lingering impacts. For instance, 62 percent of healthcare workers reported their mental health was negatively impacted, 49 percent reported their physical health was impacted, 55 percent felt burnt out, and 29 percent had considered leaving the industry. The need for union jobs has never been greater.

**Interventions:** Despite the recognition of long COVID as a real problem and potential disability under Equal Employment Opportunity laws, there is still no comprehensive U.S. federal policy.[[9]](#footnote-9) Although certain agencies have prioritized long COVID, affected people still struggle to obtain disability benefits and workplace accommodations due to unclear guidelines.[[10]](#footnote-10)

**Gaps:** The absence of comprehensive U.S. federal legislation and clear protocols for evaluating disability claims and providing support is a significant problem.[[11]](#footnote-11) Additionally, there are no established national guidelines for the diagnosis, treatment, or insurance coverage of long COVID.[[12]](#footnote-12) Research funding for understanding prevalence, risk factors, and long-term impacts remains insufficient.[[13]](#footnote-13) Furthermore, the U.S. lacks adequate paid leave policies and worker protections for individuals with chronic illnesses.[[14]](#footnote-14)

**Recommendations:** We recommend the U.S. government enact federal legislation with clear guidelines for disability evaluation, accommodations, treatment protocols, and support services tackling long COVID. Increasing research funding, implementing national paid leave policies, strengthening worker protections, and ensuring insurance coverage for long COVID care are recommended. Establishing national clinical guidelines, improving access to specialized clinics, collecting disaggregated data to identify disparities, and fostering international collaboration are recommended to help address long COVID.

**2. COVID-19 AND LONG-TERM CARE, *Eleftherios Hazapis***

Caregivers and those receiving long-term care are currently inadequately protected by the UN's human rights principles. Long-term care should be a guaranteed part of the protection of the fundamental human rights inherent in the governance of democratic countries.[[15]](#footnote-15)

The COVID-19 pandemic negatively impacted the mental and physical health, family dynamics, and social cohesion of patients and caregivers and their families and exposed the chronic problems and unaffordability of long-term care such as isolation of residents and caregivers, inadequate funding, understaffing, lack of training, overcrowding, poor facilities, and public/private funding disparities.[[16]](#footnote-16) Globally, 70 percent of patients rely on informal unpaid care by caregivers who often have to abandon the labor force.[[17]](#footnote-17) The rise in long-term care needs is due to demographic changes influenced by years worked, retirement policies, pension age, and lower fertility rates.[[18]](#footnote-18)

Only 7.5 million Americans in 2020 who were in higher income brackets could afford private long-term care insurance.[[19]](#footnote-19) For these reasons, many Americans face the choice of paying for care out of pocket or having their care needs met by unpaid caregivers, often spouses, children, or both. Limitations in government insurance coverage add to out-of-pocket expenses, as Medicare provides coverage of only short-term care needs after acute health events but not longer-term care needs due to chronic illnesses and cognitive impairment, and help needed for two or more activities of daily living. Medicaid works independently from Medicare and covers long-term care needs only for those who meet stringent asset and income requirements that confine it to use by only the neediest members of already disadvantaged populations.

Innovative solutions to the problem of long-term care should include protecting patient rights and enabling patient empowerment by promoting universal long-term care policies to allow patients and caregivers to manage health and wellness and make informed care decisions.[[20]](#footnote-20) Universal coverage would promote autonomy, financial support, social security rights, and work-related rights.[[21]](#footnote-21) Governments must address the gaps that exist today in remuneration of caregivers and treatment of patients.[[22]](#footnote-22) The lack of awareness and empathy shown by medical professionals to long-term care patients and care workers needs should be exposed and addressed.[[23]](#footnote-23)

**3. INTERSECTIONAL IMPACTS, *Monique Vaz and Courtney McGourty***

The underlying systems of inequality present before COVID-19 only became more apparent as disparities in the pandemic’s impact on health, employment, and government support intensified.

**Employment:** Large numbers of marginalized communities were disproportionately represented in labor segments classified as “essential.”[[24]](#footnote-24) There were also racial and ethnic disparities in the transition to teleworking.[[25]](#footnote-25) Young women experienced the highest rate of full-time job loss during the pandemic.[[26]](#footnote-26) This becomes a compounding issue when employment is linked to insurance and, therefore, access to quality health care. Serving as an additional barrier to employment, the closure of schools forced parents to balance work and childcare concurrently.[[27]](#footnote-27)

**Access to Healthcare:** Insurance plays a determining role in health equity. 25.6 million Americans were uninsured in 2022.[[28]](#footnote-28) Many are people with disabilities and low-income families. Another barrier to healthcare is vaccine access. The UN “stipulated that a COVID-19 vaccine should be provided without discrimination and acknowledged that a human-rights based approach is an effective pathway in the prevention of major public health threats.”[[29]](#footnote-29) Due to the lack of information surrounding the side effects of the vaccines and lack of treatment centers to acquire the vaccines, many underserved communities are left defenseless.

**Recommendations:** We urge the UN to consider the intersectional impacts of COVID-19, drawing attention to the overlapping nature of oppression and the impact of historic inequalities on social, economic, and health outcomes. We echo ICESCR Article 12(2)(d) which dictates the “creation of conditions which would assure to all medical service and medical attention in the event of sickness.”[[30]](#footnote-30)

**4. COVID-19 IMPACT ON IMMIGRANTS, *Aliza Inam & Cherisse Lewis***

COVID-19 exacerbated existing inequalities and vulnerabilities within structurally marginalized immigrant communities, as well as the flaws of U.S. healthcare and social service systems.[[31]](#footnote-31) It emphasized the need for inclusive and equitable responses to ensure the health, safety, and well-being of all individuals. Border restrictions and asylum policies limited immigrants’ ability to seek protection, and xenophobia and discrimination increased.

Despite having the human right to the highest attainable standard of physical and mental health and contributing significantly to the economy, many immigrants were excluded from economic relief measures like the U.S. CARES Act. Mixed-status households faced challenges accessing benefits, leading to financial strain and heightened unemployment rates among immigrant workers.[[32]](#footnote-32)

Immigration processing varied at U.S. land borders and inside the U.S. When “non-essential” travel was suspended through entry ports, the Department of Health and Human Services established a regulation allowing the Director of the Centers for Disease Control to “prohibit” individuals as they believe that “there is serious danger of the introduction of [a communicable] disease into the United States.”[[33]](#footnote-33) Over 147,000 people were “expelled” at the border and denied the opportunity to seek asylum.[[34]](#footnote-34) Within the U.S., all in-person services were suspended, hindering immigration benefits and asylum applications, delaying the process for tens of thousands of immigrants to become U.S. citizens.

COVID-19 severely impacted detained individuals and workers in detention centers through limited accessibility to sanitary resources, such as soap and face masks, and no social distancing practices within the centers and transports. This resulted in over 7,300 people testing positive for COVID-19 in ICE detention.[[35]](#footnote-35) The pandemic highlighted the complex relationship of migration and health, and solutions must address the health needs of migrants across all stages of migration, from pre-departure to settlement, supporting economic stability and social integration.Immigrants have been essential in the U.S. ability to respond to the pandemic, and they are essential to its recovery.

**5. PANDEMIC ASSISTANCE, *Chris Chavers***

The UN recognizes COVID-19’s complexity, addressing health, economic, humanitarian, security, and human rights aspects. This underscores the pandemic’s role in exacerbating existing vulnerabilities and disparities across nations, thereby necessitating a comprehensive and inclusive approach to recovery. The UN’s articulation of the crisis—the “pandemic” is more than a health crisis; it is an economic crisis, a humanitarian crisis, a security crisis, and a human rights crisis. Coming out of this crisis will require a whole-of-society, whole-of-government and whole-of-the-world approach driven by compassion and solidarity."[[36]](#footnote-36)

In response to these multifaceted challenges, the UN's strategic framework, characterized by its division into three core pillars—thematic areas, targeted populations, and regional concerns—represents a thorough and considered approach to guiding global and national efforts in mitigating the pandemic’s impacts. This facilitates a tailored response, ensuring that policy briefs and interventions are relevant to the specific needs and circumstances of diverse regions, thereby enhancing the inclusivity of the recovery process. The US CARES Act provided emergency aid but highlighted unequal distribution and persistent access inequities. The disparities that marginalized communities have and continue to face highlight the broader challenge of ensuring equitable assistance during global crises, underscoring the importance of adopting multifaceted and inclusive strategies akin to those proposed by the UN.[[37]](#footnote-37)

The U.S. has ceased pandemic assistance, lacks infrastructure for long COVID support, and has no federal mandate for paid sick leave for these cases. This absence of policy and economic relief measures risks continuing fatalities, disproportionately affecting marginalized communities.[[38]](#footnote-38)

It is recommended that the U.S. adopt the UN’s comprehensive approach to addressing the pandemic impacts. The US should use this guidance to tackle immediate challenges and address pandemic-exposed inequalities, fostering a more transformational and equitable world.

**6. RECOMMENDATIONS, *Jean-Philippe Beaudet & Tess Herdman***

**Develop a long-term and wide-reaching system of support for caregivers.** We expect that the demand for people providing care to those with lasting long COVID effects will rise significantly in the coming decades, alongside an aging global population requiring additional investment. Between 1948 and 2050, the ratio of children (<15) to elderly (65+) will jump from seven to one to one to one, and might include as many as 500 million individuals 85+ years old.[[39]](#footnote-39) These populations will struggle disproportionately with long-COVID effects alongside the anticipated impacts of old age. Professional caregivers *and* family members who take on a care-giving role will need to be supported.

**Dedicate significant resources to supporting research on COVID and long COVID symptoms.** Long-COVID impacts 10 to 50% of people who contract the SARS-CoV-2 virus, and can produce 200+ symptoms impacting multiple organ systems.[[40]](#footnote-40) Research has greatly increased our understanding of SARS-CoV-2, but some persistent hurdles must be overcome. Testing biases, misidentification and miscommunication of COVID’s multisystem impacts, and racialized treatment and reporting among those populations most likely to develop long COVID symptoms must be overcome, and information must be freely shared through partnerships between governments, academic institutions, and the private sector.

**Establish an international standard for informal caregiver fund provisions.** Where “respite vouchers” are available in the U.S., they are often worth $200 to $400 and available once every three months.[[41]](#footnote-41) U.S. Social Security and Supplemental Security Income provide funds for disabled and elderly citizens, and the 2023 Social Security Caregiver Program greatly expands citizen access to support funding.[[42]](#footnote-42) These programs provided $124.6 million in FY 2020 across the U.S., but they do not compensate for an informal care economy estimated to be worth $522 billion annually.[[43]](#footnote-43) An international commitment to national policies advancing this model is urgently needed.

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