

**Testimony of Monica Verduzco-Gutierrez, MD  
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**Before the Committee on Ways and Means, Subcommittee on Health  
United States House of Representatives**

**“Bridging Health Equity Gaps for People with Disabilities & Chronic  
Conditions”**

**February 3, 2022**

Chairman Doggett and Members of the Health Subcommittee:

Thank you for the opportunity to testify today regarding impacts on the disability community during the COVID-19 pandemic and a new disabling condition created by Post-Acute Sequelae of SARS-CoV-2 infection, also known as “PASC” or “Long COVID.” I would also like to take this opportunity to thank you all for the work Congress and the federal government has undertaken over the past, nearly two years to respond to the COVID-19 pandemic. I look forward to discussing issues related to disability and Long COVID with this committee in hopes that additional steps can be taken to address this alarming condition.

My name is Monica Verduzco-Gutierrez. I am a physiatrist working at the Joe. R and Teresa Lozano Long School of Medicine at the University of Texas Health Science Center San Antonio, a member of the American Academy of Physical Medicine & Rehabilitation (AAPM&R), and a trustee for the Association of Academic Physiatrists. Physiatrists are physicians who are specialists in Physical Medicine and Rehabilitation (PM&R), treating a wide variety of conditions affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles, and tendons. We evaluate and treat injuries, illnesses, and disabilities, and we are experts in designing comprehensive, patient-centered treatment plans. We utilize cutting-edge as well as time-tested treatments to maximize function and quality of life.

My own subspecialties in PM&R are Neuro Rehabilitation and Brain Injury Medicine. Prior to the pandemic, I saw patients in various settings, from the intensive care unit to the outpatient clinic. I even previously trained and worked at the rehabilitation hospital that cared for Congresswoman Giffords.

During my career, I have been blessed to see the miraculous recoveries of those waking up out of a coma or the paralyzed walking again, along with all sorts of physical and mental healing through multi-disciplinary teamwork.

### **Impacts of the COVID-19 Pandemic on Persons with Disabilities**

The Centers for Disease Control and Prevention (CDC) estimates that 1 in 4 Americans are living with some type of disability.<sup>1</sup> Historically, people with disabilities, especially those needing assistance and living in care facilities, are at increased risks during pandemics because of disruption of routine and long-term care. Psychiatrists work with patients who experience health and healthcare disparities due to an intersection of race/ethnicity, gender, socioeconomic class, and physical and cognitive disabilities. Central to the current human suffering with the pandemic is the disproportionate impact it is having on the disability community and others from marginalized communities. The pandemic has offered us a closer look into health and healthcare disparities that reinforce this trend, inclusive of the impact of structural racism and structural ableism.

There are even more barriers to provision of psychiatric care and long-term care for those from minority racial and ethnic groups, and these are especially exacerbated during the COVID-19 pandemic. I have patients with disabilities have difficulty procuring home care and getting caregiver services. Patients have had therapy services cut (especially in the first several months of the pandemic when many clinics were closed and telerehabilitation was limited). Patients have had caregivers and family members die due to COVID-19 and then need to be moved into long-term care. The affects are not just physical, but psychological. There are high amounts of isolation and mental health impacts with more depression and anxiety.

Aside from the direct illness caused by COVID-19 on the disabled community - and the disparate effect that the virus has had on marginalized communities - the global pandemic has overstretched health care resources in many regions of the country. As health care systems focus on treating those with COVID-19 infection, there are fewer assets to provide care for other chronic and acute conditions. The inpatient rehabilitation unit for Bexar County's level-1 trauma center and "safety-net" hospital has been shuttered for a total of 43 weeks over the 4 surges of the pandemic to make space for acutely ill persons with COVID-19. This remains a tremendous problem for patients recovering from injuries to their central

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<sup>1</sup> Okoro CA, Hollis ND, Cyrus AC, Griffin-Blake S. Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults – United States, 2016. MMWR Morb Mortal Wkly Rep 2018;67:882-887

nervous system and/or those requiring complex musculoskeletal interventions against the backdrop of COVID-19. Strokes, spinal cord injuries, brain injuries, and amputations did not halt during the pandemic. Patients with new and ongoing disabilities are now unable to get necessary rehabilitation services.

### **A New Population of Disabled Americans with COVID-19 Related Disabilities**

Significant long-term disability with multisystem involvement has now been seen in a growing population of patients who have survived COVID-19. There is a myriad of clinical syndromes involved in PASC and the phenotypes are yet to be elucidated. In some studies, there have been over 50 to 100 symptoms described.<sup>2</sup> The World Health Organization defines post-COVID conditions as occurring in individuals with a history of probable or confirmed SARS-CoV-2 infection, usually within 3 months from the onset of COVID-19, with symptoms that last for at least two months and cannot be explained by an alternative diagnosis.<sup>3</sup> Each of these persons with Long COVID are suffering and has a story that needs to be heard. Each of them has a different course – some even starting as asymptomatic or mild COVID – with lingering and debilitating symptoms. I have had cancer survivors get Long COVID. They tell me that their post-COVID fatigue is 100-times worse than their cancer fatigue ever was. I have treated many nurses and physicians. Some have not been able to return to the operating room or to the frontline or the patient bedside. Marathon runners who cannot even walk a mile. A young mother who can't run after her children without her heart rate going to 180 and getting short of breath.

Due to the nature of our specialty and our experience working with and coordinating care for people with complex disabilities and chronic conditions, physiatrists have been recognized as the leading specialty for assessing and treating patients experiencing the condition known as Long COVID. Common symptoms include fatigue, post-exertional malaise, cognitive dysfunction (colloquially referred to as brain fog), shortness of breath, headaches, along with others that generally have an impact on everyday functioning. It is currently estimated that 10-30%<sup>4</sup> of people who had COVID-19 will experience Long COVID symptoms. It is not yet clear whether these percentages are consistent with the Omicron variant. Even considering the conservative estimate of 10%, this represents well over 14 million people in the US

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<sup>2</sup> Davis HE, Assaf GS, McCorkell L, Wei H, Low RJ, Re'em Y, Redfield S, Austin JP, Akrami A. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *EClinicalMedicine*. 2021 Aug;38:101019.

<sup>3</sup> [https://www.who.int/publications/i/item/WHO-2019-nCoV-Post\\_COVID-19\\_condition-Clinical\\_case\\_definition-2021.1](https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1) Last updated October 6, 2021.

<sup>4</sup> Rubin R. As Their Numbers Grow, COVID-19 “Long Haulers” Stump Experts. *JAMA*. 2020;324(14):1381–1383. doi:10.1001/jama.2020.17709.

alone,<sup>5</sup> given the infection rate of this virus. Additionally, these symptoms often appear in patients who were asymptomatic and may not have known they were infected with COVID-19 in the first place.

Throughout the pandemic, starting as early as April 2020, many physiatrists and other clinicians have come together to understand and address Long COVID by opening multi-disciplinary Long COVID clinics, in addition to our existing physician duties. These multi-disciplinary clinics often serve as a “one-stop shop” to help this population address their new, varied, and often debilitating symptoms, including neurological challenges, gastrointestinal symptoms, anxiety, depression, cognitive problems such as brain fog, shortness of breath, fatigue, musculoskeletal pain, and mobility impairments. These clinics convene different physician specialists, therapists, social workers, and sometimes researchers who are gathering vital data from patients with PASC.<sup>6</sup> Furthermore, telemedicine has been vital in allowing me to provide care to my patients with disabilities during the pandemic. Patients have felt safe by having less exposure to infectious diseases, saving money and time, and I have been able to see more of their home surroundings and social determinants of health.

At the start of the pandemic, I returned to my roots to work and live in South Texas. I currently lead two such clinics, the Post-COVID Recovery Clinic at UT Health San Antonio and the Post-COVID Recovery Clinic at University Health. The AAPM&R has gathered 35 of these institutions to create a Multi-Disciplinary PASC Collaborative of experts to develop clinical guidance to improve quality of care, formal education, and resources to improve the experience of care and address health equity. These collaborative discussions have illuminated the consistent infrastructure and access barriers we are seeing. I have witnessed this in my own clinics. The clinic at UT Health is set up like an academic-private practice hybrid; the other clinic at University Health, is at the county safety-net hospital and level-1 trauma center. It is a tale of the “haves” and the “have-nots” in one city. At UT Health, most of my patients are in the 30 to 50-year-old range and are employed, have commercial insurance, FMLA and/or short-term disability benefits. They have access to specialists, specialized therapy services, and jobs that allow for accommodations such as work from home part-time. These patients can easily sign on to the electronic patient portal with their broadband internet service and do a telemedicine visit. The underinsured patients at the county hospital system have much more difficulty accessing telehealth (barriers are sometimes related to broadband or literacy to understand the technology needed). The wait time to get into clinic is up to 4-5 months. Unfortunately, the no show rate to clinic is upwards of 25%. If

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<sup>5</sup> Estimated Disease Burden of COVID-19. Centers for Disease Control and Prevention. October 2, 2021. <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/burden.html>

<sup>6</sup> Verduzco-Gutierrez M, Estores IM, Graf MJP, et al. Models of Care for Postacute COVID-19 Clinics: Experiences and a Practical Framework for Outpatient Physiatry Settings. *Am J Phys Med Rehabil.* 2021;100(12):1133-1139.

a patient gets in and they get orders for basic therapy services, there is another month wait, and longer for some specialists.

The needs of persons with Long COVID are already spreading far beyond the clinical sphere, as patients face difficulties in returning to work, receiving necessary workplace accommodations, and accessing Social Security disability insurance, and other benefits. Even in my own clinic there is not direct access to social work support.

**AAPM&R has called on the Administration and Congress to develop a comprehensive federal plan to defeat the national Long COVID crisis.** To develop such a plan, to assess the varied policy considerations and far-reaching impacts of Long COVID, and to obtain meaningful input from a wide range of stakeholders, the AAPM&R has recommended the immediate formation of a federal commission (or other designated federal body) with a diversity of expertise to develop priority recommendations for addressing infrastructure needs and other gaps in access to timely and appropriate clinical care for all individuals with PASC.

### **I. Access Barriers**

The World Health Organization has recommended the use of rehabilitation as a key to improving health outcomes of patients with COVID-19.<sup>7</sup> Not all insurers and health plans cover rehabilitation services, specialty home-based services, or post-acute care for these newly acquired COVID-19 brain injuries and neurorehabilitation. These services are vitally important for a population that is experiencing a breadth of symptoms who often have difficulty coordinating care and traveling to many different doctors' offices. Moreover, some social determinants of health (e.g., lack of health insurance) will preclude access to rehabilitation services and physicians, negatively impacting outcomes. Right now, access to vaccines is free to patients. Monoclonal antibodies are free to patients. Patients with severe COVID-19 are treated in the hospital if they require it. This contrasts with persons with Long COVID who do not have covered visits at specialty clinics nor accessible rehabilitation services. We all recognize that the COVID-19 pandemic is stressing the healthcare system. Furthermore, Psychiatry is currently undersized to deliver services to everyone in the United States who needs this care.

Unfortunately, we also see increasing reports of insurers denying coverage of these services for

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<sup>7</sup> *Rehabilitation Considerations During The COVID-19 Outbreak*. Pan American Health Organization; 2020. [https://iris.paho.org/bitstream/handle/10665.2/52035/NMHMHCOVID19200010\\_eng.pdf?sequence=6&isAllowed=y](https://iris.paho.org/bitstream/handle/10665.2/52035/NMHMHCOVID19200010_eng.pdf?sequence=6&isAllowed=y).

individuals with PASC, citing a lack of evidence-based practice guidelines, which often take years to develop and are regularly changing even for well-understood conditions. I have been told a patient with Long COVID cannot do a Neuro Rehabilitation program because they do not have a “traditional” brain injury or stroke, though a recent comprehensive review described the psychiatric and neuropsychiatric sequelae of COVID-19,<sup>8</sup> many of which overlap with symptoms seen after brain injury. The neuropsychiatric symptoms of PASC include depression, anxiety, post-traumatic stress disorder, obsessive-compulsive disorder and psychotic disorders, cognitive deficits, fatigue, sleep disturbances, along with high rate of suicidal ideation, attempts and completion. Because there is not adequate coverage, many patients cannot access these services as chronic symptoms are typically not considered as “acute” or “emergent.” Many patients are simply unable to afford the costs of Long COVID treatment out-of-pocket, especially given the wide range of services required for appropriate treatment and the long-lasting, potentially permanent, effects of this condition.

The nature of Long COVID also means that many patients present with symptoms that do not appear in a normally recognized test. For example, patients may complain of shortness of breath, but show no discernible physical signs through imaging of their lungs. A patient with brain fog who cannot find their words or have head vibrations or dizziness, may have a normal MRI of their brain. The patient with fatigue 100-times worse than cancer fatigue will have all labs return normal. This has been a longstanding problem for patients with other long-term, chronic, and poorly delineated conditions, such as chronic fatigue syndrome and other complex disease states, and often contributes to patients’ issues with insurer coverage and access to condition-specific care and disability benefits. Perhaps one silver lining of Long COVID will be an enhanced capacity for our health system to address the needs of individuals with complex and chronic conditions overall. This underscores the need for research on PASC to be conducted rapidly and translated to providers so the symptoms this new population is suffering can be more easily recognized and addressed, instead of being dismissed for not fitting within existing medical paradigms.

In addition to financial barriers, individuals experiencing PASC are subject to the same systemic barriers to care that individuals with other complex, chronic conditions experience. For instance, when a patient visits their primary care provider to discuss their PASC symptoms, they are often provided with several referrals to specialists to address the confluence of their symptoms. Such patients may receive a referral to a cardiologist, pulmonologist, neurologist, psychiatrist, and orders for various labs and other tests. This puts the patient in the position of coordinating their own complex care and having to attend many

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<sup>8</sup> Schou TM, Joca S, Wegener G, Bay-Richter C. Psychiatric and neuropsychiatric sequelae of COVID-19 - A systematic review. *Brain Behav Immun*. 2021 Oct;97:328-348. doi: 10.1016/j.bbi.2021.07.018. Epub 2021 Jul 30.

different appointments, if they are even able to secure appointments in a timely manner. This is particularly difficult for a population encountering significant fatigue, brain fog, and other debilitating PASC symptoms. The multi-disciplinary clinic approach, to the contrary, creates a central hub where a patient can see a psychiatrist and consult with all the specialists needed, complete their testing, and meet with any needed therapists through a comprehensive, coordinated approach. It is one of the reasons these clinics have months-long waiting lists just to be evaluated for the first time.

The PASC clinics that are growing across the country are typically part of an academic medical center or other health system that has the resources and capacity to develop these clinics quickly. These systems may have significant financial reserves, physical space, and existing networks of specialists to pull from when coordinating a clinic. Yet many other centers - like my own - do not have those resources. For the vast majority of health care providers across the nation, these capabilities will not be available to adequately support such multi-disciplinary clinics without some form of financial assistance to jumpstart their development, even as they are proving highly effective in meeting the needs of patients with Long COVID. To put it plainly, the need for these clinics far outstrips the resources available in many areas of the country.

## **II. Payment Issues for Patients and Providers**

Typically, clinical visits to evaluate, diagnose, and coordinate treatment for patients with Long COVID symptoms take an hour or more per patient. Such complex and lengthy visits are simply not in sync with the typical reimbursement models for medical practice, and the existing Evaluation and Management (E&M) codes are not equitable for the work required to treat these patients. Existing E&M codes are based upon a standard 15-minute patient visit, which is not a reasonable amount of time to evaluate complex PASC patients who may have 15 symptoms to discuss. This discrepancy in reimbursement and the time expended may be why more doctors are not able to adequately care for these patients. Improved reimbursement policies, such as a Long COVID add-on code, are desperately needed to ensure that physicians can dedicate the time and resources necessary to provide appropriate care to Long COVID patients. Such reforms will make it feasible for physicians to provide this care, increasing the supply of providers offering Long COVID treatment and reducing wait times and other barriers to accessing care for patients. Currently, the majority of physicians working in these clinics are doing so as an adjunct to their existing clinical responsibilities, making it difficult for many physicians to participate in this new model of care. I have often described it as, “robbing Peter to pay Paul.” I have finite clinical time. If I see more patients with Long COVID, I see less patients with an acquired brain injury and vice versa. A relative dearth of physicians has resulted in wait times of four to six months for patients before they can

be seen by many of the specialists necessary to treat their Long COVID symptoms. Unfortunately, we expect these backlogs to worsen as more and more individuals develop Long COVID symptoms, unless action is taken to support the Long COVID provider workforce. Along these lines, I appreciate your support in continuing to expand graduate medical education, so we can continue to train enough physicians to care for the growing number of individuals with disabilities.

I urge you to consider policies to support new and existing clinics to bolster this successful and sorely needed model for addressing the clinical needs of patients with Long COVID and to help patients optimize their health and function in the near term. In particular, clinics have expressed a need for: funds to support workforce capacity, including hiring patient coordinators, staff therapists, and non-physician practitioners specializing in disability documentation; “start-up” support to help new clinics open, especially in rural and underserved areas; and greater coordination and collection of data on diagnoses, treatment, and outcomes across specialty clinics addressing Long COVID.

### **III. Additional Needs of Long COVID Patients and Persons with Disabilities**

The significant and time sensitive clinical needs of Long COVID patients only reflect one aspect of the impacts of Long COVID on the country. Individuals with Long COVID are often of working age, with the average age of patients in my clinic being early 40s. Many patients are likely to experience long-term or even permanent functional impairment and disability because of Long COVID. Like my patients from before the pandemic with acquired disabilities, these individuals will face significant additional obstacles in their daily life because of their symptoms. It is critical to consider: how individuals with Long COVID will be able to access disability benefits, including Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI); the accommodations these individuals may need to return to work, if they are able; the availability of Long-Term Services and Supports (LTSS) that may be necessary; the education these individuals may need to understand the services available to them and their rights under the Americans with Disabilities Act and other federal statutes. These are just some of the additional needs identified with Long COVID patients.

My patients with acquired neurological injuries have previously waited the mandated 24-month waiting period for Medicare disability benefits. This wait time leads to major gaps in healthcare coverage and ultimately worsens outcomes. Often, the patient and their families are bankrupted by the wait. During this time, a patient with severe brain injury may have their limbs become more contracted from spasticity (making care and transfers difficult), acquire more skin wounds, be fed by a tube for a longer period of time, and may be locked-in their bodies until the 24 months when they get Medicare and can get



rehabilitative services; that is if they even survive. After the 24 months, they are worse, and it is more expensive to care for them with these sequelae. Exclusion periods and wait times harm American workers with disabilities. To truly improve access to health care and bridge health equity gaps, I agree with legislation like Chairman Doggett's Stop the Wait Act.

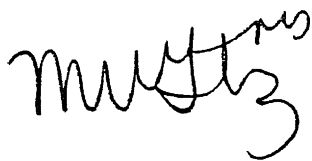
#### **IV. Need for a Coordinated, National Response**

There are many facets to the COVID-19 pandemic, and the need for policy solutions to address the Long COVID aspect of this virus is likely to grow over the coming months. In order to coordinate the federal response to Long COVID, and to ensure that recommendations for statutory and regulatory changes can be made through a unified, recognized body with the imprimatur of the federal government, there should be formation of a commission tasked with development of a crisis plan to address the immediate and long-term impacts of Long COVID. I encourage the subcommittee to consider this need. The AAPM&R will offer assistance in any way to advance policy for those living with disabilities.

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I thank the subcommittee for its leadership in recognizing this critical issue for persons with disabilities and COVID survivors and appreciate the opportunity to submit this written testimony. As the subcommittee, Congress, and the federal government continue to consider policies to address the Long COVID crisis, I offer my support as an expert and on behalf of the medical specialty of physiatry, and urge the subcommittee to consider AAPM&R and the Multi-Disciplinary PASC Collaborative as a resource.

Sincerely,

A handwritten signature in black ink, appearing to read 'M. Verduzco-Gutierrez', written in a cursive style.

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