

HOUSE WAYS & MEANS HEALTH SUBCOMMITTEE DISCUSSES HEALTH EQUITY GAPS FOR PEOPLE WITH DISABILITIES, CHRONIC CONDITIONS

EXECUTIVE SUMMARY

Yesterday, the House Ways and Means Subcommittee on Health held a hearing to discuss ways to lessen the equity gaps in health care treatment and coverage for people with disabilities and chronic conditions. Members on both sides of the aisle focused their attention toward permanently extending telehealth and telemedicine capabilities to ensure that current flexibilities do not expire at the end of the COVID-19 public health emergency (PHE). While Democrats addressed increased accessibility issues in the disabled and minority communities, Republicans spoke of the disproportionately low availability of health care services for those in rural areas.

Throughout the hearing, witnesses discussed the impact that telehealth services have on members of the disability community and encouraged the committee to ensure telehealth capabilities are accessible to all. Witnesses also highlighted the importance of increasing health care coverage and access for those who have been disabled by the effects of long-term COVID-19 (Long COVID) conditions.

OPENING STATEMENTS

Chair Lloyd Doggett (D-TX) advocated for his recently reintroduced bill, the Stop the Wait Act of 2022 (draft text), which would eliminate: (1) the five-month waiting period that applies to the payment of certain Social Security Disability Insurance (SSDI) benefits for workers and surviving spouses; and (2) the 24-month waiting period that applies to Medicare coverage for workers who are eligible for SSDI benefits.

Chair Doggett further promoted **Rep. Bill Pascrell's (D-NJ)** legislation, the Huntington's Disease Disability Insurance Access Act of 2021 (<u>H.R. 2050</u>), which would eliminate the 5-month waiting period for SSDI benefits and the subsequent 24-month waiting period for Medicare coverage for individuals with Huntington's disease. He argued that Congress must address this issue disease-wide, rather than introducing legislation to tackle one disease at a time, especially with Long COVID becoming more prevalent. Additionally, Chair Doggett discussed expanded access to telehealth services to improve health care access for those with disabilities. He expressed his desire to see his Telehealth Extension Act of 2021 (<u>H.R. 6202</u>) advance to a markup.

Ranking Member Vern Buchanan (R-FL) noted that the COVID-19 PHE has caused those with disabilities to receive even less health care services than those without a disability. He echoed Chair

Doggett's comments on the importance of extending telehealth capabilities, especially for individuals with disabilities and chronic conditions. Ranking Member Buchanan submitted to the record the National Council of Disability's (NCD) letter to the Congressional Budget Office (CBO) from April 2021, urging the CBO to no longer rely on the quality-adjusted life year (QALY) to estimate budgetary effects of the Elijah E. Cummings Lower Drug Costs Now Act (H.R. 3), citing the QALY's perceived discriminatory nature.

WITNESS TESTIMONY

Dr. Monica Verduzco-Gutierrez (<u>testimony</u>), of the University of Texas Health San Antonio, urged the committee to ensure that patients suffering from Long COVID receive proper access to health care. She stated that patients with Long COVID are experiencing difficulty paying for the out-of-pocket fees associated with their treatments and therapies, pointing out that marginalized groups with disabilities are also disproportionately disadvantaged. Further, Dr. Verduzco-Gutierrez expressed her support for Chair Doggett's Stop the Wait Act.

Dr. Rupa S. Valdez (testimony), of the University of Virginia, outlined six barriers at the health care delivery system level and her subsequent recommendations for lawmakers, including requirements that Congress: (1) formally recognize the disability community as a health disparity population; (2) enforce and expand legislation to be responsive to the needs of the disability community; (3) design, implement, and evaluate telehealth in ways that account for the needs of the disability community; (4) enforce clear and comprehensive requirements for data collection; (5) require that the education of health professionals encompass the needs and experiences of the disability community; and (6) eliminate barriers to entering and remaining in training programs and practice.

Ms. Liza Fisher (testimony), of the Long Covid Alliance, shared a personal story on her experience with Long COVID and underscored how expensive treatment can be for individuals been disabled by Long COVID without insurance due to gaps in Medicare coverage caused by the 24-month waiting period.

Ms. Bethany Lilly (testimony), of The Arc, expressed her support for Chair Doggett's Stop the Wait Act, efforts to close the Medicaid coverage gap, and intentions to improve the affordability of Affordable Care Act (ACA) subsidies. She also noted that home- and community-based services (HCBS) are highly utilized and necessary for people with disabilities and suggested that Congress enact legislation to further support these services. Ms. Lilly also urged Congress to continue to consider an out-of-pocket (OOP) cap on Medicare Part D prescription drugs and Medicare coverage of dental, hearing, and vision care.

Dr. Ray Dorsey (testimony), of the University of Rochester Medical Center, addressed disease-specific issues, such as Parkinson's Disease, and the benefit telehealth makes for patients from a clinician perspective. He emphasized that Medicare must permanently cover telemedicine: (1) regardless of geography; (2) from a broad range of clinicians; (3) for patients in their homes; and (4) from physicians in any state.

DISCUSSION

Telehealth

- In response to Chair Doggett, Dr. Valdez said that the Telehealth Extension Act will allow people with disabilities to: (1) engage in healthcare from their own homes; (2) reduce transportation and other barriers to access; and (3) expand the number of approved providers and covered services for telehealth services.
- Ranking Member Buchanan inquired about the current growth metrics and the future of telehealth. Dr. Dorsey noted that he started using telemedicine in 2007 and it has grown significantly since then, specifically as a result of COVID-19. He also stated that telehealth has just "scratched the surface" in terms of its capabilities.
- Ranking Member Buchanan asked about the cost-benefits of telehealth. Dr. Dorsey claimed telehealth has lowered health care expenditures by a significant amount, and suggested that Congress stop subsidizing institutional care and start incentivizing patient-centered care.
- **Rep. Mike Kelly (R-PA)** raised the point that some patients may feel as though they are unable to utilize telehealth effectively due to a lack of ability and support systems. Ms. Lilly recommended that Congress implement support systems and staff for those who cannot handle telehealth services on their own. She also flagged that telehealth must be compatible on multiple platforms so that it is accessible for low-income individuals.
- **Rep. Mike Thompson (D-CA)** also inquired about the importance of telemedicine for patients with disabilities. Dr. Dorsey stated that telemedicine can bring care to patients rather than patients to care. Dr. Lilly echoed his comments but emphasized that those with mental disabilities may need more help than others.
- **Rep. Jason Smith (R-MO)** addressed accessibility to care for rural populations and underscored the audio-only option as important for those in rural communities, touting his Permanency for Audio-Only Telehealth Act (<u>H.R. 3447</u>), which would expand coverage to include audio-only services for evaluation and management of behavioral health services.
- **Rep. Brad Wenstrup (R-OH)** alluded to the Department of Veterans Affairs' (VA) efforts to provide services by implementing telehealth in VA Vet Centers and asked about other ways to increase telehealth capabilities. Dr. Dorsey said that licensure restrictions for physicians and clinicians from state to state have loosened for telehealth services.

<u>Medicare Coverage</u>

- Chair Doggett inquired about reforms to expand Medicare coverage. Ms. Lilly noted that the Stop the Wait Act would start to eliminate the coverage gap and emphasized that improvements to the premium tax credits are important for telehealth coverage.
- In response to Chair Doggett's reference to hearing, dental, and vision care, Ms. Lilly highlighted that more than two-thirds of Medicare beneficiaries with disabilities have not been to the dentist in over a year to suggest that "comprehensive" coverage is necessary.
- **Rep. Terri Sewell (D-AL)** focused on inequities in health care system and touted Build Back Better Act's (BBBA) focus on HCBS for individuals with disabilities. Dr. Valdez also

- emphasized the importance of HCBS for the disability community. She noted that disabilities are overrepresented in communities of color and stated that this compounded marginalization is "invisible" in efforts to address health equity, which creates a need for programs that target people of color who are disabled.
- **Rep. Judy Chu (D-CA)** discussed contraception coverage for those with disabilities, to which Ms. Lilly responded that those people might be dual eligible, though this may create issues for patients to get covered through Medicare before being denied by other insurance coverage providers.

Long COVID

- Chair Doggett asked about reforms to address Long COVID patients. Dr. Verduzco-Gutierrez requested that clinics that treat Long COVID should be supported and the Stop the Wait Act should be passed.
- Rep. Chu spoke about COVID-19 testing for people with disabilities. Ms. Fisher noted that it
 was difficult to find a test, but since early 2021 it has been more difficult to get treatments
 and to have those treatments covered. Dr. Verduzco-Gutierrez said that patients are not able
 to access Long COVID treatments the same way they are able to access regular COVID
 treatments.
- **Rep. Bradley Schneider (D-IL)** asked about reforms to aid the COVID workforce and recompensate individuals who have lost out on wages. Dr. Verduzco-Gutierrez said that Congress must do everything it can ensure that the workforce is a priority moving forward.

Disease-specific Issues

- **Rep. Brian Higgins (D-NY)** addressed the lack of development in Parkinson's treatment since the mid-20th century. Dr. Dorsey agreed that there are no highly effective treatments for Alzheimer's or Parkinson's and that there is a need for additional funding for the National Institutes of Health (NIH) as well as for more investigations from pharmaceutical companies.
- In response to a string of questions from Rep. Higgins, Dr. Dorsey also noted that there is a rise in Parkinson's Disease diagnoses due to pesticides, industrial chemicals, and air pollution, which are preventable issues. He stated that an Operation Warp Speed-type effort to develop mRNA treatments for Parkinson's may be necessary and that vigorous exercise can decrease the symptom burden of Parkinson's.
- **Rep. Greg Murphy (R-NC)** addressed health care accessibility issues for those with cancer, praising former President Trump's elimination of the face-to-face telehealth requirement. Similarly, to Ranking Member Buchanan, he submitted the NCD letter to CBO that urged Congress to ban the use of QALYs from the BBBA.
- Rep. Pascrell, who is not a member of the Health Subcommittee, joined the hearing to speak on his bill: the Huntington's Disease Disability Insurance Access Act. He noted that an important barrier to coverage is the waiting period for coverage for eligible recipients of Medicare and SSDI who qualify for federal disability. He supported closing the insurance and income gaps for people with disabilities and chronic conditions.