

Application of the NTG Statement on LONG-COVID, Intellectual Disability, and Dementia to Direct Support Professionals

As the NTG is aware of the potential of Long (or long-term) COVID, especially in the neurological involvement (i.e., "brain fog") on individuals with intellectual and developmental disabilities, we also appreciate the established partnership and its implications to persons employed as Direct Support Professionals (DSPs). Over the past couple of years, many, if not most persons have now been affected by the COVID pandemic, either directly or indirectly. The virus is now a part of our daily lives. However, some persons are continuing to suffer the aftereffects of the infection, both with physical and cognitive symptoms. These long-term cognitive and functional impairment symptoms are known as 'Long-COVID'.

The NTG has issued an advisory and statement on Long-COVID and its application to people with intellectual disability ["Advisory on Long-COVID and Impact on Cognitive Function in Adults with Intellectual Disability" – www.the-ntg.org]. The advisory provides background on Long-COVID and recognizes the need for day-to-day symptom observation. The advisory encourages and promotes the awareness, preparedness, and action of Direct Support Professionals in being vigilant, steadfast, and intuitive in appropriately reporting to health providers the notable behavioral changes, cognitive decline, confusion, and other manifestations that might be evidence of Covid-related "brain fog." We know that Long-COVID may emerge after many weeks of the clearing up of most physical symptoms. It may affect thinking, motivation, and general day-to-day caring for one-self and one's activities. In some older adults, Long-COVID may begin to look like, what clinicians may term, mild cognitive impairment or early dementia.

Given your knowledge of the individuals you support, as a DSP you are in a unique position to notice changes in behavior, thinking, or functioning that might signal the need for further evaluation or medical attention. The NTG recognizes that agencies rely on DSPs to notice subtle and early changes and to advocate for thorough clinical evaluations and tests to determine if these are new onset signs or the intensification of previously existing co-morbidities. This is important as many of these notable signs and symptoms, if untreated, may lead to further cognitive impairment or dementia in older adults.

The NTG appreciates that you, as a DSP, could also be prone to showing signs of Long-Covid and the aftereffects of cognitive and neurological decline. We propose that DSPs should be able to recognize of this condition in yourself and report it to your

private physician or your agency's clinicians with the same vigor, insistence, and fortitude that you would exhibit when reporting concerns relating to the individuals you support. As a DSP, you should be both self-aware and monitor for noticeable and suspicious changes exhibited by your colleagues.

While there is currently no definitive therapy or treatment for "brain fog," the presumptive diagnosis of this condition made on behalf of DSPs can have significant benefit to them. Long-COVID has now been recognized as a legitimate disability by the federal government. Thus, agencies bear a responsibility to aid their staff (as well as clientele) suspected of or having been diagnosed with Long-COVID. Such aid is recognized in various statutes.

The Office for Civil Rights of the U.S. Department of Health and Human Services and the Civil Rights Division of the Department of Justice have joined together to provide a guidance considering Long-COVID as a disability. This will apply to you if you show significant symptoms of Long-COVID.

The guidance explains that Long COVID, can be a disability under Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act of 1973, and Section 1557 of the Patient Protection and Affordable Care Act. This guidance also provides resources for additional information and best practices. The federal laws noted protect people with disabilities from discrimination and call for appropriate accommodations in the workplace. The guidance, "Guidance on 'Long COVID' as a disability under the ADA, Section 504, and Section 1557," can be found at https://www.hhs.gov/civil-rights/for-providers/civil-rights-covid19/quidance-long-covid-disability/index.html

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