



Advisory on Long-COVID and Impact on Cognitive Function in Adults with Intellectual Disability

The purpose of this advisory is to provide background information on newly recognized cognitive impairments, among adults with intellectual disability, stemming from the effects of Long-COVID, and to suggest what actions might be undertaken in identifying such impairments and providing remedial supports.

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Recent reports have linked residual effects of having been infected with SARS-CoV-2 (COVID-19) with notable subsequent cognitive effects, such as a ‘brain fog’, mild cognitive impairment, and dementia.¹ These changes have been ruled out as having a temporal relationship to respiratory symptoms and are not related to respiratory insufficiency—the main factors associated with early forms of COVID.² While little data exist regarding these residuals in adults with intellectual disability³ (including Down syndrome⁴), such data are emerging in the general population.⁵ **What are the implications of these findings related to cognitive impairment in the population for adults with intellectual disability, their families, caregivers, and provider agencies and organizations is the focus of this advisory.**

The COVID-19 pandemic, since its first international spread in 2019, has had a profound effect on the world’s population, with estimates of it causing at minimum 6.53 million deaths across the globe, and some 1.05 million deaths in the United States.⁶ While the infection from COVID-19 variants continues, the availability of vaccines, antiviral medications, and social mitigation strategies has brought a new reality – where the virus has been relatively contained and semblance of ‘normality’ has returned. Many provider agencies serving adults with intellectual disability, which previously closed on-site services or curtailed supports involving direct contact, have resumed normal or partially normal operations, while being surveillant of the emergence of any new cases among their clientele.

Key Points

- Long-COVID can include ‘brain fog’ (problems with thinking, motivation, and carrying out life activities).
- Adults with intellectual disability infected with the SARS-COV-2 variant virus may experience Long-COVID.
- Partners, families, and agencies need to be on the ‘look-out’ for changes in cognitive functions that may be due to Long-COVID.
- Screening and assessment should be undertaken to determine presence of Long-COVID.
- Accommodations and adaptations should be put in place to help mitigate effects of Long-COVID.

While it is too early to understand all the long-range effects of the social isolation, loss of therapies, and daily community activities resulting from lockdowns and reductions in services, work is emerging showing that some functional residuals are present in adults who contracted the virus and may have been severely affected.^{7,8} What is unknown is to what degree, such functional residuals are associated with the physio-neurological aspects of being infected with the virus or are due to the deprivations and losses suffered during the pandemic.^{9,10,11} Study data are sparse as to the extent of these residuals within the population of adults with intellectual disability; however, studies are showing more such evidence with respect to the general population.¹² Concerns remain to what extent such residuals result in the diminution of cognitive skills and what will be the long-term impact on brain health.¹³

Whether additional cognitive impairment is transient or has chronic effects is open to speculation, but there may be a transition to mild cognitive impairment or even dementia.¹⁴ This is of concern for families and providers of intellectual disability services because agencies and families may be called upon to provide ‘dementia’ related care earlier in the lifespan. There is a need for early detection and assessment of adults showing symptoms of new cognitive impairment post COVID-19, continued surveillance of physical and mental health issues, and the redirection of services that address compensatory supports to adults who had been infected and seem at variance with their previous selves.

What is ‘Long-COVID’?

The Centers for Disease Control and Prevention (CDC) defines post-COVID conditions or Long-COVID as being infected with the COVID-19 virus and then experiencing long-term physiological and neurological effects from the infection.¹⁵ Between 7 and 23 million people in the United States have Long-COVID.¹⁶ The number affected who have an intellectual disability is unknown, however, many such adults were infected in the early months of the pandemic and had higher rates of death.¹⁷ Current infection or re-infection rates are unknown. The CDC notes that ‘post-COVID’ conditions are a wide range of new, returning, or ongoing health problems that people experience after being infected with the virus that causes COVID-19.

Most people with COVID-19 get better within a few days to some weeks after infection, so at least from between four to 12 weeks after infection is the time when post-COVID conditions may first be identified.¹⁸ Some post-COVID *cognitive* symptoms are experienced days after being diagnosed with COVID-19 but may also appear later after recovery from the *physical* effects of COVID-19. A consensus panel noted that the Long-COVID clinical picture is dominated by a combination of dyspnea, fatigue, and cognitive symptoms, such as impaired memory and concentration, which affects daily functioning and lasts beyond three months after the onset of acute COVID-19.¹⁹

In this advisory we are *focusing on the cognitive impairment aspect* and its implications among people with intellectual disability for life management, clinical and support services, and mitigating impairment with symptom progression. Important is the fact that Long-COVID can be an independent source of cognitive and functional impairment as well as excess burden and disability for individuals who already display MCI or dementia.

Currently there is no test to specifically diagnose post-COVID, but research is emerging showing clinical phenotypes²⁰ and bio-neurological markers²¹ for post-COVID. For example, one study found that those COVID-affected adults with new neurological symptoms had higher levels of t-tau, NfL, GFAP,

pTau-181, and UCH-L1 in their blood, as well as indicators of inflammation such as C-reactive protein, compared to adults without neurological symptoms.^{22,23} However, these measures are not yet available for use within community assessment settings. Researchers have also used duration as a measure of Long-COVID, characterizing its presence when adults may be experiencing fatigue and cognitive impairment and persistent symptoms from four to 12 or more weeks following COVID-19 diagnosis.^{24,25}

How long risks for Long-COVID remain, whether they affect children and adults similarly, and whether SARS-CoV-2 variants differ in their risk profiles remains unclear.²⁶ Unknown is also the impact of recurrent infections by the virus and its variants upon residuals.

Symptoms and Effects

COVID-19 is associated with clinically significant symptoms despite resolution of the acute infection. Fatigue and cognitive impairment are among the most common and debilitating symptoms of Long-COVID.²⁷ These effects include (but are not limited to) fatigue, mild cognitive issues, and low tolerance to mental activity, and can reoccur at any time with no warning.²⁸ Data from researchers indicate that some COVID-19 symptoms have a more deleterious effect upon post-COVID-19 functioning. For example, losses of taste and smell during the infectious phase have been linked to more severe cognitive impairments months later, even if other symptoms have been mild.²⁹

Additionally, it has been found that the aggregate of COVID-19 symptoms when someone is infected is a factor, such that the greater number of COVID-19 symptoms correlates with lower subjective cognitive function as well as psychosocial function.³⁰ Clinically, some common psychiatric impairments have been found to be part of Long-COVID.³¹ It has been noted that while the risks of many common psychiatric disorders returned to normal within a couple of months, albeit some adults may remain at increased risk for dementia, epilepsy, psychosis, and 'brain fog' two years after contracting COVID. Mostly, adults are at particular risk of lasting brain fog, a common complaint among coronavirus survivors. Thus, persistent symptoms of brain fog should be taken seriously.³²

Troubling are the findings that older adults may be more susceptible to significant cognitive impairment, with some reporting the presence of Alzheimer's disease-like symptoms³³ and other brain neuropathologies.^{34,35} A caution is that some adults who had recovered from COVID-19, including those no longer reporting or exhibiting notable symptoms, can present with significant cognitive deficits – and while many who were hospitalized with COVID-19 are among this group, individuals who were not hospitalized but confirmed to have had COVID-19 infection are also susceptible.³⁶ As 'brain fog' may also stem from non-COVID issues, such as chemotherapy, concussion, sleep-deprivation, feeling unwell, or the side effects from medicines (such as anticonvulsants and neuroleptics) that may cause drowsiness,³⁷ and other cognitive changes, it is important to seek a medical assessment to determine its underlying cause – even whether there wasn't known exposure to COVID-19.

While some 'brain fog' symptoms in adults with intellectual disability may be initially indicative of the presence of a form of dementia irrespective of the effects of COVID-19, it is important to use the assessment process to differentiate inherent neuropathological brain disease progression from the residual cognitive symptoms of Long-COVID. Often it may be difficult to make that differentiation but looking back at pre-pandemic functioning and early signs of decline may help with making that diagnostic distinction; thus, showing the value of a functional baseline. While interventions may be similar in the short term, if the determination is made of the presence of brain disease, then planning

and organizing long-term care may require a different process and trajectory than treating post-COVID symptoms.

What to look for?

General symptoms of COVID related ‘brain fog’ or mental fatigue include slow thinking, difficulty in focusing, confusion, lack of concentration, forgetfulness, and haziness in thought processes.³⁸ Self-reported symptoms include many of the following, as noted by Disogra,³⁹:

Confusion	Delays in responding in oral communications
Difficulty attending or staying focused	Difficulty concentrating
Difficult following conversations	Difficulty multi-tasking
Difficulty planning	Difficulty understanding or remembering instructions
Feeling ‘out of it’	Being forgetful
Impulsive	Lack of mental clarity
Language use problems	Losses in train of thought
Memory impairment	Short term memory problems
Showing poor judgment	

There are yet little data on tracking these symptoms specifically for people with intellectual disability, but they are important indicators to be considered and documented in better establishing the occurrence of Long-COVID in people with neuroatypical conditions.

What can be done to address Long-COVID cognitive-related symptoms?

Long-COVID pharmacological interventions are lacking in assurance, as the disorder is new and its neurophysiological components are still under study, and a key barrier to developing Long-COVID treatments has been uncertainty about the condition’s underlying cause.⁴⁰ Currently, there is no known pharmacological treatment available for overall Long-COVID. Without evidence of effectiveness, it would be problematic to prescribe the use of off-label pharmaceuticals for persons with intellectual disability for COVID residuals.

A cautionary note is that while this advisory concerns cognitive symptoms, Long-COVID is complex and usually also involves numerous physical symptoms that may occur across multiple bodily systems. An excellent resource for understanding the physical aspects and this complexity, as well as recommendations for medical care and treatment, is an article in *BMJ* by Greenhalgh et al⁴¹ which can be sourced at <https://www.bmj.com/content/bmj/378/bmj-2022-072117.full.pdf>

With respect to the *cognitive impairment aspect* of Long-COVID, early detection and assessment of cognitive impairment (distinct from pre-existing intellectual disability) can aid with understanding better the presentation of behaviors that have resulted from changes in cognitive functioning and consequently overall performance in activities or work, social, and personal tasks. Being alert to these changes, particularly in adults with a history of diagnosed COVID-19, even if mild and without visible symptoms, can help identify and begin to mitigate losses and disruption of daily life. Maintaining surveillance of individuals with such diagnostic histories will aid in early detection and potentially with follow-up assessments by neurologists, psychologists, primary care practitioners, and others skilled in assessing the cognitive functioning of adults with intellectual disability. Keeping track of performance and function with standard measures applicable to adults with intellectual disability (e.g., the NTG-

EDSD⁴²) can aid in assessing static or dynamic decline over time. Interventions to compensate for ‘brain fog’ can also aid with stemming anxiety, frustrations, and concerns over functional losses by affected adults.

Determining whether someone with an intellectual disability has developed additional cognitive dysfunction following a COVID infection may be an assessment challenge for a variety of reasons, including difficulties in assessing baseline language and communication skills, caregivers lacking knowledge of their recent and past abilities, as well as their own healthcare providers lacking the knowledge and skills in being able to assess objectively for changes in function. Also of concern is diagnostic overshadowing (i.e., the attribution of symptoms to an existing diagnosis rather than a potential co-morbid condition).⁴³ This often poses a significant obstacle in making such determinations as diagnostic attribution may be given to the primary and not to the concurrent condition.

Following ascertainment of the presence of Long-COVID cognitive symptoms, the best practice is to provide compensatory aid for ‘brain fog’ and general cognitive impairment, as would be applicable with someone with mild cognitive impairment or dementia.⁴⁴ Non-pharmacological interventions, recognized as best practices, would be most appropriate. These may include environmental modifications as well as aiding with memory, communication, stimulation, and other approaches that recognize subjective impairment and help compensate for confusion, forgetfulness, disorientation, and other features (e.g., help with gait problems). Instituting aids for memory, cues for carrying out routines of daily life, communication with guidance and respect, and assurances of supports when needed can provide the structure to mitigate and compensate for diminishing abilities.

Key Supports for Adults with Long-COVID
<ul style="list-style-type: none"> • Ensure appropriate periodic medical and health checks for physical symptoms • Track function and cognitive abilities and document changes • Adapt care/support approaches as you would for mild cognitive impairment or early dementia • Implement a ‘dementia care plan’ in anticipation of changing needs • Confer with clinicians with Long-COVID experience for overall post-COVID care advice • Refer to neurologist or other clinician when cognitive symptoms worsen

Preventing infection with the COVID-19 virus variants is important. With new COVID vaccines and boosters emerging as critical to mitigating severity when someone is infected, probabilities favor preventing onset of Long-COVID in populations not yet infected or re-infected when adults are vaccinated.

Long-COVID as a disability

As Long-COVID has been recognized as a disability (when an individual assessment determines that it substantially limits one or more major life activities), agencies bear a responsibility to aid their clientele suspected of or having been diagnosed with Long-COVID.⁴⁵ The U.S. Office for Civil Rights of the Department of Health and Human Services and the Civil Rights Division of the Department of Justice together issued guidance related considering Long-COVID as a disability.⁴⁶ The guidance explains that Long-COVID is a designated ‘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.

While adults with an intellectual disability are already covered under ADA, those with Long-COVID are additionally entitled to protection from discrimination associated with having Long-COVID.

They are also entitled to “full and equal opportunities to participate in and enjoy all aspects of civic and commercial life” and, more importantly, are entitled to “reasonable modifications” to accommodate their Long-COVID related limitations.⁴⁷

Position Statement of the NTG

It is the position of the NTG that the sequela of COVID-19 must be taken seriously and adults who were affected by the virus be surveilled for any significant changes in functioning from pre-pandemic levels. While there may be various socially determined causes for such behavioral change, such as mental health problems stemming from lock-downs and social connection deprivations during the most restrictive phases of the pandemic, losses of engagement in maintaining skills and relationships during and after the restrictive phases, and challenges associated with re-integration into services and community life, other neurophysiological and neuropathological factors, such as those associated with the biological aspects of Long-COVID, may be at play. Long-term COVID can be an independent source of cognitive and functional impairment as well as excess burden and disability for individuals who already display MCI or dementia. Periodic screening and assessment for presence of COVID-19 related cognitive symptoms is indicated. Efforts should be exerted to provide compensatory services to mitigate the social-behavioral factors and specialized clinical services provided to address behavioral changes associated with the neurological factors stemming from cognitive symptoms of COVID-19.

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