

# Caring for Individuals With Intellectual and Developmental Disabilities in the COVID-19 Crisis

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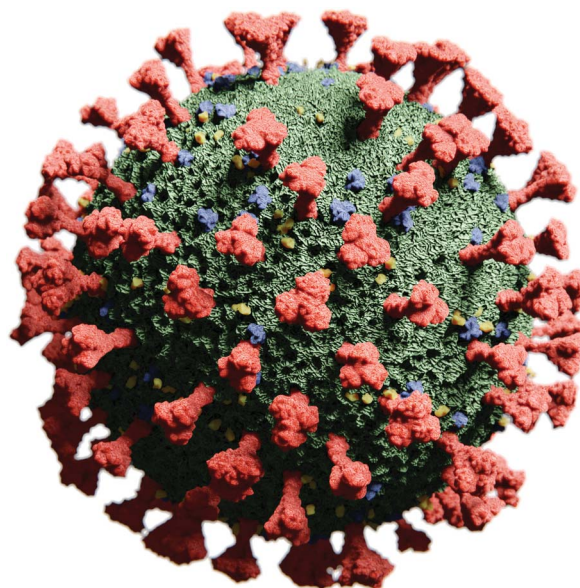
## Abstract

Individuals with intellectual and developmental disabilities (IDDs) are among our most medically vulnerable neurologic patient population. As such, they are at particular risk of psychosocial and medical harm during the coronavirus disease 2019 (COVID-19) pandemic. Here, we highlight strategies to decrease potential infectious exposures and ensure continued optimal neurologic care for individuals with IDD during the COVID-19 pandemic. Finally, in a climate of potential medical resource restriction, we offer some suggestions for advocacy on behalf of individuals with IDD.

Individuals with intellectual and developmental disabilities (IDDs) comprise a large proportion of neurology patients.<sup>1</sup> Their myriad diagnoses include cerebral palsy, Down syndrome, and autism spectrum disorder, with many of these disorders comorbid with each other. Their abilities range from complete functional independence to complete functional dependence with variable requirements at baseline for life-sustaining supports such as home ventilators, gastrostomy tubes, or personal care assistants (PCAs). Even mild medical illnesses can exacerbate many difficulties patients with IDD face including managing muscle tone, difficulty feeding, or behavioral challenges. Although the coronavirus disease 2019 (COVID-19) pandemic has made us all feel vulnerable, patients with IDD are particularly at risk of functional deterioration. At the time of this writing, the number of worldwide cases has climbed above 3 million. The United States harbors 1 million of those infected and is reporting case fatality rates of 2%–9%.<sup>2–4</sup>

Adults with IDD may be living in group homes; the support staff and associated organizations are likely under enormous pressure to ensure that COVID-19 does not create internal chaos.<sup>5</sup> Upholding a routine schedule, ensuring safety, happiness, and health maintenance are all paramount.

Routine neurology visits are critical for early detection of emerging or worsening symptoms of cognitive impairment, epilepsy, depression, or increased tone. In the setting of a significant social, economic, and medical stressor like the COVID-19 pandemic, these routine visits become even more critical. Before the COVID-19 pandemic, adoption of teleneurology services had been growing, though slowly. Barriers to use of teleneurology have included lack of affordable Health Insurance Portability and Accountability Act (HIPAA)-compliant platforms, lack of insurance



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reimbursement for services rendered, and lack of familiarity on the part of medical providers and patients.<sup>6</sup> By necessity, tele-neurology has become the primary option for nonemergent health care consultation in the setting of this pandemic.<sup>7,8</sup>

Here, we highlight strategies to capitalize on teleneurology to decrease potential infectious exposures and ensure continued optimal neurologic care for individuals with IDD during the COVID-19 pandemic.

## Strategies for Preventive Teleneurology

At this point in the pandemic, there is a tendency to cancel nonurgent or routine follow-up appointments with plans to reschedule in 2–3 months. Frequently, the 2–3-month delay is expanding to a 5–6-month delay as guidelines restricting nonessential business continue to extend. For individuals with IDD, postponing neurologic follow-up for 2–3 months, or longer, could be catastrophic. As individuals with IDD may be a population that is highly vulnerable to adverse outcomes if infected with the coronavirus, it is important to maintain contact with this fragile group. Now is the time to invest in HIPAA-compliant video-based telehealth services or use telephone visits to continue to check in on these vulnerable patients. Strategies for implementation of teleneurology have been outlined recently by the American Academy of Neurology (AAN) and Neurology Live in webinar format<sup>9,10</sup> and also by the AAN Telemedicine Working Group before the pandemic.<sup>4</sup>

As individuals with IDD have diverse needs and diverse etiologies, common care guidelines across this population do not yet formally exist. However, during the COVID-19 pandemic, there are key care features regarding ongoing health maintenance and crisis anticipation.

### Reaffirm the Value of Physical Distancing While Mitigating the Associated Challenges

Physical distancing is the best-known method for preventing coronavirus exposure.<sup>11</sup> However, deviance from one's typical daily routine, loss of interpersonal and therapeutic interactions, and limited circadian light exposure can exacerbate psychiatric comorbidities and sleep difficulties for patients with IDD. Encourage time outdoors with spaces isolated from others (e.g., a backyard or a balcony) and open windows during the day. Also encourage adherence to a daily routine including bathing, dressing, exercising, and engaging in productive activities in the main living space of the home during the day. Advocate that patients engage in similar wind-down activities at nighttime.<sup>12</sup> Maintenance of a routine can help establish some continuity of lifestyle in this time of uncertainty.

### Ensure Adequate Medication Refills

Minimizing trips to the pharmacy is critical in the interest of physical distancing. Discuss mail-order pharmacies with your

patients. If this is not a feasible option, consider prescribing 3-month supplies of medications instead of 1-month supplies. Some health insurance companies are allowing for longer duration refills in the setting of this pandemic.<sup>13,14</sup> Let the insurance companies know that longer duration refills will be one of the primary ways you can keep your patients safe.

### Ensure that Providers, Patients, and Caregivers All Share an Understanding of the Patient's Healthy Baseline

These teleneurology visits are a good time to revisit your understanding and your patient's understanding of their baseline level of functioning and status of medical comorbidities.<sup>15</sup> During this pandemic, it is best to ensure that all neurologic concerns are optimized to allow the best buffer in case of infection. Some suggested specifics to establish/reaffirm are offered in table 1.

### Create Crisis Management Plans

Individuals with IDD have a much higher rate of abuse compared with the general population.<sup>18</sup> During the global pandemic, patients with IDD are particularly at risk of the consequences of worsening mental health symptoms in themselves and of their caregivers. Table 2 provides recommendations for screening and crisis management planning.

### Set Predetermined Requirements for In-Person Visits

It is best at this time to postpone in-person visits for at least 2–3 months. Beyond scheduled baclofen pump refills, many visits for patients with IDD can be accomplished virtually. Patients who rely on botulinum toxin or phenol injections in many cases may be able to temporarily be managed with increases in other tone-related medications, specifically with night-time dosing. Consider whether injectable therapies are providing improvements in pain and/or functionality and how these resultant issues may be otherwise temporarily addressed. If injectable therapies are absolutely required, which they may be for many of your patients, try to bundle this visit in with any other requirement for the family to visit the hospital.

Previously scheduled office visits to discuss ongoing seizure management, behavioral assessments, cognitive evaluations, and other neurologic concerns should not be postponed because of the COVID-19 crisis. These visits, if at all possible, should be converted to phone or video-based teleneurology visits. Maintaining oversight on chronic neurologic conditions is mandatory to ensure that these various personal and health challenges do not lead to unforeseen disruptions.

### Evaluate Caregiving Needs

Consider empiric screening of caregivers for depression and anxiety. Caregivers cannot adequately care for your patients if they themselves are unwell. Ensure that they have access to a

**Table 1** Suggestions for Teleneurology Surveillance

Symptoms to screen for in teleneurology visit	Approach
<b>Current ability to accomplish ADLs</b>	<ul style="list-style-type: none"> <li>Define who supports the patient with ADLs.</li> <li>Ensure backup plans in place if support personnel unable to care for the patient.</li> <li>Confirm that infection mitigation measures are in place for caregivers, including social distancing, handwashing, and PPE.</li> </ul>
<b>Current status of psychiatric comorbidities</b>	<ul style="list-style-type: none"> <li>When was the last episode of behavioral dysregulation that required administration of an abortive medication?</li> <li>Assess current management of mood and behavioral symptoms.</li> <li>Provide resources<sup>16</sup> for virtual exercise, therapy, and social interactions to mitigate the effect that current social restrictions due to COVID-19 affect your patient's mood.</li> </ul>
<b>Current status of sleep</b>	<ul style="list-style-type: none"> <li>Assess current sleep hygiene and sleep schedule.</li> <li>Document use of medications to help with sleep.</li> </ul>
<b>Current status of tone</b>	<ul style="list-style-type: none"> <li>Does the patient feel that their tone is currently well managed?</li> <li>Create a shared understanding of the most effective medications/injectables for the patient's tone.</li> <li>Assess fit and use of orthotics, wheelchairs, and other assistive devices to maximize functioning and minimize discomfort.</li> </ul>
<b>Current status of pain</b>	<ul style="list-style-type: none"> <li>If experiencing pain, document the location and settings in which pain is experienced.</li> <li>Discuss pain management current strategies and devise plans for improvement if needed.</li> </ul>
<b>Current status of cognition</b>	<ul style="list-style-type: none"> <li>In children, ensure that developmental progress is ongoing and that communication needs are being met.</li> <li>In adults, consider empiric standardized cognitive assessments,<sup>17</sup> particularly in those who are at risk of progressive cognitive impairment like individuals with Down syndrome or epilepsy.</li> </ul>
<b>Current status of medical comorbidities</b>	<ul style="list-style-type: none"> <li>Emphasize importance of continued medical surveillance and preventive primary care.</li> </ul>

Abbreviations: ADLs = activities of daily living; COVID-19 = coronavirus disease 2019; PPE = personal protective equipment.

reputable online social network of other caregivers to help with coping with the unusual levels of stress and uncertainty they are currently facing. Examples include CPDailyLiving,<sup>19</sup> CPNOW,<sup>20</sup> National Down Syndrome Society,<sup>21</sup> Spina Bifida Association,<sup>22</sup> and American Academy of Developmental Medicine and Dentistry resources,<sup>23</sup> among many others available through the AAN and the Centers for Disease Control and Prevention Ensuring caregiver wellness

likely has the added benefit of reducing the risk of stress-provoked abuse or neglect of your patients.

## Ensure Food and Housing Security

It is critical to discuss basic needs in this population who is often financially compromised and underemployed. Discuss with your clinic or local hospital social worker regarding local food delivery/volunteer programs and shelters. Consider providing information about these resources to all of your patients at this time regardless of whether they endorse food or housing insecurity. For many patients and families, newfound financial hardships could be a source of embarrassment that they may be uncomfortable discussing.

## Assert Your Focus on Evidence-Based Practice

Understandably heightened emotions and the desperate desire for treatments for COVID-19 have led to a surge of requests for immediate use of poorly studied therapeutic regimens. Some of these treatments, if instituted empirically, can have serious consequences for individuals with IDD due to interactions with common medications they may already be taking. For example, chloroquine taken together with antidepressants like citalopram, fluoxetine, or antipsychotics like quetiapine can have potent QT-prolonging effects.<sup>24</sup> Urge your patients to not take these medications empirically and to consult with your or another physician familiar with their full medication list. Encourage them that a well-designed global trial is underway to determine effective treatments for COVID-19 quickly.<sup>25</sup>

**Table 2** Crisis Management Planning

Discuss	Plan
<b>Symptoms of COVID-19</b>	Follow local protocols for testing and quarantine.
<b>Depression and anxiety</b>	Adjust medication, develop therapeutic strategies virtually, while maintaining physical distancing, before the symptoms worsen to require hospitalization.
<b>Abuse and neglect</b>	If at all possible, assess the patient alone via teleneurology.
<b>Seizure frequency</b>	Confirm adequate dosing and supply of seizure medications. Ensure documentation and shared understanding of seizure rescue plan.
<b>Baclofen pump or equipment malfunctions</b>	Discuss the symptoms of withdrawal and overdose. Have a plan in place for concerns for pump failure.
<b>Muscle tone changes</b>	Create a plan in the event of emerging dystonic crisis or status dystonicus.
<b>Planning for potential inability to take oral medications</b>	Create parenteral bridge plans for essential medications.

Abbreviation: COVID-19 = coronavirus disease 2019.



## Care Coordination

Be clear which practitioner is supporting and caring for the individual's needs for a specific issue and concern. Individuals with IDD often have complex health care and behavioral concerns. Many care providers may be involved and responsible for particular social, medical, and mental health issues.<sup>26</sup>

## Too Much for 1 Visit?

Consider prioritizing medication refills, crisis management, and food and housing security in your first televisit during the pandemic and subsequently following up in 2 weeks to reassess. Ongoing, perhaps frequent, and short teleneurology visits are useful for ensuring that medical needs are met and have the added benefit of helping your patients combat social isolation.

## Advocacy

As the global pandemic grows, health care leaders across the world engage in discussions about resource allocation strategies, though rife with ethical turmoil. Legal and ethical texts have eschewed the merits of a disability-based resource utilization approach, particularly where the disability in question is not, in and of itself, life limiting. Some have proposed a lottery system as the fairest method of resource allocation.<sup>27</sup> Perhaps our job is not to offer such heart-wrenching and draconian alternatives but to instead assert that our patients' lives have inherent value and that our patients have already demonstrated remarkable emotional and medical resiliency in a world that often counts them out.

It is our responsibility to advocate for personal protective equipment, not just for us as health care workers, but also sufficient for our vulnerable patients and their caregivers if they have to come in for maintenance medical care in the middle of this pandemic. It is our responsibility to advocate for a surge in the production of medical equipment such that life or death discussions about resource utilization become moot. To this end, we strongly encourage neurologists to become involved in collectively powerful endeavors to advocate for individuals with IDD (table 3).

## For the Next Pandemic

Echoing a call to arms following our last pandemic of H1N1 in 2009, it is critical to include those with IDD and their caregivers as a part of the team devoted to developing the next pandemic plan.<sup>29,30</sup> We cannot appropriately care for individuals with IDD without being aware of their unique needs.

Ensure that crisis management plans are always clearly documented for your patients.<sup>31</sup> Also ensure that your patients have copies of this crisis management plan and that they carry this plan with them when seeking urgent medical care.

If there can be any health care silver lining to the COVID-19 pandemic, it is that this pandemic has prompted rapid

**Table 3** Suggestions for Advocacy Supporting Individuals With IDD

Advocacy option	Rationale
<b>Publicly available written or recorded commentary regarding equipment requirements to provide adequate medical care for the entire population</b>	Letters written to your local newspaper, online blogs, or posted directly to social media can be made immediately available, are often easily shareable, and can educate your community about your needs as a medical provider and the needs of your patients.
<b>Reporting of any signs of abuse or neglect</b>	Although the risk of abuse and neglect is higher during the pandemic, reporting has decreased as people become physically isolated by necessity. <sup>28</sup> In addition to being vigilant for evidence of abuse or neglect, reporting these concerns to child protective services or law enforcement will be critical for keeping our patients safe.
<b>Reaching out to your local news station offering to discuss your thoughts on the pandemic, pandemic response, and resource allocation</b>	Neurologists are in a privileged position to educate the public. Given that we have particular expertise in the care requirements of individuals with IDD, we must advocate publicly for resources on their behalf.
<b>Writing your senator and congressman regarding the abhorring nature of life valuation based on disability</b>	Laws will be made in a vacuum free of neurologist voices, unless we make ours heard.
<b>Voting whenever the opportunity is available</b>	Elect allies of medical professionals and supporters of facilitating comprehensive care, particularly for medically complex patients like individuals with IDD.
<b>Leading by example</b>	For example, continuing ongoing comprehensive telecare health maintenance visits for individuals with IDD and publicizing these efforts to your colleagues may help them understand the special needs of individuals with IDD.
<b>Advocate for visitation rights to help ensure that the person with IDD has a caregiver with them during the hospital stay</b>	A caregiver in the hospital will provide a comforting and supporting voice, which will greatly reduce stress to the patient as well as improve outcomes of care.

Abbreviation: IDD = intellectual and developmental disabilities.

adoption of teleneurology services. Those who are medically vulnerable in a pandemic remain medically vulnerable outside of a pandemic. Teleneurology follow-up visits may ultimately allow us to provide ongoing safe, equitable, patient-centered care long after this pandemic subsides.

## Conclusions

The COVID-19 pandemic has created tremendous challenges for our society as a whole, including those with IDD and their support systems. It will be important to evaluate the health outcomes of individuals with IDD throughout the pandemic to determine whether care practices in place were indeed sufficient.

The field of neurology, as it pertains to caring for adults with IDD, has extraordinary opportunities for growth; there are currently major deficits of education, training, and research targeting adult patients with IDD, despite more neurology patients living into adulthood.<sup>32</sup> Without high-quality provision of care, adults with IDD risk profound deterioration in their health and quality of life.<sup>33</sup> Future work must include robust training programs that prepare neurologists to take care of patients with IDD as well as research to strengthen our ability to make evidence-based decisions treatment plans.

It is a moral and ethical imperative for all of us to pay attention to vulnerable populations, like those with IDD. Although the global pandemic has highlighted this, the imperative remains throughout every day of our practice. Our hope is that the above recommendations have practical implications regarding the care of those with IDD now and also long after the pandemic is over.

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## Appendix Authors

Name	Location	Contribution
<b>Jessica Solomon Sanders, MD</b>	Department of Neurology, Boston Children's Hospital, Harvard Medical School, MA	Drafted intellectual content and revised the manuscript for intellectual content and provided references.
<b>Seth M. Keller, MD</b>	Neurology Associates of South Jersey, Lumberton, NJ	Drafted and revised the manuscript for intellectual content.
<b>Bhooma R. Aravamuthan, MD, DPhil</b>	Division of Pediatric Neurology, Department of Neurology, Washington University School of Medicine, St. Louis, MO	Drafted and revised the manuscript for intellectual content

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# Neurology® Clinical Practice

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## Neurofilament Light Chain Is Related to Longitudinal Decline in Frontotemporal Lobar Degeneration

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In the Research article “Neurofilament Light Chain Is Related to Longitudinal Decline in Frontotemporal Lobar Degeneration” by Zhang et al.,<sup>1</sup> the data in the third column of Table 4 labeled “F letter fluency” were incorrect. A corrected Table 4 is below. The authors regret the error.

**Table 4** Longitudinal Linear Regression Models for Patients With Known TDP Pathology

COGNITIVE MEASURE					
	MMSE	F letter fluency	Forward span	Naming	Delayed word recall
<b>MODEL 1: NFL:</b>	<b>E: -0.008379***</b>	<b>E: -0.046957*** (-0.022217**)</b>	<b>E: -0.012644***</b>	<b>E: -0.006761*</b>	<b>E: -0.015345*</b>
	<b>CI: -0.012982 → -0.003776</b>	CI: -0.055698 → -0.038217 (-0.037597 → -0.006837)	<b>CI: -0.017149 → -0.008139</b>	<b>CI: -0.011962 → -0.001561</b>	<b>CI: -0.026494 → -0.004196</b>
<b>MODEL 2: NFL:</b>	<b>E: -0.009026***</b>	<b>E: -0.047621*** (-0.022559*)</b>	<b>E: -0.012613***</b>	<b>E: -0.006484*</b>	<b>E: -0.015131*</b>
	<b>CI: -0.013953 → -0.004099</b>	CI: -0.057398 → -0.037844 (-0.041634 → -0.003285)	<b>CI: -0.017246 → -0.007979</b>	<b>CI: -0.012463 → -0.000505</b>	<b>CI: -0.027996 → -0.002266</b>
<b>Age:</b>	E: -0.539103	E: -2.540461 (0.172307)	E: 1.286465	E: -0.430257	E: 0.034448
	CI: -1.837347 → 0.739140	CI: -7.531923 → 2.451002 (-4.208014 → 4.552628)	CI: -0.111901 → 2.684831	CI: -2.131993 → 1.271478	CI: -4.029578 → 4.098474
<b>Disease Duration:</b>	E: -1.582144	E: -6.141274 (-1.151280)	E: -0.203613	E: -1.151350	E: 5.468069
	CI: -6.112281 → 2.947994	CI: -22.446089 → 10.163540 (-14.522478 → 12.219918)	CI: -4.725912 → 4.318686	CI: -6.980819 → 4.678118	CI: -7.427472 → 18.363609
<b>MODEL 3: NFL:</b>	<b>E: -0.010642***</b>	<b>E: -0.043291*** (-0.019566)</b>	<b>E: -0.012124***</b>	<b>E: -0.008474**</b>	E: -0.014940
	<b>CI: -0.015899 → -0.005384</b>	<b>CI: -0.062982 → -0.023600</b> (-0.046746 → 0.007614)	<b>CI: -0.017906 → -0.006342</b>	<b>CI: -0.013570 → -0.003379</b>	CI: -0.035001 → 0.005121
<b>Age:</b>	E: -1.069070	E: -1.971092 (0.850302)	E: 1.433268	E: -0.869494	E: 0.079860
	CI: -2.393774 → 0.255633	CI: -9.534003 → 5.591818 (-5.916915 → 7.617518)	CI: -0.192321 → 3.058856	CI: -2.284444 → 0.545455	CI: -5.724026 → 5.883746
<b>Disease Duration:</b>	E: -3.262482	E: -6.744107 (-0.916716)	E: 0.509058	E: -0.727194	E: 7.146879
	CI: -7.220694 → 0.695730	CI: -28.823462 → 15.335249 (-19.937609 → 18.104178)	CI: -4.665861 → 5.683976	CI: -5.357064 → 3.902677	CI: -12.063659 → 26.357416
<b>pTau:</b>	E: 0.240902	E: -0.291694 (-0.386154)	E: -0.101025	<b>E: 0.455251*</b>	E: 0.007813
	CI: -0.186589 → 0.668393	CI: -2.610112 → 2.026723 (-2.304869 → 1.532561)	CI: -0.533441 → 0.331392	<b>CI: 0.058677 → 0.851825</b>	CI: -1.737302 → 1.752928
<b>tTau:</b>	E: -0.046143	E: -0.138214 (-0.097699)	E: -0.056896	E: 0.008317	E: 0.229977
	CI: -0.229869 → 0.137583	CI: -1.076292 → 0.799865 (-0.874147 → 0.678750)	CI: -0.267776 → 0.153985	CI: -0.178274 → 0.194907	CI: -0.880621 → 1.340575
<b>Aβ42:</b>	E: -0.059135	E: -0.089292 (-0.047088)	E: 0.040304	E: -0.012298	E: -0.057667

Continued

**Table 4** Longitudinal Linear Regression Models for Patients With Known TDP Pathology (continued)

COGNITIVE MEASURE				
CI: -0.139921 → 0.021650	CI: -0.571806 → 0.393221 (-0.370991 → 0.465168)	CI: -0.068640 → 0.149248	CI: -0.092173 → 0.067578	CI: -0.434562 → 0.319227

Abbreviations: A $\beta$ 42 =  $\beta$ -amyloid1-42; CI = confidence interval; E = estimate; MMSE = Mini-Mental State Examination; NfL = neurofilament light chain; pTau = phosphorylated tau; TDP = TAR DNA binding protein ~43kD; tTau = total tau. Data in parentheses are Es and CIs without a potentially influential extreme value. Significant models are in bold (\* p < 0.05 \*\* p < 0.01 \*\*\* p < 0.001).

## Reference

- Zhang JV, Irwin DJ, Blennow K. Neurofilament light chain is related to longitudinal decline in frontotemporal lobar degeneration. *Neurol Clin Pract.* 2021;11(2):105-116.

## Adult-Onset Dystonia With Marfanoid Feature

*Neurology: Clinical Practice* December 2021 vol. 11 no. 6 e981 doi:10.1212/CPJ.0000000000000747

In the article, “Adult-onset dystonia with marfanoid features” by Norris et al.,<sup>1</sup> first published online September 2, 2016, the video should have included 4 segments. The corrected video appears online. The editorial office regrets the error.

## Reference

- Norris SA, Pogarcic A, Hicks M, Perlmutter JS, Shinawi M. Adult-onset dystonia with marfanoid features. *Neurol Clin Pract.* 2017;7(4):e31-e34.

## Caring for Individuals With Intellectual and Developmental Disabilities in the COVID-19 Crisis

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An incorrect version of the article “Caring for individuals with intellectual and developmental disabilities in the COVID-19 crisis” by J. Solomon Sanders, S. Keller, and B. Aravamuthan<sup>1</sup> was originally published online ahead of print on May 29, 2020. A corrected version was posted on September 11, 2020. Please note that these errors do not affect the accuracy of the data or conclusions of the article. The editorial office regrets the error.

## Reference

- Solomon Sanders J, Keller S, Aravamuthan B. Caring for individuals with intellectual and developmental disabilities in the COVID-19 crisis. *Neurol Clin Pract.* 2021;11(2):e174-e178.