

## Bibliography – COVID-19 and Intellectual Disability

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**Note –** this working bibliography also contains unpublished or non-peer reviewed materials, as well as some relevant media articles. The NTG and the HealthMatters™ Program do not validate the content in this bibliography but are offering this information as potential source matter for others. As these are abstracts, we strongly recommend reviewing the original source matter for validity and reliability. As with emerging news about COVID-19 and its impact, this bibliography is an evolving document. We will be adding to it as further studies and reports emerge. Making us aware of work that we omitted, or that is forthcoming, is most welcome; send a note to [mjanicki@uic.edu](mailto:mjanicki@uic.edu).

Citation	Abstract
<p>Alexander, R., Ravi, A., Barclay, H., Sawhney, I., Chester, V., Malcolm, C., Brolly, K., Mukherji, K., Zia, A., Tharian, R., Howell, A., Lane, T., Cooper, V., &amp; Langdon, P.E.</p> <p><b>Guidance for the treatment and management of COVID-19 among people with intellectual disabilities.</b></p> <p><i>Journal of Policy and Practice in Intellectual Disabilities</i>, (2020), 17(3), 256-269.  <a href="https://doi.org/10.1111/jppi.12352">https://doi.org/10.1111/jppi.12352</a></p>	<p><b>Abstract:</b> The current COVID-19 pandemic is a pressing world crisis and people with intellectual disabilities (IDs) are vulnerable due to disparity in healthcare provision and physical and mental health multimorbidity. While most people will develop mild symptoms upon contracting severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2), some will develop serious complications. The aim of this study is to present guidelines for the care and treatment of people with IDs during the COVID-19 pandemic for both community teams providing care to people with IDs and inpatient psychiatric settings. The guidelines cover specific issues associated with hospital passports, individual COVID-19 care plans, the important role of families and carers, capacity to make decisions, issues associated with social distancing, ceiling of care/treatment escalation plans, mental health and challenging behavior, and caring for someone suspected of contracting or who has contracted SARS-CoV-2 within community or inpatient psychiatric settings. We have proposed that the included conditions recommended by Public Health England to categorize someone as high risk of severe illness due to COVID-19 should also include mental health and challenging behavior. There are specific issues associated with providing care to people with IDs and appropriate action must be taken by care providers to ensure that disparity of healthcare is addressed during the COVID-19 pandemic. We recognize that our guidance is focused upon healthcare delivery in England and invite others to augment our guidance for use in other jurisdictions.</p>
<p><b>Avalere Health</b></p> <p><b>Impact of COVID-19 on organizations serving individuals with intellectual and developmental disabilities.</b></p> <p>Washington, DC: Avalere Health (2020). April 2020.  <a href="https://www.ancor.org/sites/default/files/impact_of_covid-19_on_organizations_serving_individuals_with_idd.pdf">https://www.ancor.org/sites/default/files/impact_of_covid-19_on_organizations_serving_individuals_with_idd.pdf</a></p>	<p><b>Abstract:</b> <i>[none – taken from text of report]</i>. In April 2020, the American Network of Community Options and Resources (ANCOR) conducted a survey to quantify the extent to which the COVID-19 pandemic has affected their members—over 1,600 community providers serving individuals with I/DD. The survey received valid responses from 689 organizations across all 50 states, District of Columbia, and two territories (Puerto Rico and Guam). Avalere was asked by ANCOR to independently analyze the survey responses and produce a report presenting findings from the analysis. Some highlights include:</p>

	<ul style="list-style-type: none"> <li>• 68% of all organizations surveyed reported that they have had to close one or more service lines due to the pandemic resulting in an average loss of revenue of 32%.</li> <li>• 52% of all organizations surveyed reported having increased staff overtime expenses.</li> </ul> <p>Organizations serving individuals with I/DD were also asked an open-ended question about the main challenges of the COVID-19 crisis. The most prevalent were staffing (57%), PPEs (34%), financial concerns (25%), providing services (19%), and safety (15%).</p>
<p><b>Bradley, V.J.</b>  <b>How COVID-19 may change the world of services to people with intellectual and developmental disabilities.</b>  <i>Intellectual and Developmental Disabilities</i>, 2020, 58(5), 355-360.  <a href="https://doi.org/10.1352/1934-9556-58.5.355">https://doi.org/10.1352/1934-9556-58.5.355</a></p>	<p><b>Abstract:</b> The COVID-19 epidemic caused disruption and dislocation in the lives of people with disabilities, their families, and providers. What we have learned during this period regarding the strengths and weaknesses of the service system for people with disabilities should provide a roadmap for building a more robust and agile system going forward. Based on a canvas of leaders in our field, I propose a way of outlining a reimagined system.</p>
<p><b>Callea, M., Cammarata-Scalisi, F., Galeotti, A., Villani, A., &amp; Valentini, D.</b>          COVID-19 and Down syndrome.  <i>Acta Paediatrica</i>, 2020, 109(9), 1901-1902.  <a href="https://doi.org/10.1111/apa.15409">https://doi.org/10.1111/apa.15409</a></p>	<p><b>Abstract:</b> [Abridged from article] As COVID-19 presents as an acute severe respiratory syndrome and DS is by far the most frequent chromosomal disease with the highest susceptibility to develop respiratory infections and complications,<sup>1</sup> it seems timely to focus on this syndrome during the ongoing pandemic. The pediatric age in general seems to be less affected by COVID-19. However, children with DS are especially vulnerable and susceptible to respiratory infections. In addition, they have comorbidities such as immunodeficiency, cardiopathies especially those with surgical valve replacement, obesity, diabetes that have been proven to worsen the outcome of COVID-19 patients. At present time, DS undergoes the same control and prevention measures established by the Public Health Services (PHSs) worldwide. The main recommendations consist in social distancing, use of protective facemasks and gloves, frequent washing of hands and disinfection of both hands and environments. Unnecessary exposure should be avoided, and non-authorized persons should stay at home either as prophylaxis or in quarantine. In extreme conditions, the lockdown can be established. The pandemic scenario raises major worries for families of children with DS for several reasons. In about 40% of the families, one member (mostly parents) had stopped working long before, while others, unless locked down, work outside, and return home, thus being at potential risk of spreading contagion. On the other hand, lifestyle and rhythms are disrupted by the loss of supports to the families because of the educational and family network isolation and because subjects with DS are usually thriving at school and by visiting relatives, especially grandparents. The main recommendations for individuals with DS are practically identical to what is recommended for others, although details may differ from one country to another. The absence of information about how the disease affects this group of</p>

	<p>subjects is a limiting factor to further discussing about the specific risk towards COVID-19. By the appearance of the coronavirus infection in Italy, we have predisposed an ad hoc protocol. The protocol contains instructions related to the importance for children with DS of having earlier access to diagnostic tests and antiviral management, especially in states of immune dysfunction, recurrent pulmonary infections, congenital heart disease and obesity.</p>
<p> <b>Centers for Disease Control (CDC).</b>  <b>Coronavirus disease 2019 (COVID-19):</b>  <b>People with disabilities.</b>        (2020).  <a href="https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html">https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html</a> </p>	<p><b>Abstract:</b> [none – taken from text]. Coronavirus disease is a respiratory illness that can spread from person to person. The virus is thought to spread mainly between people who are in close contact with one another (within about 6 feet) through respiratory droplets produced when an infected person coughs or sneezes. It is also possible that a person can get COVID-19 by touching a surface or object that has the virus on it and then touching their own mouth, nose, or eyes. For more information go to CDC’s Fact Sheet- What you need to know about coronavirus disease 2019 (COVID-19). Risk of infection with COVID-19 is higher for people who are in close contact with someone known to have COVID-19, such as healthcare workers, direct support providers, and household members. Other people at higher risk for infection are those who live or have recently been in an area with ongoing spread of COVID-19. There are some things people with disabilities can do to prepare during the COVID-19 outbreak:</p> <ul style="list-style-type: none"> <li>● Plan what you will do if you or your direct support provider gets sick. Create a contact list of family, friends, neighbors, and local service agencies that can provide support in case you or your direct support provider becomes ill or unavailable.</li> <li>● Plan at least two ways of communicating from home and work that can be used rapidly in an emergency (e.g., landline phone, cell phone, text-messaging, email). Write down this information and keep it with you.</li> <li>● Have enough household items and groceries so that you will be comfortable staying home for a few weeks, at least a 30-day supply of over the counter and prescription medicines and any medical equipment or supplies that you might need. Some health plans allow for a 90-day refill on prescription medications. Consider discussing this option with your healthcare provider.</li> <li>● Make a photocopy of prescriptions, as this may help in obtaining medications in an emergency.</li> </ul>
<p> <b>Clift, A.C., Coupland, C.A.C., Keogh, R.H., Hemingway, H., &amp; Hippisley-Cox, J.</b>  <b>COVID-19 mortality risk in Down syndrome: Results from a cohort study of 8 million adults.</b>  <i>Annals of Internal Medicine</i>, (2020), 21 October 2020 (Letters).  <a href="https://doi.org/10.7326/M20-4986">https://doi.org/10.7326/M20-4986</a> </p>	<p><b>Abstract</b> (<i>none - quoted from Discussion</i>): We estimated a 4-fold increased risk for COVID-19–related hospitalization and a 10-fold increased risk for COVID-19–related death in persons with Down syndrome, a group that is currently not strategically protected. This was after adjustment for cardiovascular and pulmonary diseases and care home residence, which our results suggest explained some but not all of the increased risk. These estimated adjusted associations do not have a direct causal interpretation because some adjusted variables may lie on causal pathways, but they can inform policy and motivate</p>

	<p>further investigation. Participation in day care programs or immunologic deficits could be implicated, for example. Down syndrome is the most common genetic cause of intellectual disability, with multiorgan manifestations (3). Predisposition to pneumonias and acute respiratory distress syndrome in children, airway anomalies, pulmonary hypoplasia, and inhibited pulmonary angiogenesis have been reported.</p>
<p><b>Constantino, J.N., Sahin, M., Piven, J., Rodgers, R., &amp; Tschida, J.</b>  <b>The impact of COVID-19 on individuals with intellectual and developmental disabilities: Clinical and scientific priorities.</b>  <i>American Journal of Psychiatry</i>, (2020), Aug 28;appiajp202020060780. doi: 10.1176/appi.ajp.2020.20060780. Online ahead of print. (Letter to the Editor). (taken from: <a href="https://www.nih.gov/news-events/news-releases/people-intellectual-developmental-disabilities-disproportionately-affected-covid-19">https://www.nih.gov/news-events/news-releases/people-intellectual-developmental-disabilities-disproportionately-affected-covid-19</a>)</p>	<p><b>Abstract:</b> [taken from news release]. The COVID-19 pandemic has taken a disproportionate toll on people with intellectual and developmental disabilities (IDDs). Many people with IDD who require in-person care have lost the support of trained caregivers and community service providers due to the pandemic. The authors note that the Centers for Disease Control and Prevention and others have issued guidelines for group homes, schools, and others entrusted with the care of people with IDD. It is vital to ensure that when they return to work, care staff exercise techniques and procedures to protect their clients from infection, the authors write. Moreover, people with IDD depend on caregivers and loved ones to help them bridge gaps in intellectual and communication abilities. In the absence of this human contact, the authors call for virtual care and support, where viable. Those who cannot benefit from screen-based supports should be prioritized to receive in-person services. Suspension of classroom time also disproportionately affects children with IDD, who often require special educational services, increased teacher-student ratios, and specialized interventions, many of which need to be administered in person, the authors note. It is difficult for families to take on these tasks, and qualified in-home surrogates should be mobilized whenever possible to meet this need and to support parents' efforts. Also, people with IDD often cannot verbalize their symptoms during telemedicine appointments, and physicians need to use their best judgement in providing in-person care for them when necessary, according to the authors. The article emphasizes that people with IDD who are infected with COVID-19 should receive equal access to testing and appropriate medical care.</p>
<p><b>Courtenay, K., &amp; Perera. B.</b>  <b>COVID-19 and people with intellectual disability: Impacts of a pandemic.</b>  <i>Irish Journal of Psychological Medicine</i>, (2020), May 14, 1-16. doi:10.1017/ipm.2020.45</p>	<p><b>Abstract:</b> The impacts of the COVID-19 pandemic affect all groups in society. People with intellectual disability (ID) are especially vulnerable to the physical, mental, and social effects of the pandemic. Cognitive impairments can limit understanding of information to protect them relying on carers to be vigilant on their behalf during quarantine. Restrictions on usual activities are likely to induce mental stress especially among those who are autistic leading to an escalation in challenging behaviors, risk of placement breakdown and increased the use of psychotropic medication. People with ID are vulnerable to exploitation by others where the usual community supports no longer function to protect them. In future pandemics, it is important that lessons are learned from the impacts COVID-19 have on people with ID. Collecting the evidence through a rigorous approach should help to empower</p>

	<p>people with ID and their carers to face future outbreaks of infectious diseases.</p>
<p> <b>Cuypers, M., Schalk, B.W.M., Koks-Leensen, M.C.J., Nägele, M.E., Bakker-van Gijssel, E.J., Naaldenberg, J., &amp; Leusink, G.L.</b>  <b>Mortality of people with intellectual disabilities during the 2017/2018 influenza epidemic in the Netherlands: potential implications for the COVID-19 pandemic.</b>  <i>Journal of Intellectual Disability Research</i>, 2020, 64(7), 482-488.         </p>	<p> <b>Abstract:</b> Data on the development of Covid-19 among people with intellectual disabilities (IDs) are scarce and it is uncertain to what extent general population data applies to people with ID. To give an indication of possible implications, this study investigated excess mortality patterns during a previous influenza epidemic. Using Dutch population and mortality registers, a historical cohort study was designed to compare mortality during the 2017–2018 influenza epidemic with mortality in the same period in the three previous years. People with ID were identified by entitlements to residential ID-care services as retrieved from a national database. Data covered the entire adult Dutch population (12.6 million; GenPop), of which 91 064 individuals were identified with an ID. During the influenza epidemic, mortality among people with ID increased almost three times as much than in the GenPop (15.2% vs. 5.4%), and more among male individuals with ID (+19.5%) than among female individuals with ID (+10.6%), as compared with baseline. In both cohorts, comparable increases in mortality within older age groups and due to respiratory causes were seen. Particularly in the ID-cohort, excess deaths also occurred in younger age groups, due to endocrine diseases and ID-specific causes. During the 2017–2018 influenza epidemic, excess mortality among people with ID was three times higher than in the general Dutch population, appeared more often at young age and with a broader range of underlying causes. These findings suggest that a pandemic may disproportionately affect people with ID while population data may not immediately raise warnings. Early detection of diverging patterns and faster implementation of tailored strategies therefore require collection of good quality data.         </p>
<p> <b>De Cauwer, H., &amp; Spaepen, A.</b>  <b>Are patients with Down syndrome vulnerable to life-threatening COVID-19?</b>  <i>Acta Neurologica Belgica</i>, 2020, 1–3.            Advance online publication.  <a href="https://doi.org/10.1007/s13760-020-01373-8">https://doi.org/10.1007/s13760-020-01373-8</a> 1-6.         </p>	<p> <b>Abstract:</b> Patients with Down syndrome are at increased risk of respiratory syncytial virus- and H1N1-related death. Literature on COVID-19 in Down syndrome patients is unavailable thus far. We describe the clinical course of 4 patients with Down syndrome during an outbreak of COVID-19. In all four patients, disease course was severe, warranting hospital care in three patients, with fatal outcome in one patient. Another patient receives supportive care in our institution. Our case series is the first report on probable increased risk of life-threatening disease course of COVID-19 in patients with Down syndrome. Proper surveillance, the adherence of social distancing, and the use of personal protective equipment will be essential in reducing morbidity and mortality in our patients.         </p>
<p> <b>del Carmen Ortega, M., Borrel, J.M., de Jesús Bermejo, T., González-Lamuño, D., Manso, C., de la Torre, R., Mayer, M-A., Real de Asúa, D., Dierssen, M. on behalf of the Spanish Trisomy 21 Research Society COVID-19 Taskforce</b> </p>	<p> <b>Abstract:</b> The COVID-19 pandemic presents some unique challenges for people with intellectual disability. Individuals with Down syndrome, the most common form of intellectual disability, exhibit a higher prevalence of respiratory tract infections, immune dysfunction, chronic inflammation, early ageing, and comorbidities associated with COVID-19 risk leading to poorer clinical outcomes, but it is currently unknown         </p>

<p> <b>Lessons from individuals with Down syndrome during COVID-19 (Correspondence)</b>  <i>The Lancet Neurology</i>, 19(12), P974-975, DECEMBER 01, 2020.  <a href="https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(20)30401-4/fulltext">https://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(20)30401-4/fulltext</a> </p>	<p>         to what extent they are more vulnerable to severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection. According to a survey, done by the Trisomy 21 Research Society, the number of SARS-CoV-2 infections in people with trisomy 21 substantially dropped after the first wave of infection between March and May 2020, and even after the resurgence of coronavirus infections in September 2020. We suspect that the lower infection rates detected since Sept 1, 2020, in individuals with Down syndrome might be partly explained by certain behavioral and cognitive traits. These traits include constancy, tenacity, and commitment to tasks that individuals have interiorized, which are not commonly reported in patients with other genetic syndromes associated with intellectual disabilities. People with Down syndrome also share a tendency to imitate and repeat behavior that might lead to ritualization and perfectionism. Therefore, the cognitive function pattern associated with this behavioral phenotype could promote compliance with recommended preventative measures against the spread of SARS-CoV-2. Finally, in our experience, individuals with Down syndrome show a high degree of commitment when they integrate habits relayed to them as important or beneficial. Of course, these notions cannot be extrapolated to people with Down syndrome with severe or profound intellectual deficit or dementia, or when the information related to the SARS-CoV-2 pandemic has not been adequately communicated. The success of individuals with Down syndrome in complying with the recommended measures depends on adequate intervention from both family members and health-care practitioners. Individuals with Down syndrome might be teaching a quiet lesson to the rest of the population. The persistency, specifically in grooming and hygiene, shown by people with Down syndrome helps them to learn (through an appropriate channel) and adopt recommended protective measures against this infection. If our observation holds, the behavioral pattern presented by these individuals should serve as a useful reminder to the general population to avoid the spread of SARS-CoV-2.       </p>
<p> <b>Department of Health &amp; Social Care (UK) Coronavirus (COVID-19): guidance for care staff supporting adults with learning disabilities and autistic adults</b>  <i>UK DH&amp;SC</i>, November 5, 2020  <a href="https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults/coronavirus-covid-19-guidance-for-care-staff-supporting-adults-with-learning-disabilities-and-autistic-adults">https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults/coronavirus-covid-19-guidance-for-care-staff-supporting-adults-with-learning-disabilities-and-autistic-adults</a> </p>	<p> <b>Abstract:</b> Guidance provided for care workers and personal assistants who provide support to adults with learning disabilities and autistic adults. This guidance aims to help care staff keep people with learning disabilities and autistic people safe, to support them to understand the changes they need to make during the COVID-19 outbreak, and to protect their own wellbeing. Built upon the COVID-19 adult social care action plan and more detailed guidance published by the Social Care Institute for Excellence it continues to be updated with resources to support those who care for people with learning disabilities and autistic people. The advice and resources are designed to be helpful for those supporting people with other needs relating to a cognitive impairment, such as dementia or mental health conditions. The UK DHSC notes that when following this guidance, it is important to understand that         </p>

	<p>people with learning [intellectual] disabilities and autistic people will have unique needs and preferences. They are more likely to need support to understand the current measures, such as the stay at home guidance, and any changes to their care and support provision. All care and support should continue to be given in the least restrictive way possible and continue to maximize independence wherever possible. The guidance includes sections on Protecting yourself and the person you care for; Maintaining good hygiene practices; Contingency planning; If you have symptoms of COVID-19; If the person being cared for has symptoms of COVID-19; Caring for someone who is clinically ‘extremely vulnerable’ (shielding); Supporting the person through change; and Maintaining your own health and wellbeing.</p>
<p><b>Embregts, P. J.C.M., Tournier, T., &amp; Frielink, N.</b>  <b>Experiences and needs of direct support staff working with people with intellectual disabilities during the COVID-19 pandemic: A thematic analysis.</b>  <i>Journal of Applied Research in Intellectual Disabilities.</i> (2020). First published: 21 September 2020  <a href="https://doi.org/10.1111/jar.12812">https://doi.org/10.1111/jar.12812</a></p>	<p><b>Abstract:</b> The study explored the experiences and needs of direct support staff during the initial stage of the COVID-19 lockdown in the Netherlands. Overall, eleven direct support staff were recruited from five intellectual disability services to participate in this descriptive qualitative study. They recorded 34 audio messages during the considered period. Thematic analysis was used to analyze these audio recordings. Four themes emerged: (1) Emotional impact, which pertained to various emotions they experienced in their work; (2) Cognitive impact, which referred to challenges and changes they had undergone in their work; (3) Practical impact, which centered on the practical impact of the pandemic on their work; and (4) Professional impact, which concerned their experiences with other professionals. This study provides valuable insights into the experiences and needs of direct support staff during the COVID-19 pandemic, which, in turn, can help inform practice in preparation for a second wave of COVID-19 or another future pandemic.</p>
<p><b>Espinosa, J.M.</b>  <b>Down syndrome and COVID-19: a perfect storm?</b>  <i>Cell Reports Medicine.</i> (2020), May 19; 1(2):100019.  <a href="https://doi.org/10.1016/j.xcrm.2020.100019">doi:10.1016/j.xcrm.2020.100019</a>. Epub 2020 May 1.</p>	<p><b>Abstract:</b> People with Down syndrome show signs of chronic immune dysregulation, including a higher prevalence of autoimmune disorders, increased rates of hospitalization during respiratory viral infections, and higher mortality rates from pneumonia and sepsis. At the molecular and cellular levels, they show markers of chronic autoinflammation, including interferon hyperactivity, elevated levels of many inflammatory cytokines and chemokines, and changes in diverse immune cell types reminiscent of inflammatory conditions observed in the general population. However, the impact of this immune dysregulation in severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection and CoV disease of 2019 (COVID-19) remains unknown. This Perspective outlines why individuals with Down syndrome should be considered an at-risk population for severe COVID-19. Specifically, the immune dysregulation caused by trisomy 21 may result in an exacerbated cytokine release syndrome relative to that observed in the euploid population, thus justifying additional monitoring and specialized care for this vulnerable population.</p>

<p><b>Gelburd, R.</b>  <b>Developmental disorders top the medical conditions that heighten the risk of dying from Covid-19</b>  <i>STAT (Reporting from the frontiers of health and medicine), November 11, 2020</i>  <a href="https://www.statnews.com/2020/11/11/developmental-disorders-among-top-conditions-heighten-risk-dying-covid-19/">https://www.statnews.com/2020/11/11/developmental-disorders-among-top-conditions-heighten-risk-dying-covid-19/</a></p> <p>The above is based upon:  <b><i>Risk Factors for COVID-19 Mortality among Privately Insured Patients (White Paper) – A Claims Data Analysis.</i></b>          November 11, 2020  <a href="https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Risk%20Factors%20for%20COVID-19%20Mortality%20among%20Privately%20Insured%20Patients%20-%20A%20Claims%20Data%20Analysis%20-%20A%20FAIR%20Health%20White%20Paper.pdf">https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Risk%20Factors%20for%20COVID-19%20Mortality%20among%20Privately%20Insured%20Patients%20-%20A%20Claims%20Data%20Analysis%20-%20A%20FAIR%20Health%20White%20Paper.pdf</a></p>	<p><b>Abstract:</b> To explore the connections between underlying conditions and Covid-19 FAIR Health collaborated with the West Health Institute and the Johns Hopkins University School of Medicine. Using FAIR Health’s vast database of private health care claims, researchers studied 467,773 patients diagnosed with Covid-19 from April 1 through Aug. 31, looking for the risk factors that increased their odds of dying from Covid-19. The STAT article extracts information on intellectual disability from the study report. The author notes that across all age groups, COVID-19 patients with intellectual disability and related conditions (e.g., Down syndrome and other chromosomal anomalies); mild, moderate, severe and profound intellectual disabilities; congenital malformation (such as certain disorders that cause microcephaly) had the third highest risk of COVID-19 death (OR=2.75, 95 percent CI, 1.657-4.558, P=0.0005). Among COVID-19 patients under age 70, intellectual disabilities and related conditions still had the third highest risk (OR=3.61, 95 percent CI, 1.878-6.930, P=0.0007).</p> <p>[Abstracted from: <i>Risk Factors for COVID-19 Mortality among Privately Insured Patients</i> – the original source for the STAT article] – “Our study highlights the high risk of COVID-19 mortality among those with developmental disorders (e.g., developmental disorders of speech and language, developmental disorders of scholastic skills, central auditory processing disorders), as well as intellectual disabilities and related conditions (e.g., Down syndrome and other chromosomal anomalies; mild, moderate, severe and profound intellectual disabilities; congenital malformations, such as certain disorders that cause microcephaly). (Autism is not included in either category; it is treated as a separate category in the CCW list.) These findings are consistent with the research literature, which indicate that COVID-19 infections and mortality are higher among those with intellectual and developmental disabilities (IDD). The nature of group settings, with higher transmissibility of the virus, is purported to be a factor in these results. IDD, like some other comorbidity risk factors (e.g., spina bifida, Alzheimer’s disease, and spinal cord injury) is associated with group homes and other forms of residential housing. Such housing has been identified as a risk factor not only for infection with SARS-CoV-2 (the virus that causes COVID-19) but for severity of COVID-19. Rates of comorbid respiratory disorders and comorbid endocrine, nutritional and metabolic disorders have been shown to be higher in the IDD patient population than among those without IDD across all age groups. People with IDD often have multiple chronic health conditions, which increase the odds of dying from COVID-19.</p>
<p><b>Grier, E., Lunskey, Y., Sullivan, W.F. &amp; Casson, I.</b></p>	<p><b>Abstract:</b> Adults with intellectual and developmental disabilities (IDD), such as Down Syndrome and autism, are a population at risk of contracting COVID-19 and of serious illness</p>

<p><b>Health care of adults with intellectual and developmental disabilities in a time of COVID-19.</b>          Canadian Family Physician, April 9, 2020, Blog Post.  <a href="https://www.cfp.ca/news/cfpnews/2020/04/09/04-09-02.full.pdf">https://www.cfp.ca/news/cfpnews/2020/04/09/04-09-02.full.pdf</a></p>	<p>associated with COVID-19. Members of this community are experiencing significant distress due to confusion and disruption in their daily lives. Their voice is notably absent from current discussions. Clear resources and supports explaining how to manage, along with in-person support would be helpful.</p> <p>In addition, the high rates of emergency department visits and hospitalizations for this group even before COVID-19 may now be exacerbated. Proactive primary care in the community to address physical and mental health needs may be useful. Communication, symptom monitoring, management and caregiving strategies need to consider comorbidities, special needs, and the variety of settings in which adults with IDD live:</p> <ul style="list-style-type: none"> <li>● 1. Some adults with IDD living in congregate care (group homes) have similar medical and behavior concerns to many long-term care residents despite their younger age. Public health guidelines should provide for expedited assessment and enhanced follow-up for this group.</li> <li>● 2. The direct care workers in group homes for adults with IDD are essential to their health care. Protocols and protections, like those for essential health care workers, should be implemented.</li> <li>● 3. Some adults with mild IDD living independently in the community are at risk of not understanding or adhering to public health guidelines. Proactive communication and support (e.g. by phone) from knowledgeable social and health care providers is necessary to help them adhere to guidelines and manage during this difficult time.</li> <li>● 4. Family caregivers, especially older parents, who live with and provide care for an adult with IDD, are at risk of severe COVID-related illness themselves. A crisis plan needs to be in place to continue the care of their family member in that situation.</li> <li>● 5. If an adult with IDD needs emergency department or other hospital services, especially during the coming surge in COVID-19 cases, a partnership between family and other community-based caregivers and hospital staff will be necessary to support the communication and other special needs of the adults with IDD. Decision making supports and advanced care plans are crucial at this time. If a substitute decision maker is required for a health care decision, it is important they are accessible to hospital staff.</li> </ul>
<p>Hüls, A., Costa, A.C.S., Dierssen, M., Asaad Baksh, R., Bargagna, S., Baumer, N.T., Brandão, A.C., Carfi, A., Carmona-Iragui, M., Chicoine, B.A., Ghosh, S., Lakhanpaul, M., Manso, C., Mayer, M-A., del Carmen Ortega, M., Real de Asua, D., Rebillat, A-S., Russell, L.A., Sgandurra, G., Valentini, D., Sherman, S.L., &amp; Strydom, A.</p>	<p><b>Abstract:</b> Health conditions and immune dysfunction associated with trisomy 21 (Down syndrome, DS) may impact the clinical course of COVID-19 once infected by SARS-CoV-2. The T21RS COVID-19 Initiative launched an international survey for clinicians or caregivers/family members on patients with COVID-19 and DS (N=1046). De-identified survey data collected between April and October 2020 were analyzed and compared with the UK ISARIC4C survey of hospitalized COVID-19 patients with and without DS. COVID-19 patients with DS from the ISARIC4C survey (ISARIC4C DS cases=100) were matched to a</p>

<p><b>An international survey on the impact of COVID-19 in individuals with Down syndrome</b>  <i>medRxiv</i>, November 5, 2020.  <a href="https://doi.org/10.1101/2020.11.03.20225359">https://doi.org/10.1101/2020.11.03.20225359</a></p>	<p>random set of patients without DS (ISARIC4C controls=400) and hospitalized DS cases in the T21RS survey (T21RS DS cases=100) based on age, gender, and ethnicity. Findings note that the mean age in the T21RS survey was 29 years (SD=18), 73% lived with their family. Like the general population, the most frequent signs and symptoms of COVID-19 were fever, cough, and shortness of breath. Pain and nausea were reported less frequently (<math>p&lt;0.01</math>), whereas altered consciousness/confusion were reported more frequently (<math>p&lt;0.01</math>). Risk factors for hospitalization and mortality were like the general population (age, male sex, diabetes, obesity, dementia) with the addition of congenital heart defects as a risk factor for hospitalization. Mortality rates showed a rapid increase from age 40 and were higher than for controls (T21RS DS versus controls: risk ratio (RR)=3.5 (95%-CI=2.6;4.4), ISARIC4C DS versus controls: RR=2.9 (95%-CI=2.1;3.8)) even after adjusting for known risk factors for COVID-19 mortality. Leading signs/symptoms of COVID-19 and risk factors for severe disease course are similar to the general population. However, individuals with DS present significantly higher rates of mortality, especially from age 40.</p>
<p>Landes, S.D, Turk, M.A., Formica, M.K., McDonald, K.E., &amp; Stevens, D.  <b>COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State.</b>  <i>Disability and Health Journal</i>. 2020, 13(4), October 2020  100969<a href="https://doi.org/10.1016/j.dhjo.2020.100969">https://doi.org/10.1016/j.dhjo.2020.100969</a></p>	<p><b>Abstract:</b> People with intellectual and developmental disabilities (IDD) may be at higher risk of severe outcomes from COVID-19. To describe COVID-19 outcomes among people with IDD living in residential group homes in the state of New York and the general population of New York State. Data for people with IDD are from a coalition of organizations providing over half of the residential services for the state of New York, and from the New York State Department of Health. Analysis describes COVID-19 case rates, case-fatality, and mortality among people with IDD living in residential group homes and New York State through May 28, 2020. People with IDD living in residential group homes were at greater risk of severe COVID-19 outcomes: case rates 7,841 per 100,000 for people with IDD compared to 1,910 for New York State; case-fatality 15.0% for people with IDD compared to 7.9% for New York State; and mortality rate 1,175 per 100,000 for people with IDD compared to 151 per 100,000 for New York State. Differences in cases and mortality rate were confirmed across regions of the state, but case-fatality rate was only higher for people with IDD in and around the New York City region. COVID-19 appears to present a greater risk to people with IDD, especially those living in congregate settings. A full understanding of the severity of this risk will not be possible until US states begin publicly sharing all relevant data they have on COVID-19 outcomes among this population.</p>
<p>Landes, S.D., Stevens, D. &amp; Turk, M.A.  <b>COVID-19 and pneumonia: increased risk for individuals with intellectual and developmental disabilities during the pandemic</b></p>	<p><b>Abstract:</b> [none – taken from Key Findings]. COVID-19 death rates are higher among adults with intellectual and developmental disabilities (IDD). Adults with IDD are more likely to develop pneumonia (a severe complication of COVID-19) than adults without IDD. Medical personnel must take extra precautions in treating COVID-19 symptoms in adults with</p>

<p>RESEARCH BRIEF #21 - April 27, 2020; (2020). <a href="https://lernercenter.syr.edu/wp-content/uploads/2020/04/Landes.Stevens.Turk_.pdf">https://lernercenter.syr.edu/wp-content/uploads/2020/04/Landes.Stevens.Turk_.pdf</a> - Lerner Center for Public Health Promotion, Syracuse University</p>	<p>IDD. Those certifying death certificates need to accurately record IDD on the death certificate.</p>
<p>Malle, L., Gao, C., Hur, C., Truong, H.Q., Bouvier, N.M., Percha, B., Kong, X-F., &amp; Bogunovic, D.  <b>Individuals with Down syndrome hospitalized with COVID-19 have more severe disease</b>  <i>Genetics in Medicine</i>, 2020, e-print on October 16, 2020, 1-5.  <a href="https://www.nature.com/articles/s41436-020-01004-w.pdf?origin=ppub">https://www.nature.com/articles/s41436-020-01004-w.pdf?origin=ppub</a></p>	<p><b>Abstract:</b> Rare genetic conditions like Down syndrome (DS) are historically understudied. Infection is a leading cause of mortality in DS, along with cardiac anomalies. Currently, it is unknown how the COVID-19 pandemic affects individuals with DS. The authors report on an analysis of individuals with DS who were hospitalized with COVID-19 in New York, New York, USA. In this retrospective, dual-center study of 7246 patients hospitalized with COVID-19, we analyzed all patients with DS admitted in the Mount Sinai Health System and Columbia University Irving Medical Center. We assessed hospitalization rates, clinical characteristics, and outcomes. Authors identified 12 patients with DS. Hospitalized individuals with DS are on average ten years younger than patients without DS. Patients with DS have more severe disease than controls, particularly an increased incidence of sepsis and mechanical ventilation. Authors report that they demonstrated that individuals with DS who are hospitalized with COVID-19 are younger than their non-DS counterparts, and that they have more severe disease than age-matched controls. We conclude that particular care should be considered for both the prevention and treatment of COVID-19 in these patients.</p>
<p>Martin-Khan, M., Bail, K., Yates, M.W., Thompson, J., Graham, &amp; Cognitive Impairment and COVID-19, Hospital Care Guidance Committee  <b>Interim guidance for health-care professionals and administrators providing hospital care to adult patients with cognitive impairment, in the context of COVID-19 pandemic.</b>  <i>Australasian Journal on Ageing</i>, 2020, 39(3), Sept, 283-286.  <a href="https://doi.org/10.1111/ajag.12831">https://doi.org/10.1111/ajag.12831</a></p>	<p><b>Abstract:</b> We developed interim guidance for the care of patients with cognitive impairment (including those with dementia or intellectual disability) in hospital during the COVID-19 pandemic. A Guidance Committee and Readers Group were recruited. The content was identified by the Committee and content-specific subgroups, resulting in a draft document, which was sent to the Readers for review. People with dementia or intellectual disability and care partners were involved in all aspects of the process. Infection control measures can lead to an escalation of distress. In an environment where visiting bans are applied to care partners/advocates, hospitals need to ensure care partners can continue to provide decision-making support. Health-care professionals can proactively engage care partners using videoconferencing technologies. Developing models of care that proactively support best practice can minimize the risk of delirium, mitigate escalating symptoms and guide the use of non-pharmacological, pharmacological (start low, go slow) or physical restraint in managing behavioral and psychological symptoms.</p>
<p>Mills, W.R., Sender, S., Lichtefeld, J., Romano, N., Reynolds, K., Price, M., Phipps, J., White, L., Howard, S., Poltavski, D., &amp; Barnes, R.</p>	<p><b>Abstract:</b> It is unknown how the novel Coronavirus SARS-CoV-2, the cause of the current acute respiratory illness COVID-19 pandemic that has infected millions of people, affects people with intellectual and developmental disability (IDD). The aim of</p>

**Supporting individuals with intellectual and developmental disability during the first 100 days of the COVID-19 outbreak in the USA.**

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this study is to describe how individuals with IDD have been affected in the first 100 days of the COVID-19 pandemic. Shortly after the first COVID-19 case was reported in the USA, our organization [Bright Spring Health Services, Louisville, KY, USA.; University of North Dakota, Grand Forks, ND, USA ], which provides continuous support for over 11 000 individuals with IDD, assembled an outbreak committee composed of senior leaders from across the health care organization. The committee led the development and deployment of a comprehensive COVID-19 prevention and suppression strategy, utilizing current evidence-based practice, while surveilling the global and local situation daily. We implemented enhanced infection control procedures across 2400 homes, which were communicated to our employees using multi-faceted channels including an electronic resource library, mobile and web applications, paper postings in locations, live webinars and direct mail. Using custom-built software applications enabling us to track patient, client and employee cases and exposures, we leveraged current public health recommendations to identify cases and to suppress transmission, which included the use of personal protective equipment. A COVID-19 case was defined as a positive nucleic acid test for SARS-CoV-2 RNA. In the 100-day period between 20 January 2020 and 30 April 2020, we provided continuous support for 11 540 individuals with IDD. Sixty-four per cent of the individuals were in residential, community settings, and 36% were in intermediate care facilities. The average age of the cohort was 46 ± 12 years, and 60% were male. One hundred twenty-two individuals with IDD were placed in quarantine for exhibiting symptoms and signs of acute infection such as fever or cough. Sixty-six individuals tested positive for SARS-CoV-2, and their average age was 50. The positive individuals were in 30 different homes (1.3% of total) across 14 states. Fifteen homes have had single cases, and 15 have had more than one case. Fifteen COVID-19-positive individuals were hospitalized. As of 30 April, seven of the individuals hospitalized have been discharged back to home and are recovering. Five remain hospitalized, with three improving and two remaining in intensive care and on mechanical ventilation. There have been three deaths. We found that among COVID-19-positive individuals with IDD, a higher number of chronic medical conditions and male sex were characteristics associated with a greater likelihood of hospitalization. In the first 100 days of the COVID-19 outbreak in the USA, we observed that people with IDD living in congregate care settings can benefit from a coordinated approach to infection control, case identification and cohorting, as evidenced by the low relative case rate reported. Male individuals with higher numbers of chronic medical conditions were more likely to be hospitalized, while younger, less chronically ill individuals recovered spontaneously at home.

Mozes, A.

**Abstract:** [none- text taken from article]. New research is shining a light on a group particularly vulnerable to the new

<p><b>Intellectual disability raises COVID-19 death risk.</b>          WebMD. (2020).  <a href="https://www.webmd.com/lung/news/20200608/intellectual-disability-raises-covid19-death-risk#1">https://www.webmd.com/lung/news/20200608/intellectual-disability-raises-covid19-death-risk#1</a></p> <p>See also: <b>People with intellectual disabilities are being hit hard by COVID-19</b>  <i>Medical Press, June 8, 2020</i>  <a href="https://medicalxpress.com/news/2020-06-people-intellectual-disabilities-hard-covid.html">https://medicalxpress.com/news/2020-06-people-intellectual-disabilities-hard-covid.html</a></p>	<p>coronavirus: People with an intellectual or developmental disability (IDD), cared for either by family at home or in group homes. People with these types of disabilities include those with Down syndrome, cerebral palsy and other conditions, and the data shows they are significantly more likely to die after contracting COVID-19 than the general public. According to the database used in the study, the virus claimed the lives of just under 3% of COVID-19 patients between the ages of 18 and 74 who did not have an IDD. But among COVID-19 patients who do have an IDD, that figure rose by half, to 4.5%. IDD patients under the age of 18 are also more likely to die from COVID-19 than their young non-IDD peers, the study found. Group homes may be especially hazardous, said one expert unconnected to the new study. "People with IDD living in residential settings experienced what I would qualify as the 'perfect storm' for COVID-19," said Michelle Ballan. She is associate dean of research in the school of social welfare at Stony Brook University in Stony Brook, N.Y. "People with IDD frequently rely on hands-on assistance from other people with daily self-care tasks, making social distancing particularly challenging and further increasing risk of disease transmission," Ballan explained. "Not only are people with IDD who do not live independently at risk," she added, "but their caregivers may also find themselves facing competing obligations: To stay home if they are feeling sick, and to help the individuals who rely on them for daily functioning." Higher risk in young -- The new study was led by Dr. Margaret Turk, a professor of physical medicine and rehabilitation at SUNY Upstate Medical University at Syracuse, N.Y. Her team tracked the experience of more than 30,000 COVID-19 patients, including just under 500 who were characterized as having an IDD. All were diagnosed with COVID-19 at some point between Jan. 20 and May 14, 2020.</p>
<p>Perera, B., Laugharne, R., Henley, W., Zabel, A., Lamb, K., Branford, D., Courtanay, K., Alexander, A., Purandare, K., Wijeratne, A., Radhakrishnan, V., McNamara, E., Daareewoo, Y., Sawhney, I., Scheepers, M., Taylor, G., &amp; Shankar, R.</p> <p><b>COVID-19 deaths in people with intellectual disability in the UK and Ireland: descriptive study.</b>  <i>BJPsych Open</i>, (2020), 6(5), 1-6, e123. DOI:  <a href="https://doi.org/10.1192/bjo.2020.102">https://doi.org/10.1192/bjo.2020.102</a></p>	<p><b>Abstract:</b> Rapid spread of coronavirus disease 2019 (COVID-19) has affected people with intellectual disability disproportionately. Existing data does not provide enough information to understand factors associated with increased deaths in those with intellectual disability. Establishing who is at high risk is important in developing prevention strategies, given risk factors or comorbidities in people with intellectual disability may be different to those in the general population. The aim was to identify comorbidities, demographic and clinical factors of those individuals with intellectual disability who have died from COVID-19. The method was an observational descriptive case series looking at deaths because of COVID-19 in people with intellectual disability was conducted. Along with established risk factors observed in the general population, possible specific risk factors and comorbidities in people with intellectual disability for deaths related to COVID-19 were examined. Comparisons between mild and moderate-to-profound intellectual disability sub-cohorts were undertaken. Data on 66 deaths in individuals with intellectual disability were</p>

	<p>analyzed. Findings revealed that this group was younger (mean age 64 years) compared with the age of death in the general population because of COVID-19. High rates of moderate-to-profound intellectual disability (n = 43), epilepsy (n = 29), mental illness (n = 29), dysphagia (n = 23), Down syndrome (n = 20) and dementia (n = 15) were observed. This is the first study exploring associations between possible risk factors and comorbidities found in COVID-19 deaths in people with intellectual disability. Our data provides insight into possible factors for deaths in people with intellectual disability. Some of the factors varied between the mild and moderate-to-profound intellectual disability groups. This highlights an urgent need for further systemic inquiry and study of the possible cumulative impact of these factors and comorbidities given the possibility of COVID-19 resurgence.</p>
<p><b>Sabatello, M. (moderator)</b>  <b>Best practices for patient-clinician communication for people with disabilities in the era of COVID-19: A Webinar</b>  <i>Webinar hosted by the National Academies of Sciences, Engineering, and Medicine, June 19, 2020.</i>  <a href="https://www.nationalacademies.org/event/06-19-2020/best-practices-for-patient-clinician-communication-for-people-with-disabilities-in-the-era-of-covid-19-a-webinar">https://www.nationalacademies.org/event/06-19-2020/best-practices-for-patient-clinician-communication-for-people-with-disabilities-in-the-era-of-covid-19-a-webinar</a>          [Presentations Archived]</p>	<p><b>Abstract:</b> Clear and consistent communication is foundational to the delivery of high-quality, patient-centered health care. The COVID-19 pandemic presents challenges to communication between clinicians and their patients due to the need for information to not only be accurate and understandable, but also to be timely. These challenges are further compounded when patients have conditions such as hearing loss, dementia, intellectual and developmental disabilities, or a range of physical disabilities. For example, the pervasive use of masks precludes people with hearing loss from reading lips. People with dementia or intellectual and developmental disabilities may not understand disruptions in their routines, or the need to observe public health guidance. People with certain physical disabilities may be unable to wear masks, or have difficulty communicating with their clinicians. This poor communication may have significant health impacts, including increased risk for infection, challenges in accessing treatment, and overall inequitable health care. This webinar featured an overview of key patient-clinician communication challenges and disability law and policies applicable for accessible and effective communication during the COVID-19 pandemic, identified techniques to facilitate health care communication with people with disabilities, and provided tools and resources to consider for better communication in the COVID world.</p>
<p><b>Sabatello, M., Blankmeyer Burke, T., McDonald, K.E., &amp; Appelbaum, P.S.</b>  <b>Disability, ethics, and health care in the COVID-19 pandemic</b>  <i>American Journal of Public Health, 2020, 110(10) (October 1, 2020);:1523-1527.</i>  <a href="https://doi.org/10.2105/AJPH.2020.305837">https://doi.org/10.2105/AJPH.2020.305837</a></p>	<p><b>Abstract:</b> This article considers key ethical, legal, and medical dilemmas arising for people with disabilities in the COVID-19 pandemic. The authors highlight the limited application of existing frameworks of emergency planning with and for people with disabilities in the COVID-19 pandemic, explore key concerns and issues affecting the health care of people with disabilities (i.e., access to information and clinician–patient communication, nondiscrimination and reasonable accommodations, and rationing of medical goods), and indicate possible solutions. Finally, we suggest clinical and public health policy measures to ensure that people with disabilities, including those with intellectual disability, are included in the planning of future pandemic-related efforts. The devastation</p>

	<p>evoked by the COVID-19 pandemic raises challenging dilemmas in bioethics. It also speaks to social justice issues that have plagued historically marginalized communities in the United States. Responses to the pandemic must be bound by legal standards, principles of distributive justice, and societal norms of protecting vulnerable populations—core commitments of public health—to ensure that inequities are not exacerbated, and should provide a pathway for improvements to ensure equitable access and treatment in the future.</p>
<p><b>Sabatello, M., Landes, S.D., &amp; McDonald, K.E.</b>  <b>People with disabilities in COVID-19: Fixing our priorities.</b>  <i>American Journal of Bioethics</i>, 2020, 20(7), 187–190. Published on line July 27.  <a href="https://doi.org/10.1080/15265161.2020.1779396">https://doi.org/10.1080/15265161.2020.1779396</a></p>	<p><b>Abstract:</b> <i>[text abridged from article]</i> While the COVID-19 pandemic has wreaked disproportionate havoc in marginalized racial/ethnic communities, little attention has been given to people with disabilities. First, we describe the most relevant and unique disadvantages that people with disabilities experience in health care and community living that place them at greater risk for disparate COVID-19 outcomes. Second, we highlight the need to ensure accurate data collection to better understand COVID-19 disparities and improve prevention and treatment of, and preparedness for, current and future infectious disease pandemics among people with disabilities. The COVID-19 pandemic has highlighted how deadly congregate care is and should provoke urgency for systems reform. Emerging reports indicate that residents in institutions, group homes, and nursing and other large, long-term residential care facilities are at far higher risk for infection and death. As more than 330,000 people with intellectual and developmental disabilities (IDD) alone are estimated to live in congregate settings, proper monitoring and transparent reporting of COVID-19 trends among people with disabilities are necessary to improve future preparedness for a second or even multiple cycles of the pandemic. A problem is a lack of public health surveillance of people with IDD and that COVID-19 outcomes may be more severe for persons with IDD, likely due to a combination of risks associated with congregate living and health factors. Systemic and holistic changes are clearly needed to address the factors leading to poorer social determinants of health among people with disabilities. These include access to affordable and high-quality care, disability competency training among health care providers, and development of community-living opportunities that promote independence and social inclusion.</p>
<p><b>Schuengel, C., Tummers, J., Embregts, P.J.C.M., &amp; Leusink, G.L.</b>  <b>Impact of the initial response to COVID-19 on long-term care for people with intellectual disability: an interrupted time series analysis of incident reports.</b>  <i>Journal of Intellectual Disability Research</i>, (2020), 64(11), 817-824. 21 September 2020  <a href="https://doi.org/10.1111/jir.12778">https://doi.org/10.1111/jir.12778</a></p>	<p><b>Abstract:</b> The lockdown-measures in response to COVID-19 taken by long-term care organizations might have impacted problem behavior and behavioral functioning of people with intellectual disability. This study tested changes in reported incidents, particularly regarding aggression, unexplained absence and, for contrast, medication errors. Metadata on weekly incident and near-incident reports from 2016 to June 2020 involving over 14 000 clients with mild to serious intellectual disability of 's Heeren Loo, a long-term care organization for people with intellectual disability, were subjected to interrupted time series analysis, comparing the</p>

	<p>COVID-19 with the pre-COVID-19 period. The imposition of lockdown-measures coincided with a significant drop in incidents (total, <math>P &lt; .001</math>; aggression, <math>P = .008</math>; unexplained absences, <math>P = .008</math>; and medication errors, <math>P &lt; .001</math>). Incidents in total (<math>P = .001</math>) and with aggression (<math>P &lt; .001</math>) then climbed from this initial low level, while medication errors remained stably low (<math>P = .94</math>). The rise in incidents involving aggression, against the background of generally lowered reporting, underlines the need for pandemic control measures that are suitable for people with intellectual disability in long-term care.</p>
<p>Sisrak, J., Janicki, M.P., Murphy, R., Marks, B., Buckley, T.  <b>Impact of COVID-19 on provider organizations serving adults with intellectual and other disabilities.</b>          September 8, 2020. Washington, DC: ACCSES. <a href="https://www.the-ntg.org/covid-19-resources">https://www.the-ntg.org/covid-19-resources</a></p>	<p><b>Abstract:</b> The current coronavirus pandemic created an urgent need to examine the impact of COVID-19 within community-based organizations (CBOs), mostly agencies serving people with intellectual and other disabilities who are at increased risk of infection and inappropriate or inadequate care and treatment. An internet-based survey was undertaken of CBOs affiliated with ACCSES, a national provider association, to identify what key issues they faced and with what they were dealing. Many people with ID have high-risk health conditions and are at risk of contagion, especially when living on their own or in congregate-care settings. CBOs providing direct services noted experiencing contagion, lockdowns, loss of staff, challenges in obtaining PPEs, and lack of state or federal guidance. Maintaining safe living environments and coping with infected staff and clientele were urgent concerns. CBOs reported financial and clinical support challenges, as well as staffing problems. As the survey was undertaken in July 2020, following the period of stringent lock-downs and agency closures and during a period of re-openings, the data indicated that CBOs were re-emerging as providers and working hard to cope with conflicting advice and a lack of aid and clear guidelines from the national government.</p>
<p>Spreat, S., Cox, R., &amp; Davis, M.  <b>COVID-19 case &amp; mortality report – intellectual or developmental disabilities</b>          New York Alliance for Inclusion and Innovation, 2020.  <a href="https://www.ancor.org/sites/default/files/covid-19_case_and_mortality_report.pdf">https://www.ancor.org/sites/default/files/covid-19_case_and_mortality_report.pdf</a></p>	<p><b>Abstract:</b> COVID-19 data from eight states through May 31, 2020 analyzed in this report suggest that although the likelihood of an individual with I/DD being diagnosed was roughly equivalent to that of a member of the general public, they are substantially more likely to die from a COVID-19 infection. Executives from state I/DD provider associations requested data from their state for individuals with an I/DD diagnosis who are on Medicaid and served by either an I/DD HCBS waiver or an ICF/ID as of May 31, 2020: the total number of confirmed diagnoses, total number of deaths, and total number of individuals served. While state data regarding COVID-19 incidence within the general public are readily available, not all states appear to be tracking and maintaining data on incidence of infection and death specifically among individuals who have I/DD. Out of the states that were contacted, eight states included in this report provided the level of data required for a comparative analysis of COVID-19 incidence among individuals who have I/DD. Given their findings, the authors made the following recommendations:</p>

	<ol style="list-style-type: none"> <li>1. Given the higher risk factors associated with I/DD, service provider organizations need to receive enhanced reimbursement to provide increased compensation to the Direct Support Professionals (DSPs) who provide support to individuals who have I/DD and enhanced training.</li> <li>2. Given the substantially higher death rate for individuals with I/DD, persons with I/DD and DSPs must be prioritized for receipt of any approved vaccine for COVID-19.</li> <li>3. In anticipation of the continuation of COVID-19 infections (with the number of infections in some states rising lately), adequate Personal Protective Equipment (PPE) must be made available to organizations that support individuals with I/DD to ensure that both staff and individuals are protected; and the availability and funding for COVID-19 rapid testing for persons with I/DD and staff with direct contact with persons with I/DD.</li> <li>4. Because of the volatility of these data, additional research would be beneficial to attempt to ascertain causal mechanisms for the apparent discrepancy in fatality rate. Caution should be exercised in attributing causation at this time</li> </ol>
<p><b>Rabin, R.C.</b>  <b>Developmental disabilities heighten risk of Covid death</b>  <i>New York Times</i>, November 11, 2020.  <a href="https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html?action=click&amp;module=Top%20Stories&amp;pgtype=Homepage">https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html?action=click&amp;module=Top%20Stories&amp;pgtype=Homepage</a></p>	<p><b>Abstract:</b> Newspaper story on findings about the impact of COVID-19 on persons with developmental disabilities. Reporter notes that such findings raise complex questions about how to allocate new vaccines as they become available in limited supplies. She notes that “So far, guidelines for distributing vaccines have recommended prioritizing emergency workers, health care providers and other essential workers, as well as people at heightened risk for severe disease, including some older adults and those with certain chronic illnesses. The guidelines, which are still evolving, have not specifically emphasized the importance of prioritizing the vaccination of children and adults with intellectual disabilities like Down syndrome and developmental disorders.” She cites a report from FAIR Health, an organization that hosts “the nation’s largest private health insurance claims database” and reports that “FAIR Health set out to identify who is at greatest risk for dying of Covid-19 by reviewing health claims from nearly half a million Americans of all ages filed from April 1 through Aug. 31, and quoted a FAIR Health executive as noting that “What we find particularly new is the identification of developmental disorders and intellectual disabilities really surfacing to the top in terms of linkages between these categories of comorbidities and the risk of death,” The executive further was quoted as saying, “As we move toward approval of a vaccine, we’re identifying at-risk populations where you could either prioritize vaccine distribution or, prior to that, begin to give special attention to the care and treatment of these individuals knowing that they’re particularly vulnerable. The reported noted also that as “Vaccination will play a broader role beyond preventing infections. It will be critical to resuming education and the full array of treatments and other services for those with intellectual disabilities and developmental disorders, whose lives have been disrupted by the pandemic.”</p>

<p><b>Thompson, J.R., &amp; Nygren, M.A.</b>  <b>COVID-19 and the field of intellectual and developmental disabilities: Where have we been? Where are we? Where do we go?</b>  <i>Intellectual and Developmental Disabilities</i>. (2020), Aug 1;58(4):257-261. doi: 10.1352/1934-9556-58.4.257. PMID: 32750709</p>	<p><b>Abstract:</b> The coronavirus (COVID-19) pandemic has affected, and will continue to affect, every aspect of the intellectual and developmental disabilities (IDD) community. We provide recommendations to (a) support people with IDD and the broader of field of IDD during the course of the pandemic, and (b) place the IDD community in a strong position when the health threats associated with the pandemic abate and post-pandemic social and policy structures are formed.</p>
<p><b>Tummers, J., Catal, C., Tobi, H., Tekinerdogan, B., &amp; Leusink, G.</b>  <b>Coronaviruses and people with intellectual disability: An exploratory data analysis</b>  <i>Journal of Intellectual Disability Research</i>, 2020, 64(7), 475-481.  <a href="https://onlinelibrary.wiley.com/doi/full/10.1111/jir.12730">https://onlinelibrary.wiley.com/doi/full/10.1111/jir.12730</a></p>	<p><b>Abstract:</b> Corona virus disease 2019 (COVID-19) has been announced as a new coronavirus disease by the World Health Organization. At the time of writing this article (April 2020), the world is drastically influenced by the COVID-19. Recently, the COVID-19 Open Research Dataset (CORD-19) was published. For researchers on ID such as ourselves, it is of key interest to learn whether this open research dataset may be used to investigate the virus and its consequences for people with an ID. From CORD-19, we identified full-text articles containing terms related to the ID care and applied a text mining technique, specifically the term frequency-inverse document frequency analysis in combination with K-means clustering. Two hundred fifty-nine articles contained one or more of our specified terms related to ID. We were able to cluster these articles related to ID into five clusters on different topics, namely: mental health, viral diseases, diagnoses and treatments, maternal care and pediatrics, and genetics. The CORD-19 open research dataset consists of valuable information about not only COVID-19 disease but also ID and the relationship between them. We suggest researchers investigate literature-based discovery approaches on the CORD-19 and develop a new dataset that addresses the intersection of these two fields for further research.</p>
<p><b>Turk, M.A., Landes, S.D., Formica, M.K., &amp; Goss, K.D.</b>  <b>Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis.</b>  <i>Disability and Health Journal</i>, (2020). Jul;13(3):100942. doi: 10.1016/j.dhjo.2020.100942. Epub 2020 May 24. PMID: 32473875 PMCID: PMC7245650 DOI: 10.1016/j.dhjo.2020.100942</p>	<p><b>Abstract:</b> Despite possibly higher risk of severe outcomes from COVID-19 among people with intellectual and developmental disabilities (IDD), there has been limited reporting of COVID-19 trends for this population. Objective: To compare COVID-19 trends among people with and without IDD, overall and stratified by age. Methods: Data from the TriNetX COVID-19 Research Network platform was used to identify COVID-19 patients. Analysis focused on trends in comorbidities, number of cases, number of deaths, and case-fatality rate among patients with and without IDD who had a positive diagnosis for COVID-19 through May 14, 2020. Results: People with IDD had higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes. Distinct age-related differences in COVID-19 trends were present among those with IDD, with a higher concentration of COVID-19 cases at younger ages. In addition, while the overall case-fatality rate was similar for those with IDD (5.1%) and without IDD (5.4%), these rates differed by age: ages ≤17 - IDD 1.6%, without IDD &lt;0.01%; ages 18-74 - IDD 4.5%, without IDD 2.7%; ages ≥75- IDD 21.1%,</p>

	<p>without IDD, 20.7%. Conclusions: Though of concern for all individuals, COVID-19 appears to present a greater risk to people with IDD, especially at younger ages. Future research should seek to document COVID-19 trends among people with IDD, with particular attention to age related trends.</p>
<p> <a href="#">Villani, E.R., Carfi, A., Di Paola, A., Palmieri, L., Donfrancesco, C., Lo Noce C., Taruscio, D., Meli, P., Salerno, P., Kodra Y., Pricci, F., Tamburo de Bella, M., Florida, M., Onder, G., &amp; Italian National Institute of Health COVID-19 Mortality Group</a>  <b>Clinical characteristics of individuals with down syndrome deceased with CoVID-19 in Italy-A case series.</b>  <i>American Journal of Medical Genetics Part A.</i>, 2020, Dec, 182(12), 2964-2970.        doi: 10.1002/ajmg.a.61867. Epub 2020 Sep 12.     </p>	<p><b>Abstract:</b> Persons with Down syndrome (DS) are presumed to be at high risk of severe CoVID-19, due to immune dysregulation and often compromised cardiopulmonary function. Aim of the present study is to assess epidemiological and clinical characteristics of individuals with DS deceased in Italian hospitals with CoVID-19. We used a nationwide database of 3,438 patients deceased with RT-PCR-confirmed SARS-CoV-2 infection in Italy (10.4% of all deaths with CoVID-19 in the country at the time of analysis). Data on demographics, pre-existing comorbidities and in-hospital complications leading to death were extracted from medical charts obtained from hospitals. Data on individuals with DS deceased with CoVID-19 were obtained from this sample. Sixteen cases of death in individuals with DS (0.5% of all charts analyzed) were identified. Acute respiratory distress syndrome occurred in all 16 cases. Compared with individuals without DS, those with DS deceased with CoVID-19 were younger (<math>52.3 \pm 7.3</math> vs. <math>78.1 \pm 10.6</math> years, <math>p &lt; .001</math>) and presented a higher incidence of superinfections (31.2 vs. 13.0%, <math>p = .029</math>). Autoimmune diseases (43.8 vs. 4%, <math>p &lt; .001</math>), obesity (37.5 vs. 11%, <math>p = .009</math>), and dementia (37.5 vs. 16.3%, <math>p = .012</math>) were more prevalent in individuals with DS. ICU admissions was similar in both groups (25 vs. 18.8%, <math>p = .129</math>). Individuals with DS deceased with CoVID-19 are younger than individuals without DS. Comorbidity burden and increased risk of complications (i.e., bacterial superinfections) can influence CoVID-19 prognosis in individuals with DS. Specific strategies to prevent and mitigate the effects of CoVID-19 in the population with DS are needed.</p>
<p> <a href="#">Villani, E.R., Vetrano, D.L., Damiano, C., Di Paola, A.D., Ulgiati, A.M., Martin, L., Hirdes, J.P., Fratiglioni, L., Bernabei, R., Onder, G., &amp; Carfi, A.</a>  <b>Impact of COVID-19-related lockdown on psychosocial, cognitive, and functional well-being in adults with Down syndrome.</b>  <i>Frontiers in Psychiatry</i>, 2020, (Oct. 28), 11:578686,  <a href="https://doi.org/10.3389/fpsy.2020.578686">https://doi.org/10.3389/fpsy.2020.578686</a> </p>	<p><b>Abstract:</b> People with Down syndrome (DS) have a high prevalence of physical and psychiatric comorbidities and experience early-onset dementia. With the outbreak of CoVID-19 pandemic, strict social isolation measures have been necessary to prevent the spreading of the disease. Effects of this lockdown period on behavior, mood, and cognition in people with DS have not been assessed so far. In the present clinical study, we investigated the impact of CoVID-19-related lockdown on psychosocial, cognitive, and functional well-being in a sample population of 46 adults with DS. The interRAI Intellectual Disability standardized assessment instrument, which includes measures of social withdrawal, functional impairment, aggressive behavior, and depressive symptoms, was used to perform a three time-point evaluation (two pre-lockdown and one post-lockdown) in 37 subjects of the study sample, and a two time point evaluation (one pre- and one post-lockdown) in 9 subjects. Two mixed linear regression models – one before and one after the lockdown – have been fitted for each scale so as to investigate the change in the time-</p>

	<p>dependent variation of the scores. In the pre-lockdown period, significant worsening over time (i.e., per year) was found for the Depression Rating Scale score (<math>\beta = 0.55</math>; 95% CI 0.34; 0.76). In the post-lockdown period, a significant worsening in social withdrawal (<math>\beta = 3.05</math>, 95% CI 0.39; 5.70), instrumental activities of daily living (<math>\beta = 1.13</math>, 95% CI 0.08; 2.18) and depression rating (<math>\beta = 1.65</math>, 95% CI 0.33; 2.97) scales scores was observed, as was a significant improvement in aggressive behavior (<math>\beta = -1.40</math>, 95% CI <math>-2.69</math>; <math>-0.10</math>). Despite the undoubted importance of the lockdown to reduce the spreading of the CoVID-19 pandemic, the related social isolation measures suggest an exacerbation of depressive symptoms and a worsening in functional status in a sample of adults with DS. At the opposite, aggressive behavior was reduced after the lockdown period. This finding could be related to the increase of negative and depressive symptoms in the study population. Studies with longer follow-up period are needed to assess persistence of these effects.</p>
<p><b>World Health Organization (WHO). Disability considerations during the COVID-19 outbreak.</b> (2020).  <a href="https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1">https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1</a></p>	<p><b>Abstract:</b> [none – text from webpage]. Why are additional considerations needed for people with disability during the COVID-19 outbreak? Actions need to be taken to ensure that people with disability can always access the health-care services and public health information they require, including during the COVID-19 outbreak. People with disability may be at greater risk of contracting COVID-19 because of:</p> <ul style="list-style-type: none"> <li>● Barriers to implementing basic hygiene measures, such as handwashing (e.g. handbasins or sinks may be physically inaccessible, or a person may have physical difficulty rubbing their hands together thoroughly).</li> <li>● Difficulty in enacting social distancing because of additional support needs or because they are institutionalized.</li> <li>● The need to touch things to obtain information from the environment or for physical support.</li> <li>● Barriers to accessing public health information.</li> </ul> <p>Depending on underlying health conditions, people with disability may be at greater risk of developing more severe cases of COVID-19 if they become infected. This may be because of:</p> <ul style="list-style-type: none"> <li>● COVID-19 exacerbating existing health conditions, particularly those related to respiratory function, immune system function, heart disease or diabetes.</li> <li>● Barriers to accessing health care.</li> </ul> <p>People with disability may also be disproportionately impacted by the outbreak because of serious disruptions to the services they rely on.</p> <p>The barriers experienced by people with disability can be reduced if key stakeholders take appropriate action.</p>
<p><b>Willner, P., Rose, J., Stenfert Kroese, B., Murphy, G.H., Langdon, P.E., Clifford, C., Hutchings, H., Watkins, A., Hiles, S., &amp; Cooper, V.</b></p>	<p><b>Abstract:</b> The measures implemented to manage the COVID-19 pandemic have been shown to impair mental health. This problem is likely to be exacerbated for carers. Informal carers (mainly parents) of children and adults with intellectual disabilities, and a comparison group of parents of children</p>

<p> <b>Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities.</b>  <i>Journal of Applied Research in Intellectual Disabilities</i>, (2020), Sep 4. doi: 10.1111/jar.12811. PMID: 32885897 DOI: 10.1111/jar.12811         </p>	<p>           without disabilities, completed an online questionnaire. Almost all the data were collected while strict lockdown conditions were in place. Relative to carers of children without intellectual disability, carers of both children and adults with intellectual disability had significantly greater levels of a wish fulfilment coping style, defeat/ entrapment, anxiety, and depression. Differences were 2-3 times greater than reported in earlier pre-pandemic studies. Positive correlations were found between objective stress scores and all mental health outcomes. Despite their greater mental health needs, carers of those with intellectual disability received less social support from a variety of sources. The greater mental health needs of carers in the context of lesser social support raises serious concerns.         </p>
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