# Bibliography – COVID-19 and Intellectual Disability

### Version 1-14-21

Note: The development of this resources is supported by a grant from the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, The Healthy Brain Initiative Award #1 NU58DP006782-01-00. The contents are solely the responsibility of the authors and do not represent the official views of CDC.

Note – this working bibliography also contains unpublished or non-peer reviewed materials, as well as some relevant media articles.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.

Acknowledgement – A grant from the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, The Healthy Brain Initiative Award #1 NU58DP006782-01-00 supported the development of this resource. Contents are solely the responsibility of the authors and do not represent the official views of CDC.

## Citation

<table>
<thead>
<tr>
<th>Citation</th>
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<td>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. <strong>Guidance for the treatment and management of COVID-19 among people with intellectual disabilities.</strong> <em>Journal of Policy and Practice in Intellectual Disabilities</em>, (2020), 17(3), 256-269. <a href="https://doi.org/10.1111/jppi.12352">https://doi.org/10.1111/jppi.12352</a></td>
<td><strong>Abstract:</strong> 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.</td>
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| Avalere Health **Impact of COVID-19 on organizations serving individuals with intellectual and developmental disabilities.** Washington, DC: Avalere Health (2020). April 2020. | **Abstract:** [none – taken from text of report]. 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:

- 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%.
- 52% of all organizations surveyed reported having increased staff overtime expenses.

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%).

**Ayers, K., Fober-Pratt, A., Kushalnagar, P., & Pilarski, C.**

*How COVID-19 impacts people with disabilities*


**Extract from text:** Emerging research on COVID-19 shows that the coronavirus pandemic has increased psychological distress both in the general population and among high-risk groups. Behaviors such as physical distancing, as well as their social and economic impacts, are worsening mental health consequences. Research on the psychological impact of mass trauma (e.g., natural disasters, flu outbreaks) suggests that the pandemic might particularly harm the mental health of marginalized populations who have less access to socioeconomic resources and supportive social networks (e.g., Goldmann & Galea, 2014). There are unique stressors and challenges that could worsen mental health for people with disabilities during the COVID-19 crisis. Research on past pandemics shows that disabled people find it harder to access critical medical supplies which can become even more challenging as resources become scarce (Campbell, Gilyard, Sinclair, Sternberg, & Kailes, 2009). Some people with disabilities report higher levels of social isolation than their nondisabled counterparts (O’Sullivan & Bourgin, 2010). They may experience intensified feelings of loneliness in response to physical distancing measures. Social isolation and loneliness have been associated with increases in heart disease, dementia and other health problems according to the National Academies of Science, Engineering, and Medicine. Furthermore, policies around rationing of medical care can intensify discriminatory attitudes towards disabled individuals during times of crisis (Priestley & Hemingway, 2006). This can understandably worsen your anxiety about getting sick and needing to seek medical care. As the virus continues to spread, data is critical to informing the public health response. While adequate research on the specific impact of COVID-19 on the disability community is not yet available, several studies are underway or in planning phase. Data is needed on rates of infections, hospitalizations, outcomes and deaths disaggregated by disability, age, race and income, among other factors, so we can understand the impact of COVID-19 on multiple vulnerable groups. It is important not to conflate health status with disability. Many people with disabilities are healthy. However, some have underlying or secondary aspects...
of their disability, like suppressed immune systems or respiratory concerns, that COVID-19 could worsen. Some have underlying acute health conditions, such as skin breakdown or urinary tract infection, which increases risk of severe symptoms associated with COVID-19. Being classified as “high risk” in the current pandemic can cause additional stress and fears. The social gradient of risk may influence policies and decision-making related to access to care or treatments. Medical discrimination is always a dangerous reality for many people with disabilities in need of healthcare. Many disabled adults (60% report being “very concerned” in a recent survey - National Disability Institute, 2020) and disability rights organizations are anxious about how these policies may prevent them from getting equitable and fair treatment.

**Bradley, V.J.**

*How COVID-19 may change the world of services to people with intellectual and developmental disabilities.*


https://doi.org/10.1352/1934-9556-58.5.355

**Abstract:** 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.

**Callea, M., Cammarata-Scalisi, F., Galeotti, A., Villani, A., & Valentini, D.**

*COVID-19 and Down syndrome.*


https://doi.org/10.1111/apa.15409

**Abstract:** [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,1 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 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.


Abstract: [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:

- 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.
- 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.
- 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.
- Make a photocopy of prescriptions, as this may help in obtaining medications in an emergency.


Abstract (none - quoted from Discussion): 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
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<td>Annals of Internal Medicine, (2020), 21 October 2020 (Letters). <a href="https://doi.org/10.7326/M20-4986">https://doi.org/10.7326/M20-4986</a></td>
<td>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 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.</td>
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<td>Constantino, J.N., Sahin, M., Piven, J., Rodgers, R., &amp; Tschida, J. The impact of COVID-19 on individuals with intellectual and developmental disabilities: Clinical and scientific priorities. American Journal of Psychiatry, (2020), Aug 28;appiajp2020020060780. 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>)</td>
<td>Abstract: [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.</td>
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<td>Courtenay, K. Covid-19: challenges for people with intellectual disability BMJ 2020; 369 doi: <a href="https://doi.org/10.1136/bmj.m1609">https://doi.org/10.1136/bmj.m1609</a> (Published 29 April 2020)</td>
<td>Abstract: People with intellectual disability are vulnerable in society because of their dependence on support from services and other people.1 The prevalence of physical and mental disorders is higher among people with intellectual disability than other people across the age span. The current pandemic poses specific challenges to people with intellectual disability and their carers that include minimizing the risk of infection; access to information on the disease; risks of home support breaking down due to infection of the person or support staff; risk of increased agitation and distress; and placement breakdown because of behavioral challenges. The rapid</td>
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changes in support structures, such as daytime support provided by local authorities in the UK, is affecting people with intellectual disability and people with autism who find it difficult to tolerate changes in their lives. Families often rely on this daily support for their own wellbeing and to continue their employment. Psychiatrists working with people with intellectual disability are seeing a rise in requests for psychotropic medication to support people and to assist families and carers manage behaviors that are challenging to them. Self-isolating or shielding a person with intellectual disability for 12 weeks is an immense challenge for families and services, especially when such support might contravene a person’s human rights and liberty. Adaptive measures are being used by support services and clinicians to ensure continuity of care and to maintain people living in the community. To be successful, such efforts will require a willingness by all agencies to collaborate in supporting services and families to reduce the risk of infection and the impact that environmental changes have on the person.


Abstract: 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 people with ID and their carers to face future outbreaks of infectious diseases.


Abstract: 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 disproportionally 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.


Abstract: 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.


Abstract: 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 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.

**Department of Health & Social Care (UK)**
**Coronavirus (COVID-19): guidance for care staff supporting adults with learning disabilities and autistic adults**
**UK DH&SC, November 5, 2020**

**Abstract:** 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 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.

**Desroches, M.L., Ailey, S., Fisher, K., & Stych, J.**

**Abstract:** People with developmental disabilities (DD) are a population at high-risk for poor outcomes related to COVID-19. COVID-19-specific risks, including greater comorbidities and congregate living situations in persons with DD compound
Impact of COVID-19: Nursing challenges to meeting the care needs of people with developmental disabilities


Existing health disparities. With their expertise in care of persons with DD and understanding of basic principles of infection control, DD nurses are well-prepared to advocate for the needs of people with DD during the COVID-19 pandemic. To assess the challenges faced by nurses caring for persons with DD during the COVID-19 pandemic and how the challenges impact people with DD. We surveyed 556 DD nurses, from April 6-20, 2020. The 35-item mixed-method survey asked nurses to rate the degree of challenges faced in meeting the care needs of people with DD. We analyzed responses based on presence of COVID-19 in the care setting and geographically. One open-ended question elicited challenges not included in the survey, which we analyzed using manifest content analysis. Startlingly, nurses reported being excluded from COVID-19 planning, and an absence of public health guidelines specific to persons with DD, despite their high-risk status. Obtaining PPE and sanitizers and meeting social-behavioral care needs were the most highly ranked challenges. COVID-19 impacted nurses’ ability to maintain adequate staffing and perform essential aspects of care. No significant geographic differences were noted. DD nurses must be involved in public health planning and policy development to ensure that basic care needs of persons with DD are met, and the disproportionate burden of COVID-19 in this vulnerable population is reduced.

Drum, C. E., Oberg, A., Ditsch, J., Cooper, K., & Carlin, R.
COVID-19 & adults with serious difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injuries: Online survey report.

Abstract: The purpose of the COVID-19 & Disability (C-19 & D) Survey was to conduct a rapid, real-time online assessment of the coronavirus pandemic’s impact on access to health care and on adults with a range of disabilities, including people with serious difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injury. Some 2,469 adults with disabilities responded to the survey of which 930 experienced serious difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injury. A high proportion of the sample used Direct Care Worker services (72%), particularly considering that 80% of the adult sample were 18-44 and 18% of the adult sample were 45-64. While most respondents (76%) continued to receive these services during the pandemic, nearly one-quarter of the sample (24%) had lost critical care services. For the fortunate respondents maintaining their Direct Care Worker services, maintaining safe distances was impossible for half of the sample (50%). A high proportion of the sample used Direct Care Worker services (72%). While most respondents (76%) continued to receive these services during the pandemic, the loss of these services among 24% of the sample could contribute to major care issues. Moreover, the lack of safe distancing among 50% of respondents receiving Direct Care Work services could increase pandemic infection rates. Strategies for developing safeguarding information for both the sample and their care providers is needed. Of concern is that 55% of respondents
who were scheduled to receive regular health care treatment services had those services disrupted during the coronavirus pandemic. In contrast, 98% of respondents taking medications reported that they could access their prescriptions. Yet, for the 2% of the sample who had prescription medication access disrupted, this represents a potentially life-threatening situation.

Espinosa, J.M.
Down syndrome and COVID-19: a perfect storm?

Abstract: 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.

Eusebio, K.
‘I hope he doesn’t feel too lonely’ – COVID-19 hit people with intellectual disabilities hard

Extract from article: The loneliness reported by many people with intellectual disabilities has been exacerbated by quarantine.
- The lockdown means sudden deprivation of specialized services and work opportunities.

- Issues over rationing of care further increase the current worry and fear.
- While many people are experiencing isolation, anxiety, and loneliness during this challenging time, we know that prior to COVID-19, 45% of people with intellectual disabilities reported feeling lonely (that’s compared to only 10.5% of the general population). The increased pressures living in quarantine can result in challenges to mental health, sleep disruptions and mood swings. We know that loneliness is correlated with serious health risks such as heart disease, weakened immune systems and stroke. For people with intellectual disabilities who had already long experienced loneliness and social ostracization, what significant impacts might this have on their mental and physical health? Many COVID-19 patients die alone. For people with intellectual disabilities already experiencing severe loneliness, this fact seems particularly cruel. People with intellectual disabilities often utilize resources such as home health aides, day programmes, drop-in centres, family respite services and group homes. For health and safety reasons, many of these services are now unavailable or closed, increasing the responsibility of family members, affecting the routine of people with intellectual disability, and significantly impacting their independence. My brother is not able to go to his state-funded part-time job, removing his interaction with others outside of our immediate family and taking away the sense of purpose he felt by doing work. These COVID-19-related service changes also reveal the complex interdependencies with families, caregivers and staff that most people with intellectual disabilities depend on in their day-to-day lives. In China, a family made headlines when a teenager with cerebral palsy died in Wuhan after his father and brother, diagnosed with coronavirus, were quarantined in a treatment facility and unable to care for him. Some people with intellectual disabilities are not able to quarantine alone or stay with their families due to their enhanced medical or behavioral needs. Remaining in group homes or similar long-term care facilities can allow people with intellectual disabilities access to the care they need, but may put them at a much greater risk of infection. For people with intellectual disabilities who live independently or semi-independently but rely on home health aides, they and their families weigh the risk of exposing themselves to infection or not receiving the daily life supports they need.

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<td>Developmental disorders top the medical conditions that heighten the risk of dying from Covid-19</td>
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<td>STAT (Reporting from the frontiers of health and medicine), November 11, 2020</td>
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**Abstract:** 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).

[Abstracted from: Risk Factors for COVID-19 Mortality among Privately Insured Patients – 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.

Health care of adults with intellectual and developmental disabilities in a time of COVID-19. 
Canadian Family Physician, April 9, 2020, Blog Post. 
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:
● 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.
● 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.
● 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.
● 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.
● 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 currently. If a substitute decision maker is required for a health care decision, it is important they are accessible to hospital staff.


An international survey on the impact of COVID-19 in individuals with Down syndrome
https://doi.org/10.1101/2020.11.03.20225359

Abstract: 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 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 (p<0.01), whereas altered consciousness/confusion were reported more frequently (p<0.01). 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.


*Changes in access to educational and healthcare services for individuals with intellectual and developmental disabilities during COVID-19 restrictions.*

*Journal of Intellectual Disability Research, 2020, 64(11), 825–833.* https://doi.org/10.1111/jir.12776

**Abstract:** COVID-19 restrictions have significantly limited access to in-person educational and healthcare services for all, including individuals with intellectual and developmental disabilities (IDDs). The objectives of this online survey that included both national and international families were to capture changes in access to healthcare and educational services for individuals with IDDs that occurred shortly after restrictions were initiated and to survey families on resources that could improve services for these individuals. Authors used an online survey of caregivers of individuals with (1) a genetic diagnosis and (2) a neurodevelopmental diagnosis, including developmental delay, intellectual disability, autism spectrum disorder or epilepsy. The survey assessed (1) demographics, (2) changes in access to educational and healthcare services and (3) available and preferred resources to help families navigate the changes in service allocation. Of the 818 responses (669 within the USA and 149 outside of the USA), most families reported a loss of at least some educational or healthcare services. Seventy-four per cent of parents reported that their child lost access to at least one therapy or education service, and 36% of respondents lost access to a healthcare provider. Only 56% reported that their child received at least some continued services through tele-education. Those that needed to access healthcare providers did so primarily through telemedicine. Telehealth (both tele-education and telemedicine) was reported to be helpful when available, and caregivers most often endorsed a need for an augmentation of these remote delivery services, such as 1:1 videoconference sessions, as well as increased access to 1:1 aides in the home. COVID-19 restrictions have greatly affected access to services for individuals with syndromic IDDs. Telehealth may provide opportunities for delivery of care and education in a sustainable way, not only as restrictions endure but also after they have been lifted.

**Kavanagh, A., Dickinson, H., Carey, G. Llewellyn, G. Emerson, E., Disney, G. & Hatton, C.**


**Abstract:** COVID-19 has exacerbated pre-existing difficulties children and adults with disability face accessing quality health care. Some people with disability are at greater risk of contracting COVID-19 because they require support for personal care and are unable to physically distance (e.g., those living in congregate settings). Additionally, some people with disability have health conditions that put them at higher risk of
**Disability and Health Journal.** Advance online publication, December 5, 2020, https://doi.org/10.1016/j.dhjo.2020.101050

Poor outcomes if they become infected. Despite this, governments have been slow to recognize, and respond to, the unique and diverse health care needs of people with disability during COVID-19. While some countries, including Australia, have improved access to high-quality health care for people with disability others, like England, have failed to support their citizens with disability. In this Commentary, the authors address the health care responses of England and Australia and make recommendations for rapidly improving health care for people with disability in the pandemic and beyond.

Landes, S.D., Turk, M.A., & Wong, A.W.W.A.


Abstract: People with intellectual and developmental disabilities (IDD) appear to be at greater risk for severe outcomes from COVID-19. The roles of congregate living and skilled nursing care needs is unclear. To determine the impact of residential setting and level of skilled nursing care on COVID-19 outcomes for people receiving IDD services, compared to those not receiving IDD services. Utilizing publicly available California data on COVID-19 outcomes for people receiving IDD services (early May through October 2, 2020), we determined outcomes based on seven types of residence, differentiated by number of residents and level of skilled nursing care provided. We compared these results to the larger California published outcomes. Compared to Californians not receiving IDD services, in general, those receiving IDD services had a 60% lower case rate, but 2.8 times higher case-fatality rate. COVID-19 outcomes varied significantly among Californians receiving IDD services by type of residence and skilled nursing care needs: higher rates of diagnosis in settings with larger number of residents, higher case-fatality and mortality rates in settings that provided 24-hour skilled nursing care. Diagnosis with COVID-19 among Californians receiving IDD services appears to be related to number of individuals within the residence, while adverse COVID-19 outcomes were associated with level of skilled nursing care. When data are available, future research should examine whether these relationships persist even when controlling for age and pre-existing conditions.

Landes, S.D, Turk, M.A., Formica, M.K., McDonald, K.E., & Stevens, D.


Abstract: 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 groups 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.


Abstract: [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 IDD. Those certifying death certificates need to accurately record IDD on the death certificate.


Abstract: Newspaper article describing situation faced by persons with ID during the COVID-19 pandemic involved with Independence Association, a provider organization in Brunswick, Maine. The article speaks to the impact of the suspension of on-site program activities and notes the financial impact on the provider and the effects of social isolation on the agency’s clientele. Author writes that “Independence Association helps nearly 450 children and adults with intellectual and developmental disabilities in the Midcoast and throughout Maine to live inclusively in their communities. Four of the most popular adult day programs supporting 145 adults, are closed, limiting clients’ ability to be out and about in said community. Staff and clients alike are struggling to keep spirits high.” Further, she quoted the agency’s director a saying “The COVID fatigue affects our population differently; when we’re under these types of restrictions, the people we support are more apt to have behavioral issues and more apt to be depressed... Being limited to the house, you get that natural sense of boredom, you remember that you’re separated from your family.” Noted also was that “Independence Association has about 40 clients in group homes and another 35 to 40 in apartments in the community living program, and while they’re receiving excellent care, the risks are still disproportionately high. Many live in group homes, require care that involves close proximity to others, and are medically fragile to begin with, with higher rates of underlying health conditions, especially lung and heart problems which make them especially susceptible to the virus.” The director was quoted as saying “, there’s a generalized malaise about the entire situation; they don’t see any light at the end of the tunnel.” The issue is compounded by significantly reduced staffing levels, a problem
for Independence Association long before but certainly exacerbated by the pandemic. To be fully operational, the organization needs 240 employees. Right now, there are about 170. In March, The Times Record reported that officials at the nonprofit closed three group homes last year and expect to close another three this year as they struggle to retain and recruit staff. Through MaineCare, the Independence Association is reimbursed for $11.22 an hour for a direct support professional. In Maine, the minimum wage is $12 per hour, and Independence Association pays a $13 starting wage for direct support professionals, paying the additional $1.78 out of pocket. In the last fiscal year, the organization lost roughly $550,000 in revenue. The director noted that the organization has been able to stay solvent partly based on previous smart decisions and assets officials have been able to save over the years, but primarily because of the employees who have stepped up the plate.

| Malle, L., Gao, C., Hur, C., Truong, H.Q., Bouvier, N.M., Percha, B., Kong, X-F., & Bogunovic, D. | Abstract: 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. |
| Individuals with Down syndrome hospitalized with COVID-19 have more severe disease | Genetics in Medicine, 2020, e-print on October 16, 2020, 1-5. https://www.nature.com/articles/s41436-020-01004-w.pdf?origin=ppub |

| Martin-Khan, M., Bail, K., Yates, M.W., Thompson, J., Graham, & Cognitive Impairment and COVID-19, Hospital Care Guidance Committee | Abstract: 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 |
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.

Abstract: 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 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
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.**  
**Intellectual disability raises COVID-19 death risk.**  

See also: People with intellectual disabilities are being hit hard by COVID-19  
Medical Press, June 8, 2020  

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

**Neece, C., McIntyre, L. L., & Fenning, R.**  
**Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities.**  

**Abstract:** The COVID-19 pandemic introduced challenges to families with young children with developmental delays. Beyond the widespread concerns surrounding illness, loss of employment and social isolation, caregivers are responsible for overseeing their children’s educational and therapeutic programs at home often without the much-needed support of professionals. The authors examined the impact of COVID-19 in 77 ethnically, linguistically, and socioeconomically diverse families with young children with intellectual and
developmental disabilities (IDDs) in California and Oregon (USA), who were participating in larger intervention studies. Parents responded to five interview questions about the impact of the pandemic, services for their child, silver linings, or positive aspects, coping and their concerns about the long-term impact of the pandemic. Parents reported that their biggest challenge was being at home caring for their children with the loss of many essential services. Parents reported some positive aspects of the pandemic, especially being together as a family. Although there were positive aspects of the situation, many parents expressed concern about long-term impacts of the pandemic on their children's development, given the loss of services, education, and social engagement opportunities. Results suggest that parents of young children with IDD report significant challenges at home during the pandemic. Professional support, especially during the reopening phases, will be critical to support family well-being and child developmental outcomes.

Nygren, M.A. & Lulinski, A. 

Abstract: This brief provides an overview of what the research to date reveals about people with intellectual and developmental disabilities (IDD), COVID-19, and vaccination. The research to date indicates that people with IDD (a) are more likely to be exposed to COVID-19 and have poorer COVID-19-related health outcomes than the general public; (b) are as likely as the general population to engage in preventive health strategies; and (c) have experienced massive disruption in health, home, and community services, exacerbating existing inequities in health care, and putting additional pressure on already over-taxed formal and informal support networks. Further the research to date underscores that people with IDD are (a) at higher risk for poor outcomes and have a higher incidence of COVID-19-related deaths than the general population, (b) just as likely as the general public to get childhood and adult vaccinations, and (c) undergoing substantial disruptions in crucial services which exacerbate existing inequities in health care and other supports and are further straining already overburdened paid and unpaid caregivers.

COVID-19 deaths in people with intellectual disability in the UK and Ireland: descriptive study. 
BJPsych Open, (2020), 6(5), 1-6, e123. DOI: https://doi.org/10.1192/bjo.2020.102

Abstract: 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 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.

Abstract: [text taken from summary of report] The Department of Health and Social Care reviewed available data on the deaths of people with intellectual [learning] disabilities (ID) in England during the COVID-19 pandemic. The review looked at: deaths from COVID-19 of people with ID, factors impacting the risk of death from COVID-19 of people with ID, and deaths in care settings of people with ID. Received were 623 reports of deaths of people with ID considered definitely or possibly COVID-19 related occurring between February and June 2020, suggesting an estimated national total of 956 deaths (a crude rate of 240 deaths per 100,000 adults with ID -- 2.3 times the rate in the general population for the same period). The estimated rate, adjusting for the likely level of under-notification, was 369 per 100,000 adults with ID, 3.6 times the rate in the general population. If people dying with ID status ‘not known’ are included the same proportion with ID as those for whom a status was recorded, there would have been 651 deaths of adults with ID, giving a rate of 254 per 100,000 population, 4 times the rate for adults without ID. In 2018 and 2019, 60% of deaths of people with ID occurred in hospital settings. In 2020, 82% of COVID-19 deaths, and 45% of deaths from other causes occurred in hospitals. In the general population a smaller proportion of COVID-19 deaths (63%) occurred in hospital. During the peak 3 weeks, number of deaths from all causes for people with ID was 3 times the average reported for the corresponding period in the 2 previous years. For the general population in the same weeks, the number was 2 times the average for the 2 previous years. COVID-19 deaths in people with ID were spread more widely across the adult age groups than in the general population. The 10-year age band with the largest number of deaths was 55 to 64 years for people with ID but over 75 for the general population. COVID-19 accounted for
54% of deaths of adults with ID in residential care in this period, slightly less than for people with ID generally, but still much more than in the general population. Data indicates that care homes looking after adults with ID were less likely than other care homes to have had COVID-19 outbreaks. This was likely to be related to the ID homes having fewer beds.

**Abstract:** The COVID-19 pandemic has caused many adults with intellectual/developmental disabilities (IDD) to lose their daily routines and social support, and as a result, many adults with IDD are increasingly reliant on their family caregivers. Siblings often play a crucial support role for their brothers and sisters with IDD. As such, this study aimed to describe the experiences of adult siblings of people with IDD during the COVID-19 pandemic. The Sibling Collaborative worked with researchers to codesign an online survey, completed by 91 people, exploring sibling supports and concerns during the COVID-19 pandemic. The survey also aimed to identify helpful resources for siblings during this time. The results showed that the majority of siblings are supporting their brother or sister with IDD during the COVID-19 pandemic and are concerned about the health and well-being of their brother/sister. The most common concern related to disruption of their brother's or sister's routine and activities. Although responses of older and younger siblings did not differ from each other, siblings whose brother or sister with IDD lived with family had some unique concerns relative to those whose siblings no longer lived with family. Siblings described how their own self-care and relationships with others, as well as support for their brother/sister, were particularly helpful during the COVID-19 pandemic. Siblings are providing key support to their brother or sister with IDD during the COVID-19 pandemic, and they too must be supported. Siblings should be included in efforts to disseminate resources targeting people with IDD and their feedback and input must be obtained. It is also important to include sibling mental wellness as caregiver supports are created and implemented. More research is needed to further understand how to support sibling caregivers.

**Sabatello, M. (moderator)**

**Best practices for patient-clinician communication for people with disabilities in the era of COVID-19: A Webinar.**

*Webinar hosted by the National Academies of Sciences, Engineering, and Medicine, June 19, 2020.*


**Abstract:** 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.

| Sabatello, M., Blankmeyer Burke, T., McDonald, K.E., & Appelbaum, P.S. | Abstract: 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 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. |


| Abstract: [text abridged from article] 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 COVID19 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.

Schuengel, C., Tummers, J., Embregts, P.J.C.M, & Leusink, G.L.

**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.**
*Journal of Intellectual Disability Research,* (2020), 64(11), 817-824. 21 September 2020 https://doi.org/10.1111/jir.12778

**Abstract:** 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 COVID-19 with the pre-COVID-19 period. The imposition of lockdown-measures coincided with a significant drop in incidents (total, P < .001; aggression, P = .008; unexplained absences, P = .008; and medication errors, P < .001). Incidents in total (P = .001) and with aggression (P < .001) then climbed from this initial low level, while medication errors remained stably low (P = .94). 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.


**Mental healthcare and service user impact of the COVID-19-pandemic: Results of a UK survey of staff working with people with intellectual disability and developmental disorders.**
(September 2, 2020) medRxiv. https://doi.org/10.1101/2020.09.01.20178848

**Abstract:** Very little is known about the impact of previous epidemics on the care of people with intellectual and developmental disabilities, particularly in terms of mental health services. The COVID-19 pandemic has the potential to exacerbate existing health inequalities as well as expose gaps in service provision for this vulnerable population group. We investigated the responses of 648 staff working in mental healthcare with people with intellectual disabilities and/or developmental disabilities. Participants contributed to a UK-wide online survey undertaken by the National Institute for Health Research Mental Health Policy Research Unit between 22nd April and 12th May 2020. Recruitment was via professional networks, social media and third sector organizations. Quantitative data describing staff experience over three domains (challenges at work, service user and carer problems, sources of help at work) were summarized and differences between groups explored using Chi square tests. Content analysis was used to organize qualitative data focusing on service changes in response to the pandemic. The majority of survey respondents worked in the NHS and in community...
mental health services. One third had managerial responsibility. Major concerns expressed by mental healthcare staff were: (1) difficulties for service users due to lack of access to usual support networks and health and social care services during the pandemic; and (2) difficulties maintaining adequate levels of support secondary to increased service user need. Staff reported having to quickly adopt new digital ways of working was challenging; nevertheless, free text responses identified remote working as the innovation that staff would most like to retain after the pandemic subsides. Understanding the experiences of staff working across different settings in mental healthcare for people with intellectual and developmental disabilities during the COVID-19 pandemic is essential in guiding contingency planning and fostering service developments to ensure the health of this vulnerable group is protected in any future disease outbreaks.

Sisrak, J., Janicki, M.P., Murphy, R., Marks, B., Buckley, T.
Impact of COVID-19 on provider organizations serving adults with intellectual and other disabilities.

Abstract: 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.

Spreat, S., Cox, R., & Davis, M.
COVID-19 case & mortality report – intellectual or developmental disabilities

Abstract: 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:

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.

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.

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.

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.

**Abstract:** 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

Rabin, R.C.
**Developmental disabilities heighten risk of Covid death**

**Abstract:** The COVID-19 pandemic has caused many adults with intellectual/developmental disabilities (IDD) to lose their daily routines and social support, and as a result, many adults with IDD are increasingly reliant on their family caregivers. Siblings often play a crucial support role for their brothers and sisters with IDD. As such, this study aimed to describe the experiences of adult siblings of people with IDD during the COVID-19 pandemic. The Sibling Collaborative worked with researchers to codesign an online survey, completed by 91 people, exploring sibling supports and concerns during the COVID-19 pandemic. The survey also aimed to identify helpful resources for siblings during this time. The results showed that most siblings are supporting their brother or sister with IDD during the COVID-19 pandemic and are concerned about the health and well-being of their brother/sister. The most common concern related to disruption of their brother’s or sister’s routine and activities. Although responses of older and younger siblings did not differ from each other, siblings whose brother or sister with IDD lived with family had some unique concerns relative to those whose siblings no longer lived with family. Siblings described how their own self-care and relationships with others, as well as support for their brother/sister, were particularly helpful during the COVID-19 pandemic. Siblings are providing key support to their brother or sister with IDD during the COVID-19 pandemic, and they too must be supported. Siblings should be included in efforts to disseminate resources targeting people with IDD and their feedback and input must be obtained. It is also important to include sibling mental wellness as caregiver supports are created and implemented. More research is needed to further understand how to support sibling caregivers.


**Abstract:** The attention of the world is focused on the coronavirus disease-2019 (COVID-19) pandemic. There is general awareness that certain groups are at greater risk. However, some other populations may be transparent and may not be receiving the attention they warrant. We focused on those with intellectual disability explaining why they are vulnerable during the current pandemic and require special attention. [Text from article >]: Lack of awareness and fear are major considerations in this population. People with IDD are exposed to news reports and social media. Unbalanced reporting, visually charged material, and even random overheard conversations may generate unbridled panic for which they or their caregivers are inadequately prepared to cope. What is the impact on children with IDD exposed to coronavirus who see their parents in masks avoiding interactions with them? Explanations that suffice for other children may be insufficient for them. Individuals with IDD may...
have difficulty expressing how they feel or discussing specific symptoms. They may come to medical attention late, and even when diagnosed, identification of warning signs such as dyspnea may be delayed with catastrophic consequences including those with rapid deterioration often characteristic of COVID-19. Given the challenges for individuals with IDD during the current pandemic, we recommend the following:
(1) When diagnostic resources are limited, those with IDD, because of their increased risk, should be given priority. (2) Increased efforts should be made to ensure that those with IDD have expeditious access to medical care. (3) Contingency plans be formulated to take care of these individuals either when they are in isolation or their caregivers are unavailable, (4) Ensure that there is sufficient inventory of medicines, nutritional supplements, and therapeutics needed for the duration of isolation. (5) Counsel Individuals with IDD about the importance of protective practices, such as avoiding large gatherings, and hygiene measures. (6) All efforts should be made to ensure that individuals with IDD are not subject to discrimination based on their disability.

**Thompson, J.R., & Nygren, M.A.**

**Abstract:** 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 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.

**Priority concerns for people with intellectual and developmental disabilities during the COVID-19 pandemic.** *BJPsych Open,* 2020, 6(6), e128. https://doi.org/10.1192/bjo.2020.122

**Abstract:** The approach taken to support individuals during the coronavirus disease 2019 (COVID-19) pandemic needs to consider the requirements of people with intellectual disabilities and/or autism, who represent a major vulnerable group, with higher rates of co-occurring health conditions and a greater risk of dying prematurely. To date, little evidence on COVID-related concerns have been produced and no report has provided structured feedback from the point of view of people with intellectual disabilities and/or autism or of their family/carers. Authors aimed to provide systemized evidence-based information of the priority concerns for people with intellectual disability and/or autism regarding the COVID-19 pandemic. To obtain information, senior representatives of major UK-based professional and service-user representative organizations with a stake in the care of people with intellectual disability and/or autism were contacted to provide a list of concerns across three domains: ‘mental health and challenging behavior’, ‘physical health and epilepsy’ and ‘social circumstances and support’. The feedback was developed into statements on frequently reported priorities. These statements were then rated independently by expert clinicians. A video-conference meeting to reconcile outliers and to generate a
consensus statement list was held. Overall, 32 organizations were contacted, of which 26 (81%) replied. From the respondent’s data, 30 draft consensus statements were generated. We found that there was initially strong consensus for seven statements (23%), increasing to 27 statements (90%) following video conferencing. These recommendations highlight the expectations of people with intellectual disability and/or autism in the current pandemic. This could support policymakers and professionals’ deliver and evidence person-centered care.

Tummers, J., Catal, C., Tobi, H., Tekinerdogan, B., & Leusink, G. 
Coronaviruses and people with intellectual disability: An exploratory data analysis 
Journal of Intellectual Disability Research, 2020, 64(7), 475-481. 

Abstract: 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.

Turk, M.A., Landes, S.D., Formica, M.K., & Goss, K.D. 

Abstract: 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 <0.01%; ages 18-74 - IDD 4.5%, without IDD 2.7%; ages ≥75- IDD 21.1%,

**Clinical characteristics of individuals with Down syndrome deceased with CoV1D-19 in Italy-A case series.**


**Abstract:** Persons with Down syndrome (DS) are presumed to be at high risk of severe CoV1D-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 CoV1D-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 CoV1D-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 CoV1D-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 CoV1D-19 were younger (52.3 ± 7.3 vs. 78.1 ± 10.6 years, p < .001) and presented a higher incidence of superinfections (31.2 vs. 13.0%, p = .029). Autoimmune diseases (43.8 vs. 4%, p < .001), obesity (37.5 vs. 11%, p = .009), and dementia (37.5 vs. 16.3%, p = .012) were more prevalent in individuals with DS. ICU admissions was similar in both groups (25 vs. 18.8%, p = .129). Individuals with DS deceased with CoV1D-19 are younger than individuals without DS. Comorbidity burden and increased risk of complications (i.e., bacterial superinfections) can influence CoV1D-19 prognosis in individuals with DS. Specific strategies to prevent and mitigate the effects of CoV1D-19 in the population with DS are needed.

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**Impact of CoV1D-19-related lockdown on psychosocial, cognitive, and functional well-being in adults with Down syndrome.**


**Abstract:** People with Down syndrome (DS) have a high prevalence of physical and psychiatric comorbidities and experience early-onset dementia. With the outbreak of CoV1D-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 CoV1D-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-
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 ($\beta = 0.55; 95\% \text{CI} \ 0.34; 0.76$).

In the post-lockdown period, a significant worsening in social withdrawal ($\beta = 3.05, 95\% \text{CI} \ 0.39; 5.70$), instrumental activities of daily living ($\beta = 1.13, 95\% \text{CI} \ 0.08; 2.18$) and depression rating ($\beta = 1.65, 95\% \text{CI} \ 0.33; 2.97$) scales scores was observed, as was a significant improvement in aggressive behavior ($\beta = −1.40, 95\% \text{CI} \ −2.69; −0.10$). Despite the undoubtful 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.

Wadman, M.
COVID-19 is 10 times deadlier for people with Down syndrome, raising calls for early vaccination
doi:10.1126/science.abg1795

Abstract: [news article – extract] Among groups at higher risk of dying from COVID-19, such as people with diabetes, people with DS stand out. If infected, they are five times more likely to be hospitalized and 10 times more likely to die than the general population, according to a large U.K. study published in October. Researchers suspect background immune abnormalities, combined with extra copies of key genes in people with DS—who have three copies of chromosome 21 rather than the usual two—make them more vulnerable to severe COVID-19. On 2 December, the United Kingdom’s Joint Committee on Vaccination and Immunization recommended prioritizing people with DS for speedy vaccination. But the more than 200,000 Americans with DS so far are not slated for early vaccination. Nor has the U.S. Centers for Disease Control and Prevention (CDC) included DS in its list of conditions it says boost the risk for severe COVID-19. Experts say the typical anatomy of people with trisomy 21, including large tongues, small jaws, and relatively large tonsils and adenoids, along with lax throat muscle tone, helps explain their higher rate of respiratory infections in general. But genetics may also make them particularly susceptible to SARS-CoV-2, the pandemic coronavirus. They have three copies of a gene on chromosome 21, TMPRSS2, which codes for an enzyme that the virus hijacks to help it enter human cells. The TMPRSS2 enzyme cleaves the spike protein that studs the virus’ surface, launching a series of steps that allows the virus to invade the host cell. The international Trisomy 21 Research Society has issued a pointed statement strongly calling for people with DS, especially those 40 and over, to be prioritized for early vaccination. In the United States, however, a panel advising CDC on vaccine prioritization has not yet defined the medically vulnerable groups that may be included in a second wave of vaccinations. Despite the new studies, a CDC spokesperson said: “At this time, there is not enough evidence to determine if adults with
| Willner, P., Rose, J., Stenfert Kroese, B., Murphy, G.H., Langdon, P.E., Clifford, C., Hutchings, H., Watkins, A., Hiles, S., & Cooper, V. | Abstract: 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 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. |
| World Health Organization (WHO). Disability considerations during the COVID-19 outbreak. (2020). https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1 | Abstract: 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:
- 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).
- Difficulty in enacting social distancing because of additional support needs or because they are institutionalized.
- The need to touch things to obtain information from the environment or for physical support.
- Barriers to accessing public health information.
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:
- COVID-19 exacerbating existing health conditions, particularly those related to respiratory function, immune system function, heart disease or diabetes.
- Barriers to accessing health care.
People with disability may also be disproportionately impacted by the outbreak because of serious disruptions to the services they rely on.
The barriers experienced by people with disability can be reduced if key stakeholders take appropriate action. |
| Zaagsma, M., Volkers, K. M., Swart, E.A.K., Schippers, A. P., & Van Hove, G. | Abstract: During the COVID-19 outbreak, service providers in the Netherlands had to switch towards providing remote... |
The use of online support by people with intellectual disabilities living independently during COVID-19

https://doi.org/10.1111/jir.12770

The use of online support by people with intellectual disabilities living independently during COVID-19

Journal of Intellectual Disability Research, 2020, 64(10), 750–756.
https://doi.org/10.1111/jir.12770

This study aimed to provide insight into the use of online support during the outbreak. Authors analyzed quantitative data on planned and unplanned contacts between the online support service DigiContact and its service users. The results indicate that the COVID-19 outbreak and the related containment measures had a strong impact on online support use, specifically on the unplanned use of online support.

Authors concluded that offering online support as a standard component of services for independently living people with intellectual disability enables service providers to be flexible and responsive towards fluctuations in both support needs and onsite support availability during a social crisis such as COVID-19.

V. 1-14-2021

Acknowledgement: A grant from the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, The Healthy Brain Initiative Award #1 NU58DP006782-01-00 supported the development of this resource. Contents are solely the responsibility of the authors and do not represent the official views of CDC.