ntg National Task Group on Intellectual Disabilities and Dementia Practices

HealthMatters™ Program

Bibliography – COVID-19 and Intellectual Disability

Version 1-6-23

Note – this working bibliography also contains unpublished or non-peer reviewed materials, as well as some relevant media articles.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 an aggregate of potential source matter for others. As some of the abstracts are terse and may represent extracts of key points from the publications, we strongly recommend reviewing the original source matter for exact content and wording. 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 (check version number). Making us aware of work that we omitted, or that is forthcoming, is most welcome; send a note to mjanicki@uic.edu. It is recommended checking the source sites for any updates of publications listed as e-print or advance online publication and not showing actual publication data.

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Citation	Abstract
Adamou, M., Jones, S.L., Fullen, T., Galab, N., Abbott, K., & Yasmeen, S. **Remote assessment in adults with autism or ADHD** *PLos One,* March 25, 2021 https://doi.org/10.1371/journal.pone.0249237 https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0249237	**Abstract:** Advances in digital health have enabled clinicians to move away from a reliance on face-to-face consultation methods towards making use of modern video and web-based conferencing technology. In the context of the COVID-19 pandemic, remote telecommunication methods have become much more common place in mental health settings. The current study sought to investigate whether remote telecommunication methods are preferable to face-to-face consultations for adults referred to an 'ADHD and Autism Service' during the COVID-19 pandemic. Also, whether there are any differences in preferred consultation methods between adults who were referred for an assessment of autism as opposed to ADHD. 117 service users who undertook assessment by the 'ADHD and Autism Service' at Southwest Yorkshire NHS Partnership Foundation Trust (UK) from April to September 2020 completed an adapted version of the Tele-health Usability Questionnaire (TUQ). Results demonstrated that service users found remote telecommunication to be useful, effective, reliable, and satisfactory. Despite this, almost half of service users stated a general preference for face-to-face consultations. There was no difference in the choice of methods of contact between Autism and ADHD pathways. Remote telecommunication methods were found to be an acceptable medium of contact for adults who undertook an assessment of autism and ADHD at an NHS Service during the COVID-19 pandemic.
Aishworiya, R., & Kang, Y.Q. **Including children with developmental disabilities in the equation during this COVID-19 pandemic** *Journal of Autism and Developmental Disorders,* 2020. [published 20 August) https://doi.org/10.1007/s10803-020-04670-6	**Abstract:** [*Abstract and text extracted from article*] Amidst the ongoing novel Coronavirus disease pandemic, children with developmental disabilities warrant specific attention to minimize having disproportionate consequences. These children are especially vulnerable to the effects of the pandemic due to (1) Greater healthcare needs, (2) Dependency on community-based services and (3) Mental health concerns. Healthcare professionals, public health systems and the society need to come together to advocate for these children by optimizing access to healthcare and community intervention services, promoting mental well-being and caregiver welfare.

	The consequences of missed present-day opportunities might only be evident in the years to come in these children. Hence, despite the prolonged pandemic, with consequent limitations in availability of resources, children with developmental disabilities should continue to be supported. The ongoing COVID-19 pandemic has highlighted social inequities and disproportionately affected certain groups including nursing home residents, prisoners, and migrant workers in the world today. Although COVID-19 amongst children was initially thought to be a mild disease with low incidence, the recent emergence of a possible COVID-19 associated multisystem inflammatory syndrome has re-shifted the focus back to children. However, there is a need to highlight that the pandemic has adverse health outcomes in children beyond the consequence of a viral infection. There has been insufficient attention paid to the mental, social, and emotional vulnerability of children during this pandemic. Children with developmental disabilities are especially vulnerable during this unprecedented period of change. As the world struggles to adapt to the ongoing pandemic, special consideration must be accorded to this group of children due to 3 key factors: (1) Greater health needs. (2) Dependency on community-based services, and (3) Mental health concerns. What can be done? 1.Maintaining access to outpatient diagnostic and intervention services; 2. Facilitating effective learning and therapy; and 3. Protecting mental health of children and caregivers Parents of children with disabilities have traditionally been the sole advocates for their children. During this pandemic where parents themselves are struggling more than ever, education, health, early intervention, and social services must keep these children in focus and collaborate to meet the challenges unique to this population of children.
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., & Langdon, P.E. **Guidance for the treatment and management of COVID-19 among people with intellectual disabilities**. *Journal of Policy and Practice in Intellectual Disabilities*, (2020), 17(3), 256-269. https://doi.org/10.1111/jppi.12352	**Abstract:** 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.
Altable, M., & de la Serna, J.M. **Down's syndrome and COVID-19: risk or protection factor against infection? A molecular and genetic approach** *Neurological Sciences* (Official journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology), 42(2), 407–413. https://doi.org/10.1007/s10072-020-04880-x	**Abstract:** Down syndrome (DS) is the most common genetic cause of learning difficulties and intellectual disabilities. DS patients often present with several congenital defects and chronic diseases, including immunity disorders. Elevated levels of pro-inflammatory cytokines such as interleukin (IL)-6 and tumor necrosis factor alpha (TNF-α) have been seen, which appear to vary with age. At birth, patients present with combined immunodeficiency, with frequent infections that decrease with age. Furthermore, high levels of IL-4 and IL-10 with anti-inflammatory properties and low levels of IL-6 and TNF-α are described in children. The immune system is believed to play an essential role in SARS-CoV-2 pathogenesis, and it has been associated with elevated levels of pro-inflammatory cytokines and an exaggerated cytokine release syndrome (CRS) that may eventually trigger a severe situation called cytokine storm. On the other hand, genetic features seem to be involved in the predisposition to illness and its severity. Overexpression of DSCR1 and ZAKI-4 inhibits the translocation of activated T lymphocyte nuclear factor (NF-AT) to the nucleus, a main step in the inflammatory responsiveness. Discussed is the possible role of immunology and genetic features of DS in the infection and prognosis in COVID-19.
Amin MA, Khan II, Nahin S, Bonna AS, Afrin S, Hawlader MDH. **COVID-19 hospitalization with later long COVID in a person with Down syndrome.** *Clinical Case Reports*. 2022 Oct 7, 10(10), e6425. doi: 10.1002/ccr3.6425. eCollection 2022 Oct.	**Abstract:** Viruses that induce pulmonary difficulties and auto-inflammation are more common in people with Down syndrome. They also have a higher number of comorbidities associated with a worse prognosis than the overall population. Adult patients with acute COVID-19 are increasingly being diagnosed with Long COVID. However, patients with Down syndrome with later long COVID-19 are the first example documented in Bangladesh.
Amor, A.M., Navas, P., Verdugo, M.A., & Crespo, M. **Perceptions of people with intellectual and developmental disabilities about COVID-19 in Spain: A cross-sectional study.** *Journal of Intellectual Disability Research*, 2021 [on-line version, 8 February 2021] https://doi.org/10.1111/jir.12821	**Abstract:** As the world battles COVID-19, there is a need to study the perceptions of people with intellectual and developmental disabilities (IDD) about the effects of the pandemic and associated lockdown on their lives. This work explores the perceptions of Spaniards with IDD during the lockdown with respect to four topics: access to information, emotional experiences, effects on living conditions and access to support. The topics were explored using a subset of 16 closed-ended questions from an online survey. In total, 582 participants with IDD completed the survey. The frequencies and percentages of responses to the questions were calculated, and chi-square tests performed to explore the relationship between participants' sociodemographic characteristics and responses. Given that people differed in the way in which they completed the survey, the relationship between participants'

	responses and completion method was also analyzed. Participants reported that the pandemic and subsequent lockdown have had a deleterious effect on their emotional well-being (around 60.0% of participants) and occupations (48.0% of students and 72.7% of workers). Although access to information and support was reportedly good overall, being under the age of 21 years and studying were associated with perceptions reflecting poorer access to information (V = .20 and V = .13, respectively) and well-being support (V = .15 and V = .13, respectively). Being supported by a third party to complete the survey was consistently related to perceptions of worse outcomes. The study yielded data on the perceptions of people with IDD regarding the effects that COVID-19 and the subsequent lockdown have had on their lives. Authors offer suggestions on how to overcome the difficulties reported and future lines of research
Avalere Health **Impact of COVID-19 on organizations serving individuals with intellectual and developmental disabilities.** *Avalere Health*, Washington, DC, April 2020. https://www.ancor.org/sites/default/files/impact_of_covid-19_on_organizations_serving_individuals_with_idd.pdf	**Abstract**: *[none – extracted from text*]. 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** *Psychology Topics/COVID-19*, May 6, 2020. https://www.apa.org/topics/covid-19/research-disabilities	**Abstract:** *[Extracted 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. 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. Some people with disabilities report higher levels of social

	isolation than their nondisabled counterparts. 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). 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 the 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 the 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.
Baez, D. **Patients with Down syndrome, COVID-19 have higher mortality rates than general population** NTK Institute, 2021 (July 26). https://ntk-institute.org/article/patients-with-down-syndrome-covid-19-have-higher-mortality-rates-than-general-population *AAIC Presentation title: COVID-19 and Older Adults With Down Syndrome: Presentation, Complications and Risk for Mortality*	**Abstract:** VIRTUAL -- July 26, 2021 -- Individuals with Down syndrome and coronavirus disease 2019 (COVID-19) present with significantly higher rates of medical complications and have higher mortality rates compared with the general population, especially from age 40 and on, according to a study presented at the Virtual 2021 Alzheimer's Association International Conference (AAIC). "Health conditions, including high rates of Alzheimer's disease, immune dysfunction, and premature aging associated with trisomy 21 may impact the clinical course of COVID-19," said Asaad Baksh, MD, King's College London. The T21RS COVID-19 Initiative launched an international survey for clinicians or caregivers on patients with COVID-19 and Down syndrome, with data on 1,046 patients collected between April 2020 and October 2020. Patients were compared with the UK ISARIC4C survey of hospitalized patients with COVID-19 without Down syndrome. Mortality rates in individuals with Down syndrome diagnosed with COVID-19 showed a rapid increase from age 40 and were considerably

	higher compared with patients hospitalized with COVID-19 without Down syndrome (risk ratio (RR) = 3.5; 95% confidence interval, 2.6-4.4), even after adjusting for known risk factors for COVID-19 mortality. Like the general population, the most frequent signs and symptoms of COVID-19 among patients with Down syndrome were fever, cough, and shortness of breath. Joint/muscle pain and vomiting or nausea were less frequent (P < .01), whereas altered consciousness/confusion were more frequent (P< .01). "The signs and symptoms of COVID-19 and risk factors for severe disease are similar to the general population," said Dr. Baksh. Risk factors for hospitalization and mortality included age, male gender, diabetes, obesity, and Alzheimer's disease, with the addition of congenital heart defects as a risk factor for hospitalization. "Those with dementia are at even greater risk, despite being younger than typical patients with Alzheimer's disease," said Dr. Baksh. "Individuals with Down syndrome should be prioritized for COVID-19 vaccination at younger ages than their peers in the general population."
Bailey, T., Hastings, R.P., & Totsika, V. **COVID-19 impact on psychological outcomes of parents, siblings, and children with intellectual disability: Longitudinal before and during lockdown design.** *Journal of Intellectual Disability Research,* 2021 [on-line version: 25 February 2021] https://doi.org/10.1111/jir.12818	**Abstract:** Parents of children with intellectual disability (ID) report comparatively lower levels of well-being than parents of children without ID. Similarly, children with ID, and to a lesser extent their siblings, are reported to show comparatively higher levels of behavior and emotional problems. Psychological problems may be accentuated by restrictions associated with the COVID-19 pandemic, due to increased social, caring, and economic stressors and reduced social support. However, existing studies have not been able to examine the impact of COVID-19 restrictions accounting for pre-COVID levels of well-being in these families. In a naturalistic design, we examined outcomes for parents, siblings, and children with ID in a two-wave longitudinal study where Wave 2 data were gathered for some families before and some during COVID-19 restrictions. Parents of children with ID who took part in a Wave 2 survey pre-lockdown (n = 294) and during/post-lockdown (n = 103) completed several measures about their well-being and the behavior and emotional problems of both their child with ID and their nearest-in-age sibling. These same measures had also been completed for all families 2–3 years previously in Wave 1 of the study. After accounting for covariates including family socio-economic circumstances, pre-lockdown and post-lockdown groups did not differ on Waves 1 to 2 change for measures of parental psychological distress, life satisfaction, the impact of caregiving on their lives or perceived positive gains: nor child or sibling internalizing or externalizing behavior problems. Findings of the current study indicate that during and shortly after the COVID-19 lockdown in the United Kingdom, well-being in families of children with an ID (as reported by parents) was at similar levels compared with prior to the lockdown period.
Belluck, P.	**Abstract:** Excerpted from newspaper article reviewing a study on post-infection physical and behavioral effects from COVID-19 undertaken by FAIR Health, a nonprofit dedicated to

After Covid, many people are struck with new ailments *New York Times,* Wednesday, June 16, 2021 (p. A14). https://www.nytimes.com/2021/06/08/business/aducanumab-alzheimers-cost.html See also: Fair Health. *An Analysis of Private Healthcare Claims: A Detailed Study of Patients with Long-Haul COVID.* A FAIR Health White Paper, June 15, 2021	bringing transparency to healthcare costs and health insurance information. The study found that the range of both those affected and the symptoms that struck them was wide. The health issues affected all ages, including children. The most common new health problems were pain; breathing difficulties; high cholesterol; malaise and fatigue; and high blood pressure. But symptoms did not stop there: Some suffered intestinal symptoms; migraines; skin problems; heart abnormalities; sleep disorders; and mental health conditions like anxiety and depression. Post-COVID health problems did not spare those who had not been seriously ill: While nearly half of patients who were hospitalized for COVID-19 experienced subsequent medical issues, so did 27 percent of people who had mild or moderate symptoms and 19 percent of people who said they were asymptomatic. The most common issue for which patients sought medical care was pain—including nerve inflammation and aches and pains associated with nerves and muscles. It was reported by more than a fifth of those who reported post-COVID problems. Breathing difficulties, including shortness of breath, were experienced by 3.5 percent of post-COVID patients. Nearly 3 percent of patients sought treatment for symptoms that were labeled with diagnostic codes for malaise and fatigue, a far-reaching category that could include issues like brain fog and exhaustion that worsens after physical or mental activity,
Bentenuto, A., Mazzoni, N., Giannotti, M., Venuti, P., & de Falco, S. **Psychological impact of Covid-19 pandemic in Italian families of children with neurodevelopmental disorders.** *Research in Developmental Disabilities,* 2021, Feb, 109, 103840. doi: 10.1016/j.ridd.2020.103840. Epub 2020 Dec 23.	**Abstract:** Research on the psychological impact of the COVID-19 pandemic highlighted negative effects on the general population and particularly on parents. However, little is known about families of children with Neurodevelopmental Disorder (NDD). The present study investigated parental stress, coparenting, and child adjustment in Italian families with children with NDD (N = 82) and typical developing children (TD, N = 82) during lockdown, using an online survey. Results of quantitative analyses showed a significant increase in parental stress and child externalizing behaviors, but not of coparenting. Parental stress is predicted by externalizing behaviors, and coparenting acted as a moderator in the relationship between the change in the amount of time spent with the children before and during lockdown and parental stress. In children with NDD, the decrease in therapeutic/rehabilitation support predicted higher externalizing behaviors. Qualitative analysis showed that beyond the difficulties and worries arising during lockdown, most of the parents appreciated the opportunity of spending more time with their children and strengthening the parent-child relationship. In conclusion, our results point out the importance of ensuring continuity of care for children with NDD (e.g., telehealth) during home confinement and of providing psychological support for parents.
Bertelli, M.O., Scuticchio, D., Bianco, A., Buonaguro, E.F., Laghi, F., Ghelma, F., Rossi, M., Vannucchi, G., Cavagnola, R., Chiodelli, G., Corti, S., Leoni, M., Gusso, S., Cappa, C.,	**Abstract:** The people most at risk of becoming seriously ill from being infected with COVID-19 are the elderly, people with underlying diseases such as hypertension, heart problems or diabetes, and patients who taking medicines that inhibit the functioning of the immune system (immunosuppressants).

Filighera, L., Simone, S., Zunino, M., Belotti, R., Perrone, F., DiSarro, R., Keller, R., Arduino, M., Brondino, N., Politi, P., Boschetto, M., Lupi, M., Lo Presti, E., Scattoni, M.L. **Tips for dealing with the psychological effects in people with intellectual disabilities and / or autism of the measures against the spread of the coronavirus in the Netherlands** [Tips voor het omgaan met de psychologische effecten bij mensen met een verstandelijke beperking en/of autisme van de maatregelen tegen de verspreiding van het coronavirus in Nederland] https://www.kennispleingehandicaptensector.nl/gehandicaptensector/media/documents/Thema's/Gezondheid/coronavirus-omgaan-psychologische-effecten-mensen-verstandelijke-beperking-autisme.pdf *Dutch translation and adaptation of report originally published in Italy by the SIDIN [Societa Italiana per I Disturbi del Neurosviluppo]. Translated and adapted for the Dutch situation by Dr. J. Wieland, LVB en GGZ, Cordaan (Amsterdam, NL)*	Having an intellectual disability or autism does not in itself seem to be a risk factor for it for (becoming seriously ill with) COVID-19, although specific epidemiological data are not yet available. People with an intellectual disability or autism have about 2-3 times more often additional diseases and / or physical disorders than the general population. Some of these illnesses can make them more vulnerable to developing more serious forms of COVID-19. For example, according to some researchers of previous respiratory viral infections, people with Down's syndrome may be extra vulnerable to developing complications with COVID-19. In consultation with RIVM and other experts, the national government has taken various measures against the spread of the corona virus in the Netherlands. These measures have important consequences for the care of people with an intellectual disability and / or autism, for example by closing daycare locations, limiting visits and the cancellation of treatment and / or support contacts. Original Italian title: “Consigli per la gestione dell'epidemia COVID-19 e dei fattori di distress psichico associati per le persone con disabilità intellettiva e autismo con necessità elevata e molto elevata di support” https://www.sidin.org/wp-content/uploads/2020/04/scudo-al-COVID-19-per-PcDI_A_SIDiN_v-1_6_def.pdf
Bishop, K. M. **A perspective on Covid-19, dementia, and intellectual disabilities** *Global Journal of Intellectual & Developmental Disabilities*, 2020, Dec, 7(2). DOI: 10.19080/GJIDD.2020.07.555710	**Abstract:** The impact of the COVID – 19 pandemics has affected the lives of billions of people around the world closing entire countries, isolating people from each other, and changing the day-to-day routines and habits. The US has been particularly hard hit economically, high loss of life, and the unknown lasting effects from the virus. Older adults have been particularly affected as the known risk factors such as cardiac disease, diabetes, and lung disease is more common in older adults. Especially vulnerable group of people negatively affected by this disease has been older adults with intellectual disabilities (ID) and a diagnosis of Alzheimer’s disease and related dementias. Their caregivers have also been challenged with attempting to provide health care supports, residential care, and activities of daily living during a time of so many unknowns and losses.
Buono, S., Zingale, M., Città, S. Mongellia, V., Trubia, G., Mascalia, G., Occhipinti P., Pettinato, E., Ferri, R., Gagliano, C., & Greco, D. **Clinical management of individuals with Intellectual Disability: The outbreak of**	**Abstract:** During the COVID-19 pandemic, the Oasi Research Institute of Troina (Italy) became an important hotbed for infection; in fact, 109 patients with different levels of intellectual disability (ID) tested positive for COVID-19. The procedures and interventions put in place at the Oasi Research Institute due to the COVID-19 pandemic are reported in this paper. The description of the clinical procedures as well as

Covid-19 pandemic as experienced in a clinical and research center *Research in Developmental Disabilities,* 2021, Mar, 110, 193856 https://www.sciencedirect.com/science/article/abs/pii/S0891422221000056	remote/in person psychological support services provided to people with ID and their families are divided into three different sections: Phase I (or Acute phase), Phase II (or Activity planning), and Phase III (or Activity consolidation). In each section are covered the main psycho-pathological characteristics of patients, the reactions of family members, and the multidisciplinary interventions put in place.
Buonaguro, E.F., & Bertelli, M.O. **COVID-19 and intellectual disability/autism spectrum disorder with high and very high support needs: issues of physical and mental vulnerability** *Advances in Mental Health and Intellectual Disabilities*, 2021, 15(1), 8-19. https://doi.org/10.1108/AMHID-07-2020-0016 .	**Abstract:** The COVID-19 outbreak has profoundly plagued the world, and current health efforts are focused on providing prevention and ensuring access to intensive services for people with the most severe symptomatology. Many reports have already described substantial psychological distress in the general population. Nevertheless, disasters tend to affect vulnerable subjects disproportionately, and individuals with intellectual disabilities/autism spectrum disorder with high and very high support needs (PwID/ASD-HSN) seem to be counted among the hardest hit populations. The present paper aims to provide a comprehensive discussion and evaluation of COVID-19 related issues specific to PwID/ASD-HSN. Commentary on available literature and analysis of new preliminary data on PwID/ASD-HSN's physical and psychic vulnerability factors. This knowledge is fundamental to providing families and caregivers special advice to counteract the risks associated with the current pandemic. PwID/ASD-HSN represent one of the most vulnerable population to the COVID-19 outbreak and the associated factors of mental distress for several reasons, including multimorbidity, low levels of health literacy, difficulties to understand and communicate, reliance on other people for care, low compliance with complex hygiene rules, the strong need of routine/sameness and low adaptive skills. In this article, the authors analyze the specific factors of physical and mental vulnerability in PwID/ASD-HSN, corroborating the dissertation with a discussion on the first data published worldwide and with preliminary data collected on the Italian territory for what concerns prevalence rates of COVID-19 and complications in persons with PwID/ASD-HSN and signs and symptoms of psychic distress during the mass quarantine period.
Bove, S.M., Basso, M., Bianchi, M.F., Savaré, L., Ferrara, G., Mura, E., Redaelli, M.G., Olivieri, I., & Veggiotti, P. **Impact of COVID-10 lockdown in children with neurological disorders in Italy.** *Disability and Health Journal*, 2021, 14(2). 101053. https://doi.org/10.1016/j.dhjo.2020.101053	**Abstract:** The costs and benefits of full lockdown measures are debated. Neurologically impaired children are a vulnerable population with specific needs in terms of protection against infection and access to health services. The authors investigated the effects of lockdown on the health of children with neurological disorders and on their access to care during lockdown. Data from 514 children (282 males – 232 females) were collected through physician-administered interviews to investigate: the occurrence of viral-like physical symptoms, the correlation between the risk of developing such symptoms and several demographic and clinical variables, the occurrence of any worsening of the children's neurological conditions during lockdown, and their access to care services during this period. 49.1% experienced at least one symptom during the study

	period, but no child developed severe complications. The prevalence of symptoms was significantly lower during lockdown than during the previous two months. The underlying neurological condition worsened in 11.5% of the patients. Children who regularly left the home during lockdown were greater risk of exhibiting symptoms. During lockdown, 67.7% had a specialist appointment cancelled, 52.6% contacted their pediatrician, and 30.9% contacted their child neuropsychiatrist. Among patients who usually receive rehabilitation, 49.5% continued remotely. Lockdown protected children from infections. Telemedicine and telerehabilitation constituted a valid alternative for the care and treatment of these children, but they should not become a widespread and definitive model of care. COVID-19 and other emergency response plans must consider the specific needs of children with disabilities.
Boyle, C.A., Fox, M.H., Havercamp, S.M., & Zubler, J. **The public health response to the COVID-19 pandemic for people with disabilities** *Disability and Health Journal,* 2020 (July), 13(3),100943 https://doi.org/10.1016/j.dhjo.2020.100943	**Abstract:** With the rapidly changing landscape of the COVID-19 outbreak, how to best address the needs and continue to protect the health and well-being of people with disabilities (PwDs) is a global public health priority. In this commentary we identify three public health areas of ongoing need and offer possible strategies to address each. These areas include: the types of data that would help clarify risks for PwDs and help assure their safety long term; the prevention, treatment, and mitigation measures for PwDs that are needed through the duration of the outbreak; and the issues of equity in access to and quality of medical care for PwDs. Because of the rapid nature of the public health response, it is critical to reassess and readjust our approach to best address the needs of PwDs in the months and years to come and to incorporate these new practices into future emergency preparedness responses.
Bradley, V.J. **How COVID-19 may change the world of services to people with intellectual and developmental disabilities.** *Intellectual and Developmental Disabilities*, 2020, 58(5), 355-360. 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.
Brooks JM, Patton C, Maroukel S, Perez AM, Levanda L. **The differential impact of COVID-19 on mental health: Implications of ethnicity, sexual orientation, and disability status in the United States.** Front Psychol. 2022 Sep 13;13:902094. doi: 10.3389/fpsyg.2022.902094. PMID: 36176783; PMCID: PMC9513514.	**Abstract:** The COVID-19 pandemic's effects on mental health interact with preexisting health risks and disparities to impact varying populations differently. This study explored the relationship between demographic variables (e.g., ethnicity, sexual orientation, and disability status), distress and mental health (e.g., depression, anxiety, somatic complaints, and pandemic distress), and vulnerability factors for COVID-19 (e.g., personal health vulnerabilities, community members' health vulnerabilities, and environmental exposure risks at work or home). An online cross-sectional study was conducted from 18 June to 17 July 2020, reflecting the impact of early phase COVID-19 pandemic and related shelter-in-place measures in the United States. Participants were adults residing in the United States (N = 594), with substantial subsamples (N ≥ 70) of

	American Indian, Asian American, African-American, and Hispanic and/or Latinx participants, as well as **people with disabilities** and sexual minorities. Outcomes measured were depression, hopelessness, somatic complaints, anxiety-related disorders, locus of control (LOC), and a novel measure of pandemic-related distress. Data were analyzed using analyses of covariance (ANCOVA), chi-square test, and correlation coefficients. Generally, younger individuals, and those with less financial power-across all identities-suffered more distress. When controlling for age, lower financial power was associated with higher scores on the Center for Epidemiologic Studies Depression Scale-Revised (CESD-R; $r = -0.21$, $p = < 0.001$), Beck Hopelessness Scale (BHS; $r = -0.17$, $p < 0.001$), Patient Health Questionnaire-15 (PHQ-15; $r = -0.09$, $p = 0.01$), Screen for Child Anxiety Related Emotional Disorders for Adults Panic Disorder (SCARED-A PD; $r = -0.14$, $p < 0.001$), SCARED-A generalized anxiety disorder (GAD; $r = -0.13$, $p = 0.002$), SCARED-A obsessive-compulsive disorder (OCD; $r = -0.08$, $p = 0.04$), and the COVID-19 Pandemic Distress restriction/disconnection scale (C19PDS; $r = -0.10$, $p = 0.009$). In addition, disparities were found, in general, for marginalized identities by gender, sexual orientation, and **disability status.** Importantly, each ethnicity subsample showed a unique pattern of relationships between COVID-19 risk variables and mental health symptoms. The results support the hypothesis that any pandemic may amplify preexisting social and financial disparities. Overall, interventions at the clinical, governmental, or health equity level should take into consideration the needs of vulnerable groups.
Buono, S., Zingale, M., Città, S., Mongellia. V., Trubia, G., Mascalia, G., Occhipinti, P., Pettinato, E., Ferri, R., Gagliano, C., & Greco, D. **Clinical management of individuals with Intellectual Disability: the outbreak of Covid-19 pandemic as experienced in a clinical and research center** *Research in Developmental Disabilities*, 2021, (online on 9 January, 103856). in press. https://doi.org/10.1016/j.ridd.2021.103856	**Abstract:** During the COVID-19 pandemic, the Oasi Research Institute of Troina (Italy) became an important hotbed for infection; in fact, 109 patients with different levels of Intellectual Disability (ID) tested positive for COVID-19. The procedures and interventions put in place at the Oasi Research Institute due to the COVID-19 pandemic are exhaustively reported in this paper. The description of the clinical procedures as well as remote/in person psychological support services provided to people with ID and their families are here divided into three different sections: Phase I (or Acute phase), Phase II (or Activity planning), and Phase III (or Activity consolidation). Highlights of what was undertaken include the following: (1) Procedures and interventions implemented after the outbreak of the COVID-19 pandemic in a research and clinical center dealing with patients with Intellectual Disability. (2) Clinical management of COVID-19-affected patients with Intellectual Disability. (3) Psychological management of affected patients, their families, and caregivers., and (4) Remote (via telephone and electronic devices) psychological support for patients and their families. The article further covers the main psycho-pathological characteristics of patients, the reactions of family members and the multidisciplinary interventions put in place.

Buonaguro, E.F., & Bertelli, M.O. **COVID-19 and intellectual disability/autism spectrum disorder with high and very high support needs: issues of physical and mental vulnerability** *Advances in Mental Health and Intellectual Disabilities*, online 4 January 2021, https://doi.org/10.1108/AMHID-07-2020-0016	**Abstract:** The COVID-19 outbreak has profoundly plagued the world, and current health efforts are focused on providing prevention and ensuring access to intensive services for people with the most severe symptomatology. Many reports have already described substantial psychological distress in the general population. Nevertheless, disasters tend to affect vulnerable subjects disproportionately, and individuals with intellectual disabilities/autism spectrum disorder with high and very high support needs (PwID/ASD-HSN) seem to be counted among the hardest hit populations. The present paper aims to provide a comprehensive discussion and evaluation of COVID-19 related issues specific to PwID/ASD-HSN. Commentary on available literature and analysis of new preliminary data on PwID/ASD-HSN's physical and psychic vulnerability factors. This knowledge is fundamental to providing families and caregivers special advice to counteract the risks associated with the current pandemic. PwID/ASD-HSN represent one of the most vulnerable population to the COVID-19 outbreak and the associated factors of mental distress for several reasons, including multimorbidity, low levels of health literacy, difficulties to understand and communicate, reliance on other people for care, low compliance with complex hygiene rules, the strong need of routine/sameness and low adaptive skills
Callea, M., Cammarata-Scalisi, F., Galeotti, A., Villani, A., & Valentini, D. **COVID-19 and Down syndrome.** *Acta Pediatrica*, 2020, 109(9), 1901-1902. https://doi.org/10.1111/apa.15409	**Abstract:** [none - *Extracted from text*] 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 of 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.
Centers for Disease Control (CDC) **Coronavirus disease 2019 (COVID-19): People with disabilities.** *CDC* (Atlanta, Georgia), updated March 16, 2021 https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html	**Abstract**: [*none – extracted 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). The 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.
Centers for Disease Control (CDC) **COVID-19: People with certain medical conditions.** *CDC,* December 29, 2020 https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html	**Abstract:** Revisions were made on December 23, 2020, to reflect recent data supporting increased risk of severe illness among persons with Down syndrome from the virus that causes COVID-19. Adults of any age with certain underlying medical conditions are at increased risk for severe illness from the virus that causes COVID-19. Severe illness from COVID-19 is defined as hospitalization, admission to the ICU, intubation or mechanical ventilation, or death. Adults of any age with the

	following conditions are at increased risk of severe illness from the virus that causes COVID-19: **** Down Syndrome ****.
Van Beusekom, M. **Intellectual disability, obesity tied to COVID-19 hospitalization, death** *CIDRAP News*, Center for Infectious Disease Research and Policy, March 8, 2021, https://www.cidrap.umn.edu/news-perspective/2021/03/intellectual-disability-obesity-tied-covid-19-hospitalization-death	**Abstract:** (*none – text abstracted from article*). Intellectual disability is second only to old age as a risk factor for COVID-19 death, and obesity is linked to coronavirus-related hospitalization and death, two new studies find. Deadlier than heart, kidney, lung disease. The first study, led by researchers from Jefferson Health in Philadelphia and published late last week as a commentary in the *New England Journal of Medicine Catalyst*, involved analyzing the medical records of 558,672 US COVID-19 patients from January 2019 to November 2020. Patients with intellectual disabilities had higher rates of coronavirus infection than those without those limitations (3.1% vs 0.9%). In unadjusted analysis, compared with the 431,669 patients without intellectual disabilities, the 127,003 patients with intellectual disabilities were more susceptible to hospitalization (63.1% vs. 29.1%), intensive care unit (ICU) admission (14.5% vs. 6.3%), and death (8.2% vs. 3.8%). Intellectual impairments were the strongest predictor of death other than older age. "The chances of dying from COVID-19 are higher for those with intellectual disability than they are for people with congestive heart failure, kidney disease or lung disease," lead study author Jonathan Gleason, MD, said in a Thomas Jefferson University news release. COVID-19 patients with intellectual disabilities were more likely to be established patients of the health system where they sought care; 22% were new patients, compared with 44% of those without intellectual disabilities. They were also more likely to be younger than those without these limitations, with only 1% older than 80 years and 18% aged 60 to 80, versus 5% and 25%, respectively.
Center for Public Representation. **Examining how crisis standards of care may lead to intersectional medical discrimination against COVID-19 patients.** *CPR*, February 11, 2021 https://www.centerforpublicrep.org/wp-content/uploads/FINAL-Intersectional-Guide-Crisis-Care-PDF.pdf	**Abstract:** CPR and a coalition of civil rights groups and legal scholars released this report, noting that crisis standards of care are used to decide who should receive priority for treatment when resources become scarce, as they have during the COVID-19 pandemic. The report notes that Black, Indigenous and People of Color, people with disabilities, higher weight people, and older adults have historically experienced and continue to experience discrimination by medical professionals. In health care settings, members of these communities face pervasive negative biases and inaccurate assumptions about their value, quality of life, capacity to communicate and make decisions, and likelihood of survival. During the COVID-19 pandemic, these biases can have serious and even deadly consequences. Such biases may be exacerbated when hospitals are faced with scarce resources and must make decisions about which critically ill patients should receive treatment. The "crisis standards of care" which are used by many states and hospitals to make these decisions, have too often reflected these biases. It is crucial that these standards be tailored to avoid unlawful discrimination The report explores and addresses how crisis standards of care may perpetuate medical discrimination against people with

	disabilities, older adults, and communities of color, in hospital care. Many of these individuals face negative biases and inaccurate assumptions about their value, quality of life, and likelihood of survival that can have deadly consequences. The report provides an explanation of crisis standards of care policies implemented by states and hospital systems and how they may discriminate against marginalized individuals and communities, the principles that should apply to prevent discrimination, the relevant civil rights legal framework, and recommended strategies to ensure that crisis standards do not discriminate during the pandemic or in the future.
Chen, S-Q., Chen, S-D., Li, X., & Ren, J. **Mental health of parents of special needs children in China during the COVID-19 pandemic** *International Journal of Environmental Research and Public Health*, 2020, 17(24), 9519; https://doi.org/10.3390/ijerph17249519	**Abstract:** We assessed the mental health of parents (N = 1450, Mage = 40.76) of special needs children during the COVID-19 pandemic. We conducted an online survey comprising items on demographic data; two self-designed questionnaires (children's behavioral problems/psychological demand of parents during COVID-19); and four standardized questionnaires, including the General Health Questionnaire, Perceived Social Support, Parenting Stress Index, and Neuroticism Extraversion Openness Five Factor Inventory. The results showed that there were significant differences among parents of children with different challenges. Parents of children with autism spectrum disorder were more likely to have mental health problems compared to parents whose children had an intellectual disability or a visual or hearing impairment. Behavioral problems of children and psychological demands of parents were common factors predicting the mental health of all parents. Parent–child dysfunctional interactions and parenting distress were associated with parents of children with autism spectrum disorder. Family support, having a difficult child, and parenting distress were associated with having children with an intellectual disability. It is necessary to pay attention to the parents' mental health, provide more social and family support, and reduce parenting pressures.
Clift, A.K., Coupland, C.A.C., Keogh, R.H., Hemingway, H., & Hippisley-Cox, J. **COVID-19 mortality risk in Down syndrome: Results from a cohort study of 8 million adults**. *Annals of Internal Medicine,* 2020, 21 October 2020 (Letters). https://doi.org/10.7326/M20-4986	**Abstract** (*none – Extracted 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 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.

Constantino, J.N., Sahin, M., Piven, J., Rodgers, R., & 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, appiajp202020060780. doi:10.1176/appi.ajp.2020.20060780. Online ahead of print. (Letter to the Editor). (taken from: https://www.nih.gov/news-events/news-releases/people-intellectual-developmental-disabilities-disproportionately-affected-covid-19)	**Abstract:** [*Extracted 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.
Courtenay, K. **Covid-19: challenges for people with intellectual disability** BMJ, 2020, 369. doi: https://doi.org/10.1136/bmj.m1609 (Published 29 April 2020)	**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 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 well-being 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.
Courtenay, K., & Perera. B. **COVID-19 and people with intellectual disability: Impacts of a pandemic.** *Irish Journal of Psychological Medicine*, 2020, May 14, 1-16. doi:10.1017/ipm.2020.45	**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.
Cuypers, M., Schalk, B.W.M., Koks-Leensen, M.C.J., Nägele, M.E., Bakker-van Gijssel, E.J., Naaldenberg, J., & Leusink, G.L. **Mortality of people with intellectual disabilities during the 2017/2018 influenza epidemic in the Netherlands: potential implications for the COVID-19 pandemic**. *Journal of Intellectual Disability Research*, 2020, 64(7), 482-488. doi: 10.1111/jir.12739	**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.
de Asua D R, Mayer MA, Ortega MDC, et al. **Comparison of COVID-19 and non-COVID-19 pneumonia in Down syndrome** Journal of Clinical Medicine, 2021 Aug 23;10(16):3748. doi: 10.3390/jcm10163748.	**Abstract:** Whether the increased risk for coronavirus disease 2019 (COVID-19) hospitalization and death observed in Down syndrome (DS) are disease specific or also occur in individuals with DS and non-COVID-19 pneumonias is unknown. This retrospective cohort study compared COVID-19 cases in persons with DS hospitalized in Spain reported to the Trisomy 21 Research Society COVID-19 survey (n = 86) with admissions for non-COVID-19 pneumonias from a retrospective clinical database of the Spanish Ministry of Health (n = 2832 patients). In-hospital mortality rates were significantly higher for COVID-19 patients (26.7% vs. 9.4%), especially among individuals over 40 and patients with obesity, dementia, and/or epilepsy. The mean length of stay of deceased patients with COVID-19 was significantly shorter than in those with non-COVID-19 pneumonias. The rate of admission to an ICU in patients with DS and COVID-19 (4.3%) was significantly lower than that reported for the general population with COVID-19. Our findings confirm that acute SARS-CoV-2 infection leads to higher mortality than non-COVID-19 pneumonias in individuals with DS, especially among adults over 40 and those with specific comorbidities. However, differences in access to respiratory support might also account for some of the heightened mortality of individuals with DS with COVID-19.
De Cauwer, H., & Spaepen, A. **Are patients with Down syndrome vulnerable to life-threatening COVID-19?** *Acta Neurologica Belgica*, 2020, 1–3. Advance online publication. https://doi.org/10.1007/s13760-020-01373-8 1-6.	**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, the 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.
De Giacomo A, Pedaci C, Palmieri R, Simone M, Costabile A, Craig F. **Psychological impact of the SARS-CoV-2 pandemic in children with neurodevelopmental disorders and their families: evaluation before and during covid-19 outbreak among an Italian sample.** *Rivisita di Psichiatria,* 2021, Jul-Aug, 56(4), 205-210. doi: 10.1708/3654.36348.	**Abstract:** The SARS-CoV-2 pandemic forced parents and children to modify their habits with a radical change in the family routine and consequent increase in psychological stress. Children with a neurodevelopmental disorder (NDDs) are particularly vulnerable to new and unexpected situations; moreover, the parents of these children generally show high levels of psychological stress due to the greater commitment that this condition imposes on them. The aim of this study is to evaluate the disease status of NDDs children before and during SARS-CoV-2 pandemic and to evaluate the psychological effects related to measures of social distancing on these children and their families. Seventy-one children with NDDs, were enrolled in this study and followed up at the Child Neuropsychiatry Unit of the University Hospital Consortium Corporation Polyclinic of Bari (Italy) along with their parents. Parents were evaluated

	before national lockdown (baseline) and recontacted during the SARS-CoV-2 emergency almost after a year. The changes in emotional/behavioral problems of children and parenting stress before and during the SARS-CoV-2 pandemic were assessed with Child Behaviour CheckList (CBCL) and Parent Stress Index - short form (PSI). The analysis of the emotional and behavioral problems of children with NDDs did not show statistically significant differences between the before and during the SARS-CoV-2 pandemic period. The evaluations conducted on parents highlight an increase in parental stress during the pandemic. Significant differences ($p<0.05$) were found in three subscales: Parenting Distress (PD) scale, Dysfunctional Interaction Parent-Child (P-CDI) scale and Defensive responding scale (DF). This study highlights the increase in parental stress and a more difficult parent-child interaction with NDDs in the period of lockdown due to the pandemic; identification of these risk targets can be useful for interventions in similar situations. Therefore, it is necessary to provide caregivers information to manage and overcome challenges experienced during a pandemic and providing psychological support for caregivers of children with NDDs.
De Toma, I., & Dierssen, M. **Network analysis of Down syndrome and SARS-CoV-2 identifies risk and protective factors for COVID-19** *Scientific Reports,* 2021, 11(1930), https://doi.org/10.1038/s41598-021-81451-w	**Abstract:** SARS-CoV-2 infection has spread uncontrollably worldwide while it remains unknown how vulnerable populations, such as Down syndrome (DS) individuals are affected by the COVID-19 pandemic. Individuals with DS have more risk of infections with respiratory complications and present signs of auto-inflammation. They also present with multiple comorbidities that are associated with poorer COVID-19 prognosis in the general population. All this might place DS individuals at higher risk of SARS-CoV-2 infection or poorer clinical outcomes. To get insight into the interplay between DS genes and SARS-cov2 infection and pathogenesis we identified the genes associated with the molecular pathways involved in COVID-19 and the host proteins interacting with viral proteins from SARS-CoV-2. We then analyzed the overlaps of these genes with HSA21 genes, HSA21 interactors and other genes consistently differentially expressed in DS (using public transcriptomic datasets) and created a DS-SARS-CoV-2 network. We detected COVID-19 protective and risk factors among HSA21 genes and interactors and/or DS deregulated genes that might affect the susceptibility of individuals with DS both at the infection stage and in the progression to acute respiratory distress syndrome. Our analysis suggests that at the infection stage DS individuals might be more susceptible to infection due to triplication of TMPRSS2, that primes the viral S protein for entry in the host cells. However, as the anti-viral interferon 1 signaling is also upregulated in DS, this might increase the initial anti-viral response, inhibiting viral genome release, viral replication, and viral assembly. In the second pro-inflammatory immunopathogenic phase of the infection, the prognosis for DS patients might worsen due to upregulation of inflammatory genes that might favor the typical cytokine storm of COVID-19. We also detected strong downregulation of the

	NLRP3 gene, critical for maintenance of homeostasis against pathogenic infections, possibly leading to bacterial infection complications.
del Carmen Ortega, M., Borrel, J.M., de Jesús Bermejo, T., González-Lamuño, D., Manso, C., de la Torre, R., Mayer, M-A., Real de Asúa, D., Dierssen, M. on behalf of the Spanish Trisomy 21 Research Society COVID-19 Taskforce **Lessons from individuals with Down syndrome during COVID-19 (Correspondence)** *The Lancet Neurology*, 19(12), P974-975, December 01, 2020. https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(20)30401-4/fulltext	**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:** *[none - Extracted from text]* 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-

https://www.gov.uk/government/publications/covid-19-supporting-adults-with-learning-disabilities-and-autistic-adults/coronavirus-covid-19-guidance-for-care-staff-supporting-adults-with-learning-disabilities-and-autistic-adults	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 (a) Protecting yourself and the person you care for; (b) Maintaining good hygiene practices; (c) Contingency planning; (d) If you have symptoms of COVID-19; (e) If the person being cared for has symptoms of COVID-19; (f) Caring for someone who is clinically 'extremely vulnerable' (shielding); (g) Supporting the person through change; and (h) Maintaining your own health and wellbeing.
Desroches, M.L., Ailey, S., Fisher, K., & Stych, J. **Impact of COVID-19: Nursing challenges to meeting the care needs of people with developmental disabilities** *Disability and Health Journal,* 2021, Jan, 14(1), 101015 https://doi.org/10.1016/j.dhjo.2020.101015	**Abstract:** People with developmental disabilities (DD) are a population at high-risk for poor out-comes related to COVID-19. COVID-19-specific risks, including greater comorbidities and congregate living situations in persons with DD compound 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-specialty 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.

Dhiman, S., Sahu, P.K., Reed, W.R., Ganesh, G.S., Goyal, R.K., & Jain, S. **Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs.** *Research in Developmental Disabilities,* 2020, 107, 103790. DOI: 10.1016/j.ridd.2020.103790	**Abstract:** While COVID-19 outbreak has had adverse psychological effects in children with special needs, the mental state and burden on their caregivers during this pandemic has yet to be reported. The objectives of this study were to describe the mental health status and the change in perceived strain among caregivers during the COVID-19 outbreak. Two hundred sixty-four caregivers completed an online survey that assessed demographics, use and perspective on tele-rehabilitation, homecare therapy, caregiver's strain, and mental health. The prevalence of depression, anxiety and stress symptoms were found to be 62.5 %, 20.5 % and 36.4 % respectively. A significant difference in caregiver strain ($p < 0.001$, effect size = 0.93) was observed during the outbreak compared to levels pre-outbreak (pre-outbreak strain was measured retrospectively). Caregivers not using tele-rehabilitation along with a perception of it being a poor medium for rehabilitation were at greater risks for poor mental health whereas a negative perception on homecare therapy were strongly associated with higher psychological symptoms and strain. This study identified a high prevalence of depression and significant change in strain displayed by caregivers during the COVID-19 outbreak. We identified several factors associated with poor mental health and perceived strain that can be used to help safeguard caregivers.
Doody, O., & Keenan, P.M. **The reported effects of the COVID-19 pandemic on people with intellectual disability and their carers: a scoping review** *Annals of Medicine*, 2021, 53(1), 786-804. https://doi.org/10.1080/07853890.2021.1922743	**Abstract:** People with an intellectual disability are a vulnerable group during COVID-19 due to multi-morbidity, frailty, underlying conditions/health problems, social circumstances, and limitations in understanding. This places them at greater risk of more severe outcomes from COVID-19. To chart the evidence of the effects of the COVID-19 pandemic on people with intellectual disability and their carers reported in the research. A scoping review method was used to review literature published across eight databases in 2020 and included manual searches of reference lists of included articles. Sixteen studies were selected for inclusion. The findings highlight that professionals, people with intellectual disability, and their caregivers were keen to comply with pandemic related public health guidance. However, implementing infection prevention and control measures in certain contexts for people with intellectual disability was challenging. Thereby a rights-based, person-centered approach to care is essential and professionals need to extend their understanding and practice of collaborative working to include people with intellectual disability and their family/carers. The findings highlight that compliance with public health guidance and infection control measures can be difficult for people with intellectual disability to implement. There is limited good quality robust research on COVID-19 and people with intellectual disability and/or their carers experiences.
Drum, C. E., Oberg, A., Ditsch, J., Cooper, K., & Carlin, R.	**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

COVID-19 & adults with serious difficulties concentrating, remembering, or making decisions due to an intellectual disability, autism, epilepsy, or brain injuries: Online survey report. Rockville, MD: American Association on Health and Disability, 2020, pp1-15 https://aahd.us/wp-content/uploads/2020/06/COVID-19_DCRM_Intellectual-Disability_Autism_Epilepsy_or_Brain_Injury BMSF_508.pdf	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 safe-guarding information for both the sample and their care providers are 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 representants a potentially life-threatening situation.
Embregts, P. J.C.M., Tournier, T., & Frielink, N. **Experiences and needs of direct support staff working with people with intellectual disabilities during the COVID-19 pandemic: A thematic analysis.** *Journal of Applied Research in Intellectual Disabilities*. (2020). First published: 21 September 2020 https://doi.org/10.1111/jar.12812	**Abstract**: This study explored the experiences and needs of direct support staff during the initial stage of the COVID-19 lockdown in the Netherlands. Overall, eleven direct support staff were recruited from five intellectual disability services to participate in this descriptive qualitative study. They recorded 34 audio messages during the considered period. Thematic analysis was used to analyze these audio recordings. Four themes emerged: (1) Emotional impact, which pertained to various emotions they experienced in their work; (2) Cognitive impact, which referred to challenges and changes they had undergone in their work; (3) Practical impact, which centered on the practical impact of the pandemic on their work; and (4) Professional impact, which concerned their experiences with other professionals. This study provides valuable insights into the experiences and needs of direct support staff during the COVID-19 pandemic, which, in turn, can help inform practice in preparation for a second wave of COVID-19 or another future pandemic.
Embregts PJCM, Tournier T, Frielink N. **The experiences of psychologists working with people with intellectual disabilities during the COVID-19 crisis.**	**Abstract:** The aim of this study was to explore the experiences of psychologists working with people with intellectual disabilities during the initial stage of the COVID-19 lockdown in the Netherlands. Five psychologists, who were affiliated with three intellectual disability services, participated in this

Journal of Applied Research in Intellectual Disabilities, 2022 Jan, 35(1), 295-298. doi: 10.1111/jar.12916. Epub 2021 Jul 1. PMID: 34197019; PMCID: PMC8420360.	descriptive qualitative study. Overall, they recorded 22 audio messages during the period under examination, which were analyzed using thematic analysis. Three themes were identified: (a) Working from home; (b) Adapting to the new reality; and (c) Advising and coaching support staff. This study provides critical insights into the experiences of psychologists working with people with intellectual disabilities during the initial stage of the COVID-19 lockdown. These insights can help policymakers and practitioners to prepare for either a potential second wave of COVID-19 or a future pandemic.
Emmerton, D., & Abdelhafiz, A.H. **Care for older people with dementia during COVID-19 pandemic** SN Comprehensive Clinical Medicine, 2021 Jan 27, 1–7. doi: 10.1007/s42399-020-00715-0 [Epub ahead of print] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7837877/	**Abstract:** Older people living with dementia, who are likely frail with multiple comorbidities, appear particularly vulnerable to COVID-19. Care for older people with comorbid dementia and COVID-19 is a challenge to health care professionals due to their complex needs. COVID-19 is a respiratory disease which typically presents with respiratory symptoms; however, in older people with dementia, it may present atypically with delirium. Delirium may precede respiratory symptoms, and in some cases, it may be the only symptom, leading to a delay in the diagnosis. Therefore, screening for delirium should be part of the routine clinical practice for older people with dementia and suspected COVID-19 infection. Due to the complexity of care required for older people with dementia affected by COVID-19, a holistic and individualized approach that includes acute, transitional, and long-term care is required. Advanced decision-making, for example, ceiling of care and resuscitation decisions, should be made early on admission to hospital. Screening for frailty with clinical frailty scale may help to aid decision-making. Palliative care and relief of suffering should be considered from the outset. Early and regular involvement of patients and their families in care plans and periodic updates regarding any changes in the clinical condition are good clinical practice. The introduction of telehealth programs that are suitable for older people with poor cognitive function and cover diverse cultural backgrounds are urgently required for the future support of this vulnerable group of patients.
Esparcia-Pinedo, L. Yarci-Carrion, A. Mateo-Jimenez, G. et al. **Development of an effective immune response in adults with Down syndrome after SARS-CoV-2 vaccination** *Clinical Infectious Diseases*, 23 July 2022, ciac590, https://doi.org/10.1093/cid/ciac590	**Abstract:** Immune dysregulation in individuals with Down syndrome (DS) leads to an increased risk for hospitalization and death due to coronavirus disease 2019 (COVID-19) and may impair the generation of protective immunity after vaccine administration. The cellular and humoral responses of 55 individuals with DS who received a complete SARS-CoV-2 vaccination regime at 1 to 3 (visit [V 1]) and 6 (V2) months were characterized. SARS-CoV-2–reactive CD4+ and CD8+ T lymphocytes with a predominant Th1 phenotype were observed at V1 and increased at V2. Likewise, an increase in SARS-CoV-2–specific circulating Tfh (cTfh) cells and CD8+ CXCR5+ PD-1hi lymphocytes was already observed at V1 after vaccine administration. Specific immunoglobulin G (IgG) antibodies against SARS-CoV-2 S protein were detected in 96% and 98% of subjects at V1 and V2, respectively, although IgG titers decreased significantly between both time points. Author found that that individuals with Down syndrome develop an

	effective immune response to usual regimes of SARS-CoV-2 vaccination.
Espinosa, J.M. **Down syndrome and COVID-19: a perfect storm?** *Cell Reports Medicine,* 2020, May 19, 1(2):100019. doi:10.1016/j.xcrm.2020.100019. Epub 2020 May 1.	**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** *The World Economic Forum COVID Action Platform,* 24 April 2020. https://www.weforum.org/agenda/2020/04/covid19-coronavirus-intellectual-disabilities-loneliness/	**Abstract:** *[none - Extracted from article]:* The loneliness reported by many people with intellectual disabilities has been exacerbated by quarantine: (1) The lockdown meant sudden deprivation of specialized services and work opportunities; and (2) Issues over rationing of care further increased 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 is 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 programs, drop-in centers, 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.
Fair Health **An Analysis of Private Healthcare Claims: A Detailed Study of Patients with Long-Haul COVID.** *A FAIR Health White Paper*, June 15, 2021 https://s3.us-east-1.amazonaws.com/media2.fairhealth.org/whitepaper/asset/A%20Detailed%20Study%20of%20Patients%20with%20Long-Haul%20COVID--An%20Analysis%20of%20Private%20Healthcare%20Claims--A%20FAIR%20Health%20White%20Paper.pdf	**Abstract:** Many patients recover from COVID-19 within a few weeks, but some exhibit persistent or new symptoms more than four weeks after first being diagnosed. Patients with such post-COVID conditions are variously referred to as having long-haul COVID, long COVID or post-acute sequelae of COVID-19 (PASC). Using longitudinal data from a database of over 34 billion private healthcare claim records, FAIR Health studied a total of 1,959,982COVID-19 patients for the prevalence of post-COVID conditions 30 days or more after their initial diagnosis with COVID-19. To FAIR Health's knowledge, this is the largest population of COVID-19 patients so far studied for post-COVID conditions. The patients' post-COVID conditions were analyzed, with the most common conditions identified. Particular attention was given to age and gender, mental health conditions and death. Among the key findings: Of patients who had COVID-19, 23.2 percent had at least one post-COVID condition. Post-COVID conditions were found to a greater extent in patients who had more severe cases of COVID-19, but also in a substantial share of patients whose cases lacked symptoms. Of patients who were hospitalized with COVID-19, the percentage that had a post-COVID condition was 50 percent; of patients who were symptomatic but not hospitalized, 27.5 percent; and of patients who were asymptomatic, 19 percent. The five most common post-COVID conditions across all ages, in order from most to least common, were pain, breathing difficulties, hyperlipidemia, malaise and fatigue, and hypertension. The ranking of the most common post-COVID conditions varied by age group. For example, in the pediatric population (0-18), pain and breathing difficulties were the top two conditions, as in the all-ages cohort, but intestinal issues, rather than hyperlipidemia, were the third most common. Most of the post-COVID conditions that were evaluated were associated more with females than males. In the case of 12 conditions, however, males more commonly had the condition diagnosed than females. For example, of patients who had post-COVID cardiac inflammation, 52 percent were male and 48 percent female. By age, the largest share (25.4 percent) with this condition was found in a young cohort—

	individuals aged 19-29. Of the four mental health conditions evaluated as post-COVID conditions, anxiety was associated with the highest percentage of patients after COVID-19 in all age groups. Depression was second, adjustment disorders third and tic disorders fourth. The odds of death 30 days or more after initial diagnosis with COVID-19 were 46 times higher for patients who were hospitalized with COVID-19 and discharged than patients who had not been hospitalized (odds ratio [OR]=46.020,95percentconfidence interval [CI], 34.778-60.897, P<0.001). Of COVID-19 patients who were hospitalized and discharged, 0.5 percent died 30 days or more after their initial diagnosis. Among COVID-19 patients with preexisting conditions**, intellectual disabilities** were associated with the highest odds of death 30 days or more after initial COVID-19diagnosis (OR=3.082,95percentCI, 1.183-8.029, P=0.0212). This is consistent with a finding in a previous FAIR Health study that COVID-19 patients with intellectual disabilities and related conditions had the third highest risk of death from COVID-19 across all age groups. Individuals with Alzheimer's disease and/or senile dementia also had higher odds of dying (OR=3.007, 95 percent CI, 2.136-4.232, P<0.001). The reference group for each preexisting condition was patients without that preexisting condition. This analysis of the largest population of COVID-19 patients so far studied for post-COVID conditions makes several notable findings. Of patients who had COVID-19, 23.2 percent had at least one post-COVID condition 30 days or more after their initial diagnosis with COVID-19. Post-COVID conditions were found to a greater extent in patients who had more severe cases of COVID-19, but also in a substantial share (19 percent) of patients whose cases were asymptomatic. The five most common post-COVID conditions across all ages, in order from most to least common, were pain, breathing difficulties, hyperlipidemia, malaise and fatigue, and hypertension. The ranking of the most common post-COVID conditions varied by age group. Most of the post-COVID conditions that were evaluated were associated more with females than males. In the case of 12 conditions, however, males more commonly had the condition diagnosed than females. For example, of patients who had post-COVID cardiac inflammation, 52 percent were male and 48 percent female. By age, the largest share (25.4 percent) with this condition was found in individuals aged 19-29. Of the four mental health conditions evaluated as post-COVID conditions, anxiety was associated with the highest percentage of patients after COVID-19 in all age groups. Depression was second, adjustment disorders third and tic disorders fourth. The odds of death 30 days or more after initial diagnosis with COVID-19 were 46 times higher for patients who were hospitalized with COVID-19 and discharged than patients who had not been hospitalized. Of COVID-19 patients who were hospitalized and discharged, 0.5 percent died 30 days or more after their initial diagnosis.

Farajzadeh A, Dehghanizadeh M, Maroufizadeh S, Amini M, Shamili A. **Predictors of mental health among parents of children with cerebral palsy during the COVID-19 pandemic in Iran: A web-based cross-sectional study.** *Research in Developmental Disabilities,* 2021, May, 112:103890. doi: 10.1016/j.ridd.2021.103890. Epub 2021 Feb 16.	**Abstract:** Caring for children with cerebral palsy (CP) for many aspects of their lives may affect caregiver's psychological health. The emergence of COVID-19 put added pressure on caregivers. The aim of this study was to investigate the psychological health of Iranian caregivers of children with CP and associated risks during a lockdown period. Using online snowball sampling, 160 caregivers of children with CP participated in this web-based cross-sectional study. The Hospital Anxiety and Depression Scale (HADS), Perceived Stress Scale (PSS-4), Caregiver Difficulties Scale (CDS), and a demographic questionnaire were administered. Hierarchical multiple linear regression analysis was applied to identify risk factors related to caregiver psychological health. Mental health problems were prevalent; (depression = 45.0% and anxiety = 40.6%). Significant correlations were found between CDS and HADS-Anxiety (r = 0.472, P < 0.001), HADS-depression (r = 0.513, P < 0.001), and perceived stress (PSS) related to COVID-19 (r = 0.425, P < 0.001). After controlling demographic and clinical variables, burden (CDS) was found to significantly predict caregiver anxiety, depression, and stress. Furthermore, several demographic characteristics (being married, low educational level and low income) were significantly related to high HADS Anxiety scores. For depression, only having a physical problem was significantly related to HADS among demographic variables. No significant correlations were found between PSS-4 and demographic variables. During COVID-19 outbreak, the mental health of caregivers of children with CP is affected by multiple factors such as burden of care and demographic characteristics. Due to the importance of well-being among caregivers of disabled children, a comprehensive plan including psychological consultation, remote education, or in-person handouts for the self-care or handling of the children and adequate distance support may enable better mental health for these caregivers.
Francis, L.P. **Employees with intellectual disabilities during the Covid-19 pandemic: new directions for disability anti-discrimination law?** *Oklahoma Law Review*, 2021;74(1):1-26. (August 19, 2021). University of Utah College of Law Research Paper No. 465, Available at SSRN: https://ssrn.com/abstract=3908223	**Abstract:** This Article addresses employment risks and challenges presented by the COVID-19 pandemic for people with intellectual disabilities, in particular people with Down syndrome. Part II presents the risks and challenges of employment for people with Down during the COVID-19 pandemic. Part III lays out aspects of Title I of the Americans with Disabilities Act of 1990 (ADA) that are most relevant to these challenges. Part IV explores whether the ADA may be helpful in taking on these risks and challenges. It argues that limits long apparent in Title I of the ADA as it applies to people with intellectual disabilities may be exacerbated by the COVID-19 pandemic. Part V concludes by suggesting several ways these limits might be addressed.
Garcia, J.M., Lawrence, S., Brazendale, K., Leahy, N., & Fukuda, D. **The impact of the COVID-19 pandemic on health behaviors with autism spectrum disorder**.	**Abstract:** There is concern that the COVID-19 pandemic may negatively affect health behaviors in youth, especially youth diagnosed with autism spectrum disorder (ASD). The purpose of this paper was to examine changes in physical activity, screen-time, and sleep in adolescents with ASD due to the COVID-19 pandemic. Nine adolescents with ASD completed

Disability and Health Journal, 2021, 14(2), 101021 https://doi.org/10.1016/j.dhjo.2020.101021	surveys measuring physical activity, screen-time, and sleep duration prior to and during the pandemic. A significant decrease in days of physical activity (4.17 vs 2.27; *p*=0.0006), and a significant increase in hours of both weekday (3.69 vs 6.25; *p*=0.007) and weekend screen-time (5.94 vs. 7.39; *p*=0.004) was observed during the pandemic. No changes regarding sleep duration were observed. Although preliminary, results suggest that physical activity and screen-time may be negatively affected by the COVID-19 outbreak in youth with ASD. The development of interventions to promote health behaviors in ASD populations during long periods of less-structured time (quarantine)should be considered.
Gelburd, R. **Developmental disorders top the medical conditions that heighten the risk of dying from Covid-19** *STAT* (Reporting from the frontiers of health and medicine), November 11, 2020 https://www.statnews.com/2020/11/11/developmental-disorders-among-top-conditions-heighten-risk-dying-covid-19/ The above is based upon: ***Risk factors for COVID-19 mortality among privately insured patients* (White Paper) – A claims data analysis.** November 11, 2020 https://s3.amazonaws.com/media2.fairhealth.org/whitepaper/asset/Risk%20Factors%20for%20COVID-19%20Mortality%20among%20Privately%20Insured%20Patients%20-%20A%20Claims%20Data%20Analysis%20-%20A%20FAIR%20Health%20White%20Paper.pdf	**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.
Gil-Llario, M.D., Díaz-Rodríguez, I., Morell-Mengual, V., Gil-Juliá, B., & Ballester-Arnal, R. **Sexual health in Spanish people with intellectual disability: the impact of the lockdown due to COVID-19** *Sexuality Research and Social Policy*, 2021, https://doi.org/10.1007/s13178-021-00621-7	**Abstract:** The lockdown due to COVID-19 affected the sexual health of the people with intellectual disabilities by differentially modifying the frequency and characteristics of people's sexual activity depending on whether they lived with a partner during this period. The aim of this study was to analyze the extent to which the sexual behavior of people with intellectual disabilities (with and without a partner) was affected during the lockdown. The sample consisted of 73 people with intellectual disabilities between 21 and 63 years old (M = 39.63; SD = 10.11). The variables analyzed were the physical, social, and technological environment during the lockdown, sexual appetite, sexual behavior, online sexual activity, and sexual abuse. The data were collected between the months of May and June of 2020. The lockdown increased the sexual appetite of a third of the sample (38%), especially the youngest participants. Sexual activity focused on autoeroticism and online behavior, particularly sending nude images of oneself (88%) and viewing pornography (83.6%). Rates of sexual abuse during this period were relatively high (6.8%). The sexual activity of people with ID was important during the lockdown, and they had to adapt to the circumstances of isolation in a similar way to the general population. Technological improvements in terms of devices and connection quality at home allowed their sexual behavior to be reoriented, opening the door to new risks for the sexual health of people with ID. Cybersex and the increase in sexual abuse due to confinement are aspects that should be included in programs to improve the sexual health of this group.
Gleason, J, Ross, W., Fossi, A., Blonsky, H, Tobias, J. & Stephens, M. **The devastating impact of Covid-19 on individuals with intellectual disabilities in the United States.** *NEJM Catalyst*, March 5, 2021 https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051 DOI: 10.1056/CAT.21.0051	**Abstract:** A cross-sectional study of 64,858,460 patients across 547 health care organizations revealed that having an intellectual disability was the strongest independent risk factor for presenting with a Covid-19 diagnosis and the strongest independent risk factor other than age for Covid-19 mortality. Screening for Covid-19, care coordination, and vaccination efforts should be intense within this population that is less able to consistently use masks and socially distance. Some 558,672 (0.87%) persons presented with a diagnosis of Covid-19. Established patients with intellectual disabilities had higher rates of Covid-19 incidence than those without intellectual disabilities and with Covid-19 (3.1% vs 0.9%, p<.001), and were more likely to be admitted to the hospital if diagnosed (63.1% vs. 29.1%, p<.001). Those with intellectual disabilities and a diagnosis of Covid-19 had higher rates of ICU stay (14.5% vs. 6.3%, p<.001), and patients with intellectual disabilities were more likely to die following diagnosis of Covid-19 (8.2% vs.

	3.8%, p<.001). Those with intellectual disabilities were more likely to be existing patients of the institution where they presented with Covid-19 (22% new patients compared with 44% of those without intellectual disabilities), less likely to be in a higher age group (1% over 80 and 18% from 60–80 compared with 5% and 25% in the general population, respectively), and more likely to have a health care payer status associated with low socioeconomic status (44% vs. 28%, p<.001). Patients with intellectual disabilities also had higher rates of all comorbidities other than cancer prior to Covid-19. The risks to patients with intellectual disabilities incorporate not only risks associated with intellectual disability itself, but also the risks associated with these comorbidities that were overrepresented among those with intellectual disabilities. If diagnosed with Covid-19, patients with intellectual disabilities were more likely to be admitted to the hospital, and while they were not more likely to be admitted to the ICU following an admission, they were more likely to experience mortality due to Covid-19 following an admission. These odds of mortality in this population are significantly higher than other conditions such as congestive heart failure, kidney disease, and lung disease. The risk of exposure in this population can be explained by a number of factors, including the need for daily care that many with intellectual disabilities have, which requires regular contact with home-care support personnel and others, use of shared transportation, and in many cases residence in high-contact housing such as long-term care facilities. Some individuals with intellectual disabilities have sensory issues that make tolerating mask-wearing for long periods of time difficult. Cognitive impairments and communication difficulties also raise the question of need for family or caregiver support when hospitalized
Global Council on Brain Health **COVID-19 and brain health: The Global Council on Brain Health's recommendations on what to do now.** *Global Council on Brain Health* (AARP), 2021, 17pp. www.GlobalCouncilOnBrainHealth.org; DOI: ttps://doi.org/10.26419/pia.00104.001.	**Abstract:** *[none – taken from the introduction]* The staggering impact of the COVID-19 pandemic continues to spread. As of February 24, 2021, there have been more than 112 million confirmed cases of COVID-19 across the globe, resulting in about 2.5 million deaths. Older adults and members of underserved communities have been disproportionately harmed. Sadly, we know those numbers will continue to increase before the virus is contained. While we still do not know the full extent of damage the pandemic will cause, scientific evidence has emerged that, in addition to severe illness and deaths, the virus is also causing damage to people's brain health. The Global Council on Brain Health's mission is to offer the best possible advice about what adults aged 50 and older can do to maintain and improve their brain health. With growing evidence that COVID-19 harms brain health, the GCBH determined it was important to inform people about this impact and what if anything might be done about it. First and foremost, a COVID-19 infection itself can directly harm brain health. Second, although social distancing is one of the best ways to reduce the risk of infection, isolation can negatively impact mental well-being of adults, thereby indirectly harming

	brain health. This report explores both the direct and indirect ways the virus may undermine brain health and offers 10 recommendations to people based upon the current state of the science on how to try to avoid the harms the pandemic poses. *[Contains referencing to intellectual disability but no specific allusion in the text – of general interest.]*
Grier, E., Lunsky, Y., Sullivan, W.F. & Casson, I. **Health care of adults with intellectual and developmental disabilities in a time of COVID-19**. *Canadian Family Physician,* April 9, 2020, Blog Post. (https://www.cfp.ca/news/cfpnews/2020/04/09/04-09-02.full.pdf)	**Abstract:** *[none - Extracted from text]* Adults with intellectual and developmental disabilities (IDD), such as Down Syndrome and autism, are a population at risk of contracting COVID-19 and of serious illness associated with COVID-19. Members of this community are experiencing significant distress due to confusion and disruption in their daily lives. Their voice is notably absent from current discussions. Clear resources and supports explaining how to manage, along with in-person support would be helpful. In addition, the high rates of emergency department visits and hospitalizations for this group even before COVID-19 may now be exacerbated. Proactive primary care in the community to address physical and mental health needs may be useful. Communication, symptom monitoring, management and caregiving strategies need to consider comorbidities, special needs, and the variety of settings in which adults with IDD live: ● 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. ● 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. ● 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. ● 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. ● 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.
Grumi S, Provenzi L, Gardani A, Aramini V, Dargenio E, Naboni C, Vacchini V, Borgatti R.	**Abstract:** The present study investigated the impact of the COVID-19-related rehabilitation services lockdown on the mental health of caregivers of children with neurodevelop-

Rehabilitation services lockdown during the COVID-19 emergency: the mental health response of caregivers of children with neurodevelopmental disabilities. **Engaging with Families through On-line Rehabilitation for Children during the Emergency (EnFORCE) Group.** *Disability and Rehabilitation,* 2021, Jan, 43(1), 27-32. doi: 10.1080/09638288.2020.1842520. Epub 2020 Nov 10.	mental disabilities. Between 26 March and 11 May 2020, 84 caregivers filled out ad-hoc and standardized questionnaires through an online survey to measure their psychological response to the emergency and lockdown as well as their levels of parenting stress, anxiety, and depression. Worries about COVID-19 contagion and concerns for the child left without rehabilitation programs were the greatest sources of mental health burden for caregivers. Nonetheless, only the concerns for the child were significantly associated with caregivers' reports of stress, depression and anxiety symptoms. These findings highlight the burden faced by caregivers of children with neurodevelopmental disabilities during the COVID-19 emergency in Italy. These families should be considered as a high-risk population that requires dedicated healthcare attention, such as promoting continuity of care by investing in tele-rehabilitation programs. Implications for rehabilitation Caregivers of children with disability reported symptoms of anxiety and depression during COVID-19 emergency. Major concerns regarded COVID-19 contagion risk and child development during rehabilitation lockdown. Caregivers' psychological symptoms were associated with concerns for child development during the lockdown. Parents of children with disability may face relevant stress during and after COVID-19 psychological burden. During COVID-19 recovery, policymakers and clinicians should dedicate specific care actions for families of children with disability.
Gulati, G., Dunne, C.P., & Kelly, B.D. **Do COVID-19 responses imperil the human rights of people with disabilities?** *Health and Human Rights Journal*, June 3, 2020. https://www.hhrjournal.org/2020/06/do-covid-19-responses-imperil-the-human-rights-of-people-with-disabilities/	**Abstract:** (*none provided - extract from text*] In the case of people with disabilities, the pandemic poses a threat to rights to equal treatment and autonomy. COVID-19 created a risk that available healthcare resources would be overwhelmed, and some form of triage would become necessary for critical life-saving interventions, such as mechanical ventilation. Many countries developed policies and guidance for frontline clinicians to guide decision-making. Some of this guidance, even if unintentionally, disadvantaged people with disabilities. One example from the UK was the recommendation to use the "clinical frailty scale" in advance care-planning for making end-of-life decisions. After human rights concerns were raised, further guidance was produced clarifying this was unsuitable for use in people with intellectual disabilities. Separately, media reports cited cases where groups of individuals with disabilities were targeted in respect of making advance directives around end-of-life decisions or where such directives were made without involving the individual themselves or their families—an unacceptable breach of the right to equality and autonomy. COVID-19 related changes in legislation and policy have the potential to impact rights to liberty, equality, and autonomy in people with disabilities. Death rates from COVID-19 in vulnerable populations, such as those in care, now exceed those of the general population. For these populations, the pandemic arguably poses a greater threat to the right to life. Where decisions taken for the good of society disproportionately impact a minority group, there is a duty on states to

	act responsibly to safeguard rights. A healthy debate must be encouraged whenever the powers of the state are increased in a way that threatens to eradicate or weaken individual rights, so as to prevent unjustified erosion of those rights. People with disabilities must have a voice in this debate.
Gulati, G., Fistein, E., Dunne, C.P., Kelly, B.D., & Murphy, V.E. **People with intellectual disabilities and the COVID-19 pandemic** *Irish Journal of Psychological Medicine*, 2020, 1-5, published online on May 27, 2020, doi:10.1017/ipm.2020.66 [Letter to Editor]	**Abstract:** *[none - extracted from text]* Comment on two areas of health delivery that merit attention related to ensuring equitable access to life-saving treatments and ensuring health care resources are not diverted inappropriately at a time of enhanced need. One issue is the stating of DNR (Do Not Resuscitate) orders for adults with intellectual disability when the persons or their family have not been consulted. Another issue is the 'potential inappropriate diversion of resources.' These include the psychological distress arising in response to fears about personal familial infection as well as the sequelae of social distancing and quarantine measures. Authors note that in this context, persons with intellectual disability may be particularly vulnerable to isolation and psychological distress. Further, adults with intellectual disability already experience substantial barriers to accessing medical care and are often more likely to be at increased risk of both the infection and the challenges associated with accessing information, testing, and treatment. Article 25 of the UN Convention on the Rights of Persons with Disabilities (CRPD) requires that member States do not discriminate against people with disabilities in the provision of healthcare. This is particularly important when considering resources during a pandemic. Evolving experience from the UK and Ireland suggests that people in care homes and other residential facilities are particularly vulnerable to outbreaks of COVID-19
Hotez, E., Hotez, P.J., Rosenau, K.A., & Kuo, A.A. **Prioritizing COVID-19 vaccinations for individuals with intellectual and developmental disabilities** *EClinical Medicine*, in Press, online 5 February 2021, 100749. https://doi.org/10.1016/j.eclinm.2021.100749	**Abstract:** [*none – extracted from text*] In December 2020, the Advisory Committee on Immunization Practices (ACIP) Coronavirus Disease 2019 (COVID-19) Vaccine Working Group issued recommendations for prioritizing and allocating vaccinations for the first available mRNA vaccines. Notably absent from the Phase 1 tiered guidelines are almost all individuals with intellectual and/or developmental disabilities (I/DD). The exclusion of most I/DD diagnoses from the guidelines represents yet another barrier to health and well-being for this population that will have significant consequences. The omission of most individuals with I/DD from the guidelines presents a significant public-health concern. There is growing consensus that individuals with I/DDs are particularly susceptible to COVID-19, demonstrating more severe illness, greater risk of hospitalization, and almost twice the case fatality rates for individuals aged 18–74. The exclusion of individuals with I/DD from the priority guidelines stems, in part, from a continued inattention to this population in research studies. We propose that all individuals with I/DD should be prioritized for vaccinations – which requires a broadening of current Phase 1 prioritizations. Further, I/DD populations should expressly be integrated into state vaccination guidelines and such guidelines should consistently

	include those in group homes or other settings, as well as their direct support professionals, and make procedures understandable and easy to navigate. Lastly, researchers and funders should prioritize studies that will promote the health and well-being of individuals with I/DDs during the pandemic.
Houghton, K. **People with intellectual disabilities are often overlooked in pandemic response** *NPR – Shots – Health News from NPR*. February 12, 2021. https://www.npr.org/sections/health-shots/2021/02/12/967190126/people-with-intellectual-disabilities-are-often-overlooked-in-pandemic-response	**Abstract:** [*news article – extract from text*] No one knows how many of the estimated 300,000 people who live in such facilities nationwide have caught COVID-19 or died as a result. That creates a blind spot in understanding the impact of the virus. And because data drives access to scarce COVID-19 vaccines, those with disabilities could be at a disadvantage for getting prioritized for the shots to keep them safe. While facilities ranging from state institutions that serve hundreds to small group homes with a few people have been locked down throughout the pandemic, workers still rotate through every day. Residents live in close quarters. Some don't understand the dangers of the virus. Those who need help eating or changing can't keep their distance from others. Many facilities also have struggled to keep enough masks and staffers on hand.' A Centers for Medicare & Medicaid Services press officer, said in an email that 'states, not federal officials, manage Medicaid-funded intermediate care facilities and group homes for people with developmental disabilities.' He said many of those facilities serve fewer than eight residents and don't "pose the same concerns as larger congregate settings." Centers for Disease Control and Prevention guidelines recommend that states prioritize long-term care facilities early in the vaccine rollout, but few states specified that people with disabilities who live in group homes should be candidates for that initial vaccine distribution. Some states are tracking the caseloads, but the type of information they collect varies. New York state data revealed disability group home residents there are dying at higher rates than the general population. New York is one of the few that specifically included certified-group facilities, and in February opened access to all people with intellectual or developmental disabilities. In Illinois — which called on the National Guard to respond to outbreaks in two of the state's largest developmental centers in April — more than half of the 1,648 residents in state-run developmental facilities have had the virus. In Montana, people in group living settings including disability housing were in the phase initially right behind health care workers and nursing home residents on the list for vaccines. But the new governor instead prioritized anyone 70 and older and those with underlying health conditions, with the goal of protecting the most vulnerable. The change nearly tripled how many people qualify for that phase of the vaccine rollout. Group home administrators have said many of their clients may still qualify for a vaccine under the governor's new rule because of their medical risks. The new plan also allows health providers to include people with medical conditions on a case-by-case basis. In Florida, the state's COVID-19 vaccine plan included group living settings for those with disabilities in its early vaccine rollout to long-term

	care facilities, but there have been instances where local authorities are not aware of this policy.
Hughes, N., & Anderson, G. (2020). **The experience of the COVID-19 pandemic in a UK learning disability service: Lost in a sea of ever-changing variables – A perspective.** *International Journal of Developmental Disabilities*, 1-4. Published online: 01 Jun 2020 https://doi.org/10.1080/20473869.2020.1773711	**Abstract:** [*none – extracted from text]* The COVID-19 pandemic has had significant ramifications across the world. In turn this has had an enormous impact on Learning [Intellectual] Disability Services (LDS). The restrictions made by governments will likely have a variety of consequences on people with Intellectual disabilities, which will include the pandemic's effect on care and support, welfare benefits and finance, social and emotional supports, and physical and mental health. In March 2020, government sources and national and social media put the UK on a 'war footing', with the virus as the identified enemy. Daily briefings provided advice and guidance to all medical specialties, directorates, and disciplines. 'Business as usual' was effectively suspended and it was clear that there would likely be some deployment of staff to different areas of the nation. From the 16th of March onwards clinical practice started to change and on the 23rd of March the UK went into lockdown. In the ensuing weeks five themes emerged with both clinical and social implications: (1) Working in a Learning Disability Service reinforces the importance of routine, structure, and boundaries; however, as daily briefing brought daily change (which may be uncomfortable for many persons working in a LDS, particularly when workers were unable to give direct, clear and consistent advice to patients and their families. Such stressors had a significant impact on staff morale and raised anxiety among service users. (2) An increasing vulnerability was noted due to comorbid conditions (such as cerebral palsy, epilepsy, diabetes, obesity, and respiratory conditions). Adults with ID began 'shielding' with families sending away carer supports and enacting greater levels of care themselves in the hope of preventing exposure to the virus; consults and support via telephonic means were introduced, but these provided difficult for some adults with ID – social activity was curtailed further contributing to isolation. (3) Among clinicians interservice contact was confounded by use of various, often not integrated, communication platforms; increased edits to wear protective equipment (PPEs) produced confusion early on as conflicting advice on value and integrity of the PPEs circulated. (4). Service users were keen to know when they would be able to enjoy visits from family, go swimming, go to the cinema and such, but the exact dates and schedules were not determined, and these uncertainties were having a detrimental effect on mental health. (5) In retrospect, some adaptation to a new normal has been noted; some service users have expressed a preference for remote clinical contacts and in future there may be a long-term role for the use of technology. For the staff there was a fine balance between the anxiety created by coming to work each day with the increased exposure risk it bought to staff and their households *and* the benefits to mental health of getting out of the house and having a bit of routine.

Hüls, A., Costa, A.C.S., Dierssen, M., Asaad Baksh, R., Bargagna, S., Baumer, N.T., Brandão, A.C., Carfi, A., Carmona-Iragui, M., Chicoine, B.A., Ghosh, S., Lakhanpaul, M., Manso, C., Mayer, M-A., del Carmen Ortega, M., Real de Asua, D., Rebillat, A-S., Russell, L.A., Sgandurra, G., Valentini, D., Sherman, S.L., & Strydom, A. **An international survey on the impact of COVID-19 in individuals with Down syndrome** *medRXiv*, November 5, 2020. 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 like the general population. However, individuals with DS present significantly higher rates of mortality, especially from age 40.
Hüls, A., Costa, A.C.S., Dierssen, M., Baksh, R.A., Bargagna, S., Baumer, N.T., Brandão, A.C., Carfi, A., Carmona-Iragui, M., Chicoine, B.A., Ghosh, S., Lakhanpaul, M., Manso, C., Mayer, M-A., del Carmen Ortega, M., Real de Asua, D., Rebillat, A-S., Russell, L.A., Sgandurra, G., Valentini, D., Sherman, S.L. & Strydom, A. **Medical vulnerability of individuals with down syndrome to severe COVID-19 – data from the trisomy 21 research society and the UK ISARIC4C survey** *EClinicalMedicine*, Published: February 22, 2021. DOI:https://doi.org/10.1016/j.eclinm.2021.100769	**Abstract:** Health conditions, immune dysfunction, and premature aging associated with trisomy 21 (Down syndrome, DS) may impact the clinical course of COVID-19. The T21RS COVID-19 Initiative launched an international survey for clinicians or caregivers on patients with COVID-19 and DS. Data collected between April and October 2020 (N=1046) were analyzed and compared with the UK ISARIC4C survey of hospitalized COVID-19 patients with and without DS. The mean age of COVID-19 patients with DS in the T21RS survey was 29 years (SD = 18). Like the general population, the most frequent signs and symptoms of COVID-19 were fever, cough, and shortness of breath. Joint/muscle pain and vomiting or nausea were less frequent (p < 0.01), whereas altered consciousness/confusion were more frequent (p < 0.01). Risk factors for hospitalization and mortality were similar to the general population 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 in patients with DS (T21RS DS versus non-DS patients: risk ratio (RR) = 3.5 (95%-CI=2.6;4.4), ISARIC4C DS versus non-DS patients: 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 like the general population. However, individuals with DS present significantly higher rates of medical complications and mortality, especially from age 40.
Inclusion Europe **Neglect and discrimination. Multiplied. How COVID-19 affected the rights of people with intellectual disabilities and their families.** *Inclusion Europe* (Brussels), November 2020. 55pp. https://www.inclusion-europe.eu/covidreport-2020/#more http://www.inclusion-europe.eu/wp-content/uploads/2020/11/COVID-report-Final.pdf Inclusion Europe, Avenue des Arts 3, 1210 Brussels, Belgium secretariat@inclusion-europe.org [Authors: Helen Portal, Gerlinde Schmidt, Rita Crespo Fernández, Bárbara Marcondes, Milan Šveřepa, Valentina Dragičević, David Lysaght]	**Abstract:** [*none – extracted from text*] The Covid-19 sanitary crisis did not in fact bring new issues concerning the situation of people with intellectual disabilities: it intensified, magnified the segregation and discrimination of people with intellectual disabilities. Many human rights of people with intellectual disabilities were violated during this period. People with intellectual disabilities were not properly considered before the crisis (e.g., the consultation of people with intellectual disabilities was not a priority and, in some countries, people with intellectual disabilities still do not have legal capacity, which means they are denied their right to participate in civil and political life). The coronavirus crisis sheds light on their exclusion. Conclusions noted: • *Discrimination in access to health care:* For people with intellectual disabilities who contracted Covid-19, access to healthcare and treatment in hospitals was not guaranteed in many EU countries. • *Lack of protective equipment:* Protective equipment took time to arrive and was not given to care workers and workers coming into residential institutions. Even as supply of protective equipment started to improve, services for people with disabilities and families supporting them were overlooked. • *Living conditions*: Life quality of people living in residential institutions during the Covid-19 was overall bad. At the beginning of lockdown, social isolation and prohibition to see family members was the norm. People were isolated in their rooms, there were restrictions to the mobility and prohibitions to go see family members and friends. • *Death rates in institutions:* Collecting accurate information on death rates in institutions is still difficult, as countries throughout the European Union collect and publish data in a different manner and the death rates of people with intellectual disabilities in institutions are nearly never reported. • *Access to support:* As there were some strict lockdown measures, a lot of community-based care and support had to stop during the coronavirus emergency, and this led people living independently to very problematic situations. Some people with intellectual disabilities had to go live with their families during the lockdown, and families had to care for them as there was no access to support of any kind. • *Family carers*: The coronavirus crisis is having immediate impact on the lives of persons with disabilities, and families also feel the burden of this crisis. • *Access to information and consultation:* At the beginning of the Coronavirus emergency, people with intellectual disabilities were not given accessible information (i.e., it

	was not provided in easy–to–read and understand language), which is problematic for people with intellectual disabilities because some cannot access the internet without support to find the information, some have difficulties reading, and some need support to understand the guidelines.
Jeste, S., Hyde, C., Distefano, C., Halladay, A., Ray, S., Porath, M., Wilson, R. B. & Thurm, A. **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 session, 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.
Jesus TS, Bhattacharjya S, Papadimitriou C, Bogdanova Y, Bentley J, Arango-Lasprilla JC, Kamalakannan S **The Refugee Empowerment Task Force International Networking Group Of The American Congress Of Rehabilitation Medicine. Lockdown-Related Disparities Experienced by People with Disabilities during the First Wave of the COVID-19**	**Abstract:** People with disabilities may be disproportionally affected by the COVID-19 pandemic. We synthesize the literature on broader health and social impacts on people with disabilities arising from lockdown-related measures. Methods: Scoping review with thematic analysis. Up to mid-September 2020, seven scientific databases and three pre-print servers were searched to identify empirical or perspective papers addressing lockdown-related disparities experienced by people with disabilities. Snowballing searches and experts' consultation also occurred. Two independent reviewers took eligibility decisions and performed data extractions. Authors found that out of 1026 unique references, 85 addressed

Pandemic: Scoping Review with Thematic Analysis. Int J Environ Res Public Health. 2021 Jun 8;18(12):6178. doi: 10.3390/ijerph18126178. PMID: 34200979; PMCID: PMC8228347.	lockdown-related disparities experienced by people with disabilities. Ten primary and two central themes were identified: (1) Disrupted access to healthcare (other than for COVID-19); (2) Reduced physical activity leading to health and functional decline; (3) From physical distance and inactivity to social isolation and loneliness; (4) Disruption of personal assistance and community support networks; (5) Children with disabilities disproportionally affected by school closures; (6) Psychological consequences of disrupted routines, activities, and support; (7) Family and informal caregiver burden and stress; (8) Risks of maltreatment, violence, and self-harm; (9) Reduced employment and/or income exacerbating disparities; and (10) Digital divide in access to health, education, and support services. Lack of disability-inclusive response and emergency preparedness and structural, pre-pandemic disparities were the central themes. Authors concluded that lockdown-related measures to contain the COVID-19 pandemic can disproportionally affect people with disabilities with broader impact on their health and social grounds. Lack of disability-inclusive response and emergency preparedness and pre-pandemic disparities created structural disadvantages, exacerbated during the pandemic. Both structural disparities and their pandemic ramifications require the development and implementation of disability-inclusive public health and policy measures.
Kantar, A., Mazza, A., Bonanomi, E., Odoni, M., Seminara, M., Dalla Verde, I., Lovati C., Bolognini, s., & D'Antiga, L. **COVID-19 and children with Down syndrome: is there any real reason to worry? Two case reports with severe course.** *BMC Pediatrics*, 2020, Dec 18, 20(1), 561. doi: 10.1186/s12887-020-02471-5.	**Abstract:** Down syndrome (DS) is characterized by a series of immune dysregulations, of which interferon hyperreactivity is important, as it is responsible for surging antiviral responses and the possible initiation of an amplified cytokine storm. This biological condition is attributed to immune regulators encoded in chromosome 21. Moreover, DS is also characterized by the coexistence of obesity and cardiovascular and respiratory anomalies, which are risk factors for coronavirus disease (COVID-19) caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). A total of 55 children were admitted to the pediatric ward in Bergamo, between February and May 2020 for COVID-19. Here, we describe the cases of two children with DS and a confirmed COVID-19 diagnosis who had a severe course. In addition, both cases involved one or more comorbidities, including cardiovascular anomalies, obesity, and/or obstructive sleep apnea. Our observations indicate that children with DS are at risk for severe COVID-19 disease course.
Kavanagh, A., Dickinson, H., Carey, G. Llewellyn, G. Emerson, E., Disney, G. & Hatton, C. **Improving health care for disabled people in COVID-19 and beyond: Lessons from Australia and England.** *Disability and Health Journal,* 2021, 14(2), 101050. [Advance online publication, December 5, 2020]	**Abstract:** COVID-19 has exacerbated pre-existing difficulties children and adults with disability face accessing quality health care. Some people with disability (including intellectual 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 poor outcomes if they become infected. Despite this, governments have been slow to recognize, and respond to, the unique and diverse health care

https://doi.org/10.1016/j.dhjo.2020.101050	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.
Kim, M.A., Yi, J., Jung, S.M., Hwang, S., & Sung, J. **A qualitative study on parents' concerns about adult children with intellectual disabilities amid the COVID-19 pandemic in South Korea** *Journal of Applied Research in Intellectual Disabilities*, 2021, 34(4), 1145-1155. https://doi.org/10.1111/jar.12875	**Abstract:** This study aimed to understand parents' concerns about their adult child with intellectual disabilities due to the restriction of community-based services amid the COVID-19 pandemic in South Korea. In-depth interviews were conducted face-to-face or by telephone with 19 parents of adult children with intellectual disabilities who had to stop using community-based services. Participants worried that their adult child was not aware of the seriousness of COVID-19, was more susceptible to the COVID-19 virus, could not recognize self-infection and could have fatal consequences of getting infected with COVID-19. They expected challenges in their adult child's life (losing a daily routine, being isolated, regression in skills, becoming bored, lacking physical activities and increased behavioral challenges) but also experienced adjustments and hopes. The study demonstrated parents' worry about their adult child becoming infected with COVID-19, highlighting the urgent need for community-based services to address psychosocial challenges during the pandemic.
Kim MA, Yi J, Sung J, Hwang S, Howey W, Jung SM. **Changes in life experiences of adults with intellectual disabilities in the COVID-19 pandemics in South Korea.** Disability Health Journal, 2021 Oct, 14(4), 101120. doi: 10.1016/j.dhjo.2021.101120. Epub 2021 May 23. PMID: 34074618.	**Abstract:** The COVID-19 pandemic has had a significant impact on adults with intellectual disabilities who are dependent on community services. This study explored the experiences of adults with intellectual disabilities from their perspective during the COVID-19 pandemic in South Korea, where most community-based services were suspended. We conducted in-depth interviews with 15 adults with intellectual disabilities who lost access to services during COVID-19 pandemic. Inductive thematic analysis was conducted. Five overarching themes emerged: changes in (a) daily life, (b) health behaviors, (c) family relationships, (d) social relationships, and (e) social participation. Most participants experienced the loss of daily routines and healthy behaviors, family conflicts, and social isolation, but they also developed new ways of adapting and finding a new normal. The findings offer valuable evidence of ways to develop and stabilize community-based services during a pandemic, with insights into the experiences of people with intellectual disabilities.
Krishnan, U.S., Krishnan, S.S., Jain, S., Chavolla-Calderon, M.B., Lewis, M., Chung, W.K., & Rosenzweig, E.B. **SARS-CoV-2 Infection in Patients with Down Syndrome, Congenital Heart Disease, and Pulmonary Hypertension: Is Down Syndrome a Risk Factor?**	**Abstract:** With increasing information available about the epidemiology, pathophysiology, and management of patients affected with severe acute respiratory syndrome corona virus-2 infection, patients with Down syndrome, congenital heart disease, airway obstruction, and pulmonary hypertension present a unique challenge. This case series describes 3 patients with Down syndrome and respiratory failure secondary to coronavirus infection.

The Journal of Pediatrics, 2020 (Oct), 225, 246-248. https://www.sciencedirect.com/science/article/abs/pii/S0022347620308301	
Kumar, S., Veldhuis, A., & Malhotra, T. **Neuropsychiatric and cognitive sequelae of COVID-19** *Frontiers in Psychology*, 02 March 2021; https://doi.org/10.3389/fpsyg.2021.577529 ***NOTE: This report does not directly focus on intellectual disability but is of value as it refers to the residual effects of COVID-19 and can be applied to adults with intellectual disability.***	**Abstract:** Coronavirus disease 2019 (COVID-19) is likely to have long-term mental health effects on individuals who have recovered from COVID-19. Rightly, there is a global response for recognition and planning on how to deal with mental health problems for everyone impacted by the global pandemic. This does not just include COVID-19 patients but the public and health care workers as well. There is also a need to understand the role of the virus itself in the pathophysiology of mental health disorders and longer-term mental health sequelae. Emerging evidence suggests that COVID-19 patients develop neurological symptoms such as headache, altered consciousness, and paranesthesia. Brain tissue oedema and partial neurodegeneration have also been observed in an autopsy. In addition, there are reports that the virus has the potential to cause nervous system damage. Together, these findings point to a possible role of the virus in the development of acute psychiatric symptoms and long-term neuropsychiatric sequelae of COVID-19. The brain pathologies associated with COVID-19 infection is likely to have a long-term impact on cognitive processes. Evidence from other viral respiratory infections, such as severe acute respiratory syndrome (SARS), suggests a potential development of psychiatric disorders, long-term neuropsychiatric disorders, and cognitive problems. The short-term neuropsychiatric and cognitive complications following COVID-19 are varied and affect a large proportion of COVID-19 survivors. In the medium- and long-term period, there is going to be an influx of patients with psychiatric and cognitive problems who were otherwise healthy prior to COVID-19 infection. Increased neuropsychiatric manifestations could be observed in the form of an increase in cases of depression, anxiety, PTSD, and in certain cases severe mental illnesses. Cognitive sequelae are also likely to be varied and a detailed cognitive evaluation should be considered for such individuals to monitor the emergence of new neurological cases. Robust neuropsychiatric and cognitive monitoring will enable health care providers to plan adequate health care delivery and allocate resources adequately. Early intervention for emerging cognitive problems will be critical for independent functioning and improved quality of life for many COVID-19 survivors.
Landes, S.D., Turk, M.A., Damiani, M.R., Proctor, P., & Baier, S. **Outcomes among people with intellectual and developmental disabilities receiving residential services.**	**Abstract:** Although there is evidence of more severe COVID-19 outcomes, there is no information describing the risk factors for COVID-19 diagnosis and/or mortality among people with intellectual and developmental disabilities (IDD) receiving residential support services in the US. The authors sought to o identify associations between demographic characteristics, residential characteristics, and/or preexisting health conditions

JAMA Network Open, 2021, 4(6), e2112862. doi:10.1001/jamanetworkopen.2021.12862	and COVID-19 diagnosis and mortality for people with IDD receiving residential support services. This cohort study tracked COVID-19 outcomes for 543 individuals with IDD who were receiving support services from a single organization providing residential services in the 5 boroughs of New York City from March 1 to October 1, 2020. Statistical analysis was performed from December 2020 to February 2021. Resident-level characteristics, including age, sex, race/ethnicity, disability status, residential characteristics, and preexisting medical conditions. COVID-19 diagnosis was confirmed by laboratory test. COVID-19 mortality indicated that the individual died from COVID-19 during the study. Logistic regression models were used to evaluate associations between demographic characteristics, residential characteristics, and preexisting health conditions and COVID-19 diagnosis and mortality. Among the 543 individuals with IDD in the study, the median (interquartile range) age was 57.0 (45-65) years; 217 (40.0%) were female, and 274 (50.5%) were Black, Asian/Pacific Islander, American Indian or Alaskan Native, or Hispanic. The case rate was 16 759 (95% CI, 13 853-20 131) per 100 000; the mortality rate was 6446 (95% CI, 4671-8832) per 100 000; and the case-fatality rate was 38.5% (95% CI, 29.1%-48.7%). Increased age (odds ratio [OR], 1.04; 95% CI, 1.02-1.06), Down syndrome (OR, 2.91; 95% CI, 1.49-5.69), an increased number of residents (OR, 1.07; 95% CI, 1.00-1.14), and chronic kidney disease (OR, 4.17; 95% CI, 1.90-9.15) were associated with COVID-19 diagnosis. Heart disease (OR, 10.60; 95% CI, 2.68-41.90) was associated with COVID-19 mortality. This study found that, like the general population, increased age and preexisting health conditions were associated with COVID-19 outcomes for people with IDD receiving residential support services in New York City. As with older adults living in nursing homes, number of residents was also associated with more severe COVID-19 outcomes. Unique to people with IDD was an increased risk of COVID-19 diagnosis for people with Down syndrome
Landes, S.D., Turk, M.A., & Wong, A.W.W.A. **COVID-19 Outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs.** *Disability and Health Journal*, 2021, 14(2), 101051. [Published 5 Dec 2020], https://doi.org/10.1016/j.dhjo.2020.101051	**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. **COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State.** *Disability and Health Journal.* 2020, 13(4), October 2020 100969 https://doi.org/10.1016/j.dhjo.2020.100969	**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.
Landes, S.D., Stevens, D. & Turk, M.A. **COVID-19 and pneumonia: increased risk for individuals with intellectual and developmental disabilities during the pandemic** *RESEARCH BRIEF #21* - April 27, 2020. Lerner Center for Public Health Promotion, Syracuse University https://lernercenter.syr.edu/wp-content/uploads/2020/04/Landes.Stevens.Turk_..pdf	**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.
LaClaire, H. **For those with intellectual disabilities, COVID presents unique risks** *Portland (ME) Press Herald,* November 19, 2020	**Abstract:** [none - *Extracted from text*] 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

pressherald.com/2020/11/19/for-those-with-intellectual-disabilities-covid-presents-unique-risks/	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 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 $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.
Lobato Pontes, G.C., Rego Lobato, A.C., da Silva, S.M., Alves da Silva, D.F., Ferreira da Silva, A., Barbosa, Rocha, R.S., Duarte de Oliveira, B., Calvinho Martins, T.O., Gomes Chermont, A., & da Costa Cunha, K. **COVID-19 in a Down syndrome newborn** *International Journal of Clinical Pediatrics,* 2020, Dec, 9(4), 116-119.	**Abstract:** A 36-week premature newborn with trisomy 21, had a fever, runny nose, and mild dyspnea at 27 days old. Parents had flu-like symptoms. He was admitted to intensive care unit (ICU), in isolation with support therapy. His reverse transcription-polymerase chain reaction (RT-PCR) test for coronavirus disease 2019 (COVID-19) was positive. He had leukopenia and lymphopenia and increased C-reactive protein (CRP) levels, associated with mixed and interstitial opacities on chest radiography. Antibiotic therapy was performed with

https://theijcp.org/index.php/ijcp/article/view/396/345	ampicillin and gentamicin for 10 days. He had improvement of symptoms, with worsening of CRP levels. On the 11th day of hospitalization antibiotic therapy was replaced by clarithromycin, which was performed for 5 days, with laboratory improvement after introduction. Chest computed tomography (CT) showed bilateral ground-glass lesions. He had a good recovery and was discharged from hospital with 17 days of hospitalization.
Lund, E.M., Forber-Pratt, A.J., Wilson, C., & Mona, L.R. **The COVID-19 pandemic, stress, and trauma in the disability community: A call to action** *Rehabilitation Psychology*, 2020, 65(4), 313-322. http://dx.doi.org/10.1037/rep0000368	**Abstract:** To inform the field of rehabilitation psychology about the impacts of the 2019 novel coronavirus (COVID-19) on the disability community in the United States and the additional sources of stress and trauma disabled people face during these times. A review of the literature on disability and COVID-19 is provided [authors use an inclusive definition of "disability" that includes physical, psychiatric, learning, sensory, and developmental disabilities], with an emphasis on sources of trauma and stress that disproportionately impact the disability community and the ways in which disability intersects with other marginalized identities in the context of trauma and the pandemic. We also reflect on the potential impacts on the field of psychology and the ways in which psychologists, led by rehabilitation psychologists, can support disabled clients and the broader disability community at both the individual client and systemic levels. The COVID-19 pandemic introduces unique potential sources of trauma and stress within the disability community, including concerns about health care rationing and ableism in health care, isolation, and the deaths and illnesses of loved ones and community members. Rehabilitation psychologists and other professionals should be aware of the potential for trauma and stress among disabled clients and work with them to mitigate its effects. Additionally, psychologists should also work with the disability community and disabled colleagues to address systemic and institutional ableism and its intersections with other forms of oppression.
Lunsky, Y., Kithulegoda, N., Thai, K., Benham, J.L., Lang, R., Desveaux, L., & Ivers, N.M. **Beliefs regarding COVID-19 vaccines among Canadian workers in the intellectual disability sector prior to vaccine implementation.** *Journal of Intellectual Disability Research*, 2021 [First published 31 March 2021] https://doi.org/10.1111/jir.12838	**Abstract:** Workers supporting adults with intellectual disabilities (ID) experience significant stress in their essential role during COVID-19 due to the high risk of their clients contracting COVID-19 and having adverse outcomes. The purpose of the current study was to describe the attitudes of workers towards COVID-19 vaccination prior to vaccination rollout, with a view to informing strategies to promote vaccine uptake within this high-risk sector. An online survey was sent via email to workers supporting adults with ID in Ontario, Canada, between January 21 and February 3, 2021, by agency leadership and union representatives. Three thousand and three hundred and seventy-one workers, representing approximately 11.2% of Ontario workers supporting adults with ID completed an online survey. Most reported that they were very likely (62%) or likely (20%) to get a COVID-19 vaccine (vaccination intent) although 18% reported they were less likely to do so (vaccination nonintent). Workers with vaccination nonintent were younger and were more likely to endorse the beliefs that (1) it will not benefit them or those around them,

	(2) it was not part of their job, (3) rapid development confers uncertainties and risks, and (4) they feared potential vaccine side effects. There is a need to address common misconceptions among workers supporting adults with ID to help activate them as vaccine advocates in the communities they serve. Partnered efforts between workers, unions, and agency leadership with public health experts to address concerns are required.
Malle, L., Gao, C., Bouvier, N.M., Percha, B., & Bogunovic, D. **COVID-19 hospitalization is more frequent and severe in Down syndrome and affects patients a decade younger.** *medRxiv,* 2020, doi: https://doi.org/10.1101/2020.05.26.20112748	**Abstract:** Individuals with rare disorders, like Down syndrome (DS) are historically understudied. Currently, it is not known how COVID-19 pandemic affects individuals with DS. Herein, we report an analysis of individuals with DS who were hospitalized with COVID-19 in the Mount Sinai Health System in New York City, USA. In this retrospective, single-center study of 4,615 patients hospitalized with COVID-19, we analyzed all patients with DS admitted in the Mount Sinai Health System. Hospitalization rates, clinical and outcomes were assessed. Contrary to an expected number of one, we identified six patients with DS. We found that patients with DS are at an 8.9-fold higher risk of hospitalization with COVID-19 when compared to non-DS patients. Hospitalized DS individuals are on average 10 years younger than non-DS patients with COVID-19. Moreover, type 2 diabetes mellitus appears to be an important driver of this susceptibility to COVID-19. Finally, patients with DS have more severe outcomes than controls, and are more likely to progress to sepsis. We demonstrate that individuals with DS represent a higher risk population for COVID-19 compared to the general population and conclude that particular care should be taken for both the prevention and treatment of COVID-19 in these patients. [Text extracted from article] We compared the hospitalization rates of DS patients to over 4,500 individuals without DS, and we assessed comorbidities and outcomes of individuals with DS compared to age, race, and sex-matched controls hospitalized with COVID-19. To the best of our knowledge, we provide the first evidence that patients with DS with are at higher risk of hospitalization with COVID-19 and more severe disease progression than non-DS patients. We demonstrated that individuals with DS are a high-risk population for COVID-19 and suggest appropriate measures should be taken for both the prevention and treatment of COVID-19 in these patients.
Malle, L., Gao, C., Hur, C., Truong, H.Q., Bouvier, N.M., Percha, B., Kong, X-F., & Bogunovic, D. **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	**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.
Marra AR, Kobayashi T, Suzuki H, et al. **Short-term effectiveness of COVID-19 vaccines in immunocompromised patients: A systematic literature review and meta-analysis.** *Journal of Infection*, 2022;84(3):297-310. doi: 10.1016/j.jinf.2021.12.035. Epub 2022 Jan 1.	**Abstract:** The authors aimed to assess the short-term effectiveness of COVID-19 vaccines among immunocompromised patients to prevent laboratory-confirmed symptomatic COVID-19 infection. This was done via systematic review and meta-analysis. They calculated the pooled diagnostic odds ratio [DOR] (95% CI) for COVID-19 infection between immunocompromised patients and healthy people or those with stable chronic medical conditions. VE was estimated as 100% x (1-DOR). We also investigated the rates of developing anti-SARS-CoV-2 spike protein IgG between the 2 groups. Twenty studies evaluating COVID-19 vaccine response, and four studies evaluating VE were included in the meta-analysis. The pooled DOR for symptomatic COVID-19 infection in immunocompromised patients was 0.296 (95% CI: 0.108-0.811) with an estimated VE of 70.4% (95% CI: 18.9%- 89.2%). When stratified by diagnosis, IgG antibody levels were much higher in the control group compared to immunocompromised patients with solid organ transplant (pOR 232.3; 95% Cl: 66.98-806.03), malignant diseases (pOR 42.0, 95% Cl: 11.68-151.03), and inflammatory rheumatic diseases (pOR 19.06; 95% Cl: 5.00-72.62). Authors found COVID-19 mRNA vaccines were effective against symptomatic COVID-19 among the immunecompromised patients but had lower VE compared to the controls. Further research is needed to understand the discordance between antibody production and protection against symptomatic COVID-19 infection.
Martin-Khan, M., Bail, K., Yates, M.W., Thompson, J., Graham, & Cognitive Impairment and COVID-19, Hospital Care Guidance Committee **Interim guidance for health-care professionals and administrators providing hospital care to adult patients with cognitive impairment, in the context of COVID-19 pandemic.** *Australasian Journal on Ageing*, 2020, 39(3), Sept, 283-286. https://doi.org/10.1111/ajag.12831	**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 videoconferencing technologies. Developing models of care that proactively support best practice can minimize the risk of delirium, mitigate escalating symptoms, and guide the use of non-pharmacological, pharmacological (start low, go slow) or

	physical restraint in managing behavioral and psychological symptoms.
Masi, A., Mendoza, D., Tully, L., Azim, S.I., **Impact of the COVID-19 pandemic on the well-being of children with neurodevelopmental disabilities and their parents** *Journal of Pediatrics and Child Health,* 2021, 57(5), 631-636. https://doi.org/10.1111/jpc.15285	**Abstract:** Authors undertook a study to examine the impact of COVID-19 pandemic on child mental health and socio-emotional and physical well-being (including sleep, diet, exercise, use of electronic media; care giver perceptions of symptoms of child neurodevelopmental disability [NDD] and comorbidities), and care giver mental health and well-being, social support and service use. An online cross-sectional self-report survey was distributed via disability service providers and support groups. Care givers of children aged 2–17 years with a NDD were invited to respond to questions on child symptom severity and well-being, parent well-being and service access and satisfaction. Overall, 302 care givers (94.7% female) completed the survey. Average child age was 9.7 years and 66.9% were male. Worsening of any child NDD or comorbid mental health symptom was reported by 64.5% of respondents and 76.9% reported child health and well-being was impacted by COVID-19. Children were viewing more television and digital media (81.6%), exercising less (68.0%), experiencing reduced sleep quality (43.6%) and had a poorer diet (32.4%). Almost one fifth (18.8%) of families reported an increase in the dosage of medication administered to their child. Parents reported COVID-19 had impacted their own well-being (76.1%). Over half of respondents were not satisfied with services received during COVID-19 (54.8%) and just 30% reported that telehealth works well for their child. Targeted interventions are required to address worsening child neurodevelopmental disability, mental health symptoms and poor diet, sleep and exercise patterns. Improved access to telehealth services is indicated, as is further research on barriers and enablers of effective telehealth services. Authors note that children with NDDs are struggling as a result of the COVID-19 restrictions, with adverse impacts on NDD symptoms, stress, health and well-being
McCarron, M., McCausland, D., Luus, R., Allen, A., Sheerin, F., Burke, E., McGlinchy, E., Flannery, F., & McCallion. P. **The impact of coronavirus disease 2019 (COVID-19) on older adults with an intellectual disability during the first wave of the pandemic in Ireland** *HRB Open Research,* 2021, 4:93 (August 19) https://doi.org/10.12688/hrbopenres.13238.1	**Abstract:** People with intellectual disability have increased risk of exposure to and adverse outcomes from coronavirus disease 2019 (COVID-19). They also face challenges to mental health and well-being from COVID-19-related social restrictions and service closures. Data from a supplemental COVID-19 survey from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) (n=710) was used to assess outcomes from the first infection wave of COVID-19 among adults with intellectual disability aged 40+ years in Ireland. Data was gathered on testing, for symptoms and outcomes; procedures to manage COVID-19; and both stress/anxiety and positive experiences during the pandemic. Demographic and health-related data from the main IDS-TILDA dataset was included in analyses. High rates were identified of health conditions associated with poorer COVID-19 outcomes, including overweight/obesity (66.6%, n=365), high cholesterol (38.6%, n=274) and cardiovascular disease (33.7%, n=239). Over half (53.5%, n=380) reported emotional, nervous, or psychiatric disorders. Almost two-thirds (62.4%, n=443) were

	tested for COVID-19, with 10% (n=71) reporting symptoms and 2.5% (n=11) testing positive. There were no instances of COVID-19 related mortality. Common symptoms included fatigue, fever, and cough. Some participants (7.8%, n=55) moved from their usual home to isolate, most often (n=31) or relocate to a family home (n=11). Three-quarters (78.7%) of those who were symptomatic or who tested positive had plans to manage self-isolation and two-thirds were able to comply with guidelines. Over half (55%, n=383) reported some COVID-19 related stress/anxiety; and a similar proportion reported positive aspects during this period (58%, n=381). Our data suggests that people with intellectual disability avoided the worst impacts of COVID-19 during the first infection wave in Ireland. Nevertheless, participants' health profiles suggest that this population remains at high risk for adverse infection outcomes. Repeated measures are needed to track health and well-being outcomes across multiple infection waves.
McCausland, D. Luis, R., & McCallion, P., Murphy, E., McCarron, M. **The impact of COVID-19 on the social inclusion of older adults with an intellectual disability during the first wave of the pandemic in Ireland** *Journal of Intellectual Disability Research*, 2021, 24 June, https://doi.org/10.1111/jir.12862	**Abstract:** Social restrictions and service closures from COVID-19 have negatively impacted social inclusion and well-being for some people with intellectual disabilities (IDs). The fourth wave of a national longitudinal study on ageing in people with ID in Ireland was interrupted during the COVID-19 outbreak. Social inclusion data for pre-existing participants interviewed before COVID-19 (n = 444) were compared with data for pre-existing participants interviewed during/after lockdown (n = 62). More people interviewed after the lockdown reported frequent family contact. Significantly greater numbers in the post-lockdown group reported access to and use of technology than the pre-lockdown group. Technology use was higher among those living in grouped residences supported by services compared with individuals living independently or with family. During the early stages of the COVID-19 pandemic in Ireland, many older adults with ID stayed connected with family and reported rates of contact higher than were reported by others before COVID-19. This connection may have been supported by a significant increase in technology use during the pandemic. However, uneven use of technology may disadvantage some including individuals living with family or independently. Given that COVID-19 restrictions are likely to continue to restrict social opportunities, increased digital support may assist more people with ID to use technology to maintain their social connections.
McGonigal, M. **Providing quality care to the intellectually disadvantaged patient population during the Covid-19 pandemic** *Critical Care Nursing Quarterly*, 2020 (October/December), 43(4), 480-483. doi: 10.1097/CNQ.0000000000000331	**Abstract:** The coronavirus pandemic has impacted global health care delivery within a short period of time and has spotlighted the needs of vulnerable patient populations. The recommended initiatives to prevent the viral spread have included strategies such as social distancing, hand hygiene, and wearing protective personal equipment. These activities are community-wide focused, however, may be difficult to achieve for those individuals with intellectual disabilities, thus making this population susceptible to viral spread of infection. This article discusses the experience at a large urban teaching

	hospital regarding the care of intellectually disadvantaged patients with COVID-19 infection.
McMahon, M., Hatton, C., Stansfield, J., & Cockayne, G. **An audit of the well-being of staff working in intellectual disability settings in Ireland during the COVID-19 pandemic** *Tizard Learning Disability Review*, 2020, 25(4). 237-246. https://doi.org/10.1108/TLDR-09-2020-0027	**Abstract:** The severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) has infected millions of people worldwide. Individuals with intellectual disability are at a disproportionate risk of mortality, given the health inequalities they experience. This puts a significant burden of responsibility on staff who support these individuals. Consequently, the aim was to establish a baseline of the well-being of staff working in intellectual disability services in Ireland during the COVID-19 pandemic. An online survey was carried out using the Copenhagen Burnout Inventory, a brief measure of depression (Patient Health Questionnaire-9) and a brief measure of anxiety (General Anxiety Disorder-7). In total, 285 staff in the Republic of Ireland completed the survey. These staff reported moderate levels of personal and work-related burnout and mild levels of anxiety and depression. Higher mean scores were recorded across scales from staff who worked in independent living settings and from staff who supported individuals with challenging behavior.
Mills, W.R., Sender, S., Lichtefeld, J., Romano, N., Reynolds, K., Price, M., Phipps, J., White, L., Howard, S., Poltavski, D., & Barnes, R. **Supporting individuals with intellectual and developmental disability during the first 100 days of the COVID-19 outbreak in the USA.** *Journal of Intellectual Disability Research,* 2020, Jul, 64(7), 489-496. doi: 10.1111/jir.12740. Epub 2020 Jun 3.	**Abstract**: [*Abstract and extract from article text*] 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 home and are recovering. Five remain hospitalized, with three improving and two remaining in intensive care and on mechanical ventilation. There have been three deaths. We found that among COVID-19-positive individuals with IDD, a higher number of chronic medical conditions and male sex were characteristics associated with a greater likelihood of hospitalization. In the first 100 days of the COVID-19 outbreak in the USA, we observed that people with IDD living in congregate care settings can benefit from a coordinated approach to infection control, case identification and cohorting, as evidenced by the low relative case rate reported. Male individuals with higher numbers of chronic medical conditions were more likely to be hospitalized, while younger, less chronically ill individuals recovered spontaneously at home.
Mozes, A. **Intellectual disability raises COVID-19 death risk.** *WebMD,* (2020. https://www.webmd.com/lung/news/20200608/intellectual-disability-raises-covid19-death-risk#1 See also: **People with intellectual disabilities are being hit hard by COVID-19** *Medical Press, June 8, 2020* https://medicalxpress.com/news/2020-06-people-intellectual-disabilities-hard-covid-.html	**Abstract**: [*none – extracted from text*]. 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.
Musumeci, MB., & Chidambaram, P. **COVID-19 vaccine access for people with disabilities** *KFF Issue Brief*, March 1, 2021. https://www.kff.org/medicaid/issue-brief/covid-19-vaccine-access-for-people-with-disabilities/	**Abstract:** [*none – abstracted from text*] The COVID-19 pandemic has taken a heavy toll on people in nursing homes, with those in long-term care facilities accounting for a disproportionate share of all deaths attributable to COVID-19 to date. However, less attention has been paid to nonelderly people with disabilities who use long-term services and supports (LTSS) but live outside of nursing homes. This population includes people with a range of disabilities, such as people with autism or Down syndrome who live in group homes, people with physical disabilities who receive personal care services at home, and people who are receiving behavioral health treatment in residential facilities. Some nonelderly people with disabilities receive LTSS in a variety of community-based settings such as group homes, adult day health programs, and/or their own homes. Other nonelderly people with disabilities receive LTSS in institutional settings such as intermediate care facilities for people with intellectual or developmental disabilities (ICF/IDDs) or behavioral health treatment centers for people with mental illness or substance use disorder. As of February 11, 2021, 31 states report at least some data on COVID-19 cases and deaths in LTSS settings that primarily serve nonelderly people with disabilities. These settings include both home and community-based settings such as group homes, personal care homes, adult day programs, and other community-based settings; and institutional settings such as intermediate care facilities and psychiatric institutions. The wide variety in state reporting makes it difficult to compare between states or have a complete understanding of how people with disabilities have been impacted by the pandemic. Among states reporting data, there were 111,000 cases and over 6,500 deaths across these settings as of February 11, 2021. Of the 31 states reporting data, 8 states report data only for institutional settings, 8 states report data only for home and community-based settings, and 15 states report data for both settings. Data from a limited number of states suggest that LTSS residents in institutions other than nursing and assisted living facilities, as well as those in some community-based settings, face an elevated risk of COVID-19 infection. Overall, limited data on the number of people in HCBS and institutional settings other than nursing and assisted living facilities makes calculating case or death rates difficult. Direct care workers who provide LTSS to people with disabilities outside of nursing homes also face increased risks from COVID-19, similar to their nursing home counterparts. Few state vaccination plans explicitly mention people with disabilities (other than people with "high risk medical conditions"). Prioritizing certain high risk medical conditions may include some but not all people with disabilities. People with disabilities who receive services in the community or in non-nursing facility institutions may face

	accessibility barriers at vaccine distribution sites. In many cases, people with disabilities will need to travel to a distribution site to receive their vaccines. People with disabilities and their direct care providers may benefit from focused messaging as part of general vaccine outreach and public education efforts. Outreach efforts targeted to people with disabilities could be part of broader public education strategies related to vaccine distribution. Making information available in plain language and in accessible formats (such as for people with vision, hearing, or cognitive disabilities) can help ensure that it is useful to people with disabilities
Navas, P., Amor, A.M., Crespo, M., Wolowiec, Z., & Verdugo, M.A. Supports for people with intellectual and developmental disabilities during the COVID-19 pandemic from their own perspective *Research in Developmental Disabilities,* 2021, 108, 103813. doi.org/10.1016/j.ridd.2020.103813.	**Abstract:** Individuals with intellectual and developmental disabilities (IDD) represent a particularly vulnerable group to the threats posed by COVID-19. However, they have not yet been given a voice on how their living conditions have been affected by COVID-19. This study aimed to report the impact on people with IDD of COVID-19 and the response measures applied in Spain during the lockdown. Data on 582 individuals with IDD were collected through a survey. Seven open questions were included to capture the perspectives of people with IDD on COVID-19 and its consequences. Content analysis was performed to identify themes and categories across participant responses. Chi-square tests were used to analyze the relationship between reporting a specific category and participants' characteristics. Supports have been conditioned by the living context. People living in specific settings had fewer natural supports, while those living with their family relied heavily on it. Participants also lacked supports considered necessary. It is worth stressing that persons with IDD have also provided support to others. Although people with IDD have generally received the assistance they need during the lockdown, it must be ensured that appropriate supports are provided regardless of the context in which they live.
Navas, P., Verdugo, M.Á., Martínez, S., Amor, A.M., Crespo, M., & Deliu, M.M. **Impact of COVID-19 on the burden of care of families of people with intellectual and developmental disabilities.** Journal of Applied Research in Intellectual Disability, 2022 Mar, 35(2), 577-586. doi: 10.1111/jar.12969. Epub 2021 Dec 9. PMID: 34888996.	**Abstract:** This study analyzed the impact that COVID-19 and the response measures implemented by the Spanish Government have had on families of individuals with intellectual and developmental disabilities. Data on 323 family members (M = 52.3 years old; SD = 10.5) were collected through an online survey, which was focused on analyzing difficulties experienced and service provision during lockdown. Many families (66.3%) have seen their level of stress increase during lockdown because of, among other reasons, a greater burden of care. Difficulties were associated with the closure and changes in disability-related services. Families of people with extensive support needs have generally experienced greater difficulties. Support services should have been considered essential services during lockdown. The failure to receive support has resulted in excessive burden on families, who had to assume a multitude of roles to support their family member with intellectual and developmental disability.
Neece, C., McIntyre, L. L., & Fenning, R.	**Abstract**: The COVID-19 pandemic introduced challenges to families with young children with developmental delays. Beyond the widespread concerns surrounding illness, loss of

Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 2020, 64(10), 739–749. https://doi.org/10.1111/jir.12769	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. 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.
Newman, A.M., Jhaveri, R., Patel, A.B., Tan, T.Q., Toia, J.M., & Arshad, M. **Trisomy 21 and coronavirus disease 2019 in pediatric patients** *Journal of Pediatrics,* 2021, Jan, 228, 294–296. doi: 10.1016/j.jpeds.2020.08.067	**Abstract:** We present 4 pediatric patients with trisomy 21 (T21) and associated comorbidities who developed coronavirus disease 2019 requiring hospitalization. A review of the literature revealed that comorbidities associated with T21 may predispose patients to severe disease. Children with T21 should be considered high risk and monitored carefully if infected with severe acute respiratory syndrome coronavirus 2.
Nygren, M.A. & Lulinski, A. **State of the science on COVID-19 and people with IDD [Research brief].** (December 17, 2020). American Association on Intellectual and Developmental Disabilities (Washington, DC USA). https://www.aaidd.org/docs/default-source/publication/state-of-the-science-on-covid-19-and-people-with-idd---dec-2020.pdf?sfvrsn=25893421_0	**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.
Pacheco, F.L., Noll, M., & Rodrigues Mendonça, C **Challenges in teaching human anatomy to students with intellectual disabilities during the Covid-19 pandemic** *Anatomical Sciences Education*, 2020 (Sept/Oct), 13(5), 556-557 [Letter to the Editor]	**Abstract:** [*none - Extracted from text*] Understanding the current state of inclusion in a higher education institution is essential for the development of opportunities for young adults with special educational needs (SEN). Accordingly, we seek to report the pandemic's positive and negative impacts on higher education based on our experience as anatomy teachers in Brazil. Discussed are the possible implications of the absence of face-to-face human anatomy classes on the teaching-learning process, especially for students with intellectual disabilities

	who are studying physical education. The challenges and difficulties faced by students with intellectual disabilities in higher education are well known. Therefore, there is a need to pay continued attention to inclusive education for students with SEN worldwide, considering that physical inclusion alone is not enough to promote inclusion. In our state public institution, in mid-western Brazil, anatomy is taught to physical education students through theoretical classes (approximately, 30 students, 3 with diagnosed intellectual disability) and practical classes in the anatomy laboratory (approximately 15 students per class), but without dissection. However, after government decrees imposed social isolation and closed schools, the university adopted the system of remote classes. we used the Zoom platform to teach anatomy classes. This proved to be an excellent tool, as it was possible to interact with students in a direct and quality manner. We were able to easily share videos and content while viewing the students. However, the free version of this feature allows conferences of only up to 40 minutes, after which we had make a new video call. This discouraged students and sometimes wasted a lot of time until everyone was able to rejoin. Subsequently, we chose to use Google Meet, a free communication and video chat platform which does not limit conference time. To verify the students' performance, weekly assessments were made through WhatsApp video calls. The calls were made between the student, special education teacher (support professor), and the full professor of the discipline. Despite the use of new and excellent technological options, we maintain that face-to-face teaching is still the safest and most effective method to guarantee student success in the teaching-learning process.
Perera, B., Laugharne, R., Henley, W., Zabel, A., Lamb, K., Branford, D., Courtanay, K., Alexander, A., Purandare, K., Wijeratne, A., Radhakrishnan, V., McNamara, E., Daureeawoo, Y., Sawhney, I., Scheepers, M., Taylor, G., & Shankar, R. **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.
Provenzi, L., Grumi, S., Gardani, A., Aramini, A., Dargenio, E., Naboni, C., Vacchini, V., & Borgatti, R. **Italian parents welcomed a telehealth family-centred rehabilitation programme for children with disability during COVID-19 lockdown** *Acta Oaediatrica (*Oslo, Norway), 2020, 2020, Nov, 110(1), 194-196. DOI: 10.1111/apa.15636	**Abstract:** [none - text taken from report]. The Child Neurology and Psychiatry Unit of the IRCCS Mondino Foundation in Pavia, Italy, developed the Engaging with Families in Online Rehabilitation of Children during the Epidemic (EnFORCE) telehealth program. This provided families with uninterrupted care and rehabilitation during the COVID-19 lockdown. The program comprised case-specific tailored telehealth sessions that include parental support and child rehabilitation sessions. The sessions were conducted by the same therapists and psychologists that were working with the children before lockdown. This paper reports the parents' perceptions of the effectiveness of the EnFORCE program after 6 weeks. They consecutively enrolled 36 parents of children with pediatric neurological conditions. The parents were at least 18 years old, able to understand Italian and provided written, informed consent. More than 80% of the parents reported child growth and development benefits and up to 40% rated the online program as effective or more effective than the usual care provided. The majority reported increased feelings of engagement, self-relevance, perceived support, and recognition of their role in childcare, with percentages ranging from 86%–95%. The reported challenges with the program were Internet connection issues (19%), web literacy gaps (17%) and difficulties in following the instructions given by the therapist (22%). The emotional burden faced by parents during lockdown mainly involved fears about being alone and caring for children with special healthcare needs without specialist support. These preliminary findings suggest that an emergency program that provides continuity of care and support with remote rehabilitation interventions may be beneficial for both child and parental well-being, with limited practical challenges. The benefits of telehealth programs appear to be more relevant for continuity of care, rather than achieving better outcomes than face-to-face sessions. At the same time, practical challenges, such as Internet connections and web literacy, were obstacles for up to a quarter of our sample, suggesting that educational and policy investments are needed to optimize the benefits of telehealth programs for the general population. Investing in telehealth programs should be a priority during the COVID-19 pandemic and appropriate policy measures are needed to cope with future emergencies

Public Health England **Deaths of people identified as having learning disabilities with COVID-19 in England in the Spring of 2020** https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/933612/COVID-19__learning_disabilities_mortality_report.pdf	**Abstract:** [*none - 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, the 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.
Rauf, B., Sheikh, H., Majid, H., Roy, A., Pathania, R. **COVID-19-related prescribing challenge in intellectual disability** *BJPsychiatry Open,* 2021, March 19, 7(2), e66. doi: https://doi.org/10.1192/bjo.2021.26	**Abstract:** The COVID-19 pandemic and associated restrictions are expected to affect the mental health of the population, especially people with intellectual disability and/or autism spectrum disorder, because of a variety of biological and psychosocial reasons. The authors aimed to estimate if COVID-19 restrictions are associated with a change in number of total consultations carried out by psychiatrists and prescription of psychotropic medication in people with intellectual disability and/or autism spectrum disorder, within a community intellectual disability service. A quantitative observational study was conducted, involving retrospective and prospective data collection before and during lockdown. Data were collected on a spreadsheet and emailed to all psychiatrists working within the Coventry and Warwickshire Partnership NHS Trust-wide

	community intellectual disability service. Variables included total consultations, medication interventions, types of medications used, multidisciplinary team input and clinical reasons for medication interventions. Data were analyzed separately for child and adolescent mental health services (CAMHS) and adult intellectual disability teams, and for the whole service. During the lockdown period, total consultations in the community intellectual disability service increased by 19 per week and medication interventions increased by two per week. Multidisciplinary team input increased in CAMHS from 0.17 to 0.71 per week and in adult intellectual disability from 5.7 to 6.5 per week. Hypnotics and benzodiazepines were the most prescribed psychotropic medications during the lockdown period. COVID-19-related lockdown resulted in an increase in medication interventions, total consultations, and involvement of multidisciplinary teams to manage mental health and behavioral issues in people with intellectual disability and/or autism spectrum disorder
Redquest, B. K., Tint, A., Ries, H., & Lunsky, Y. **Exploring the experiences of siblings of adults with intellectual/developmental disabilities during the COVID-19 pandemic.** *Journal of Intellectual Disability Research*, 2021, 65(1), 1–10. Epub Oct 30, 2020, https://doi.org/10.1111/jir.12793	**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 is 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.
Rogers, G., Perez-Olivas, G., Stenfert Kroese, B., Patel, V., Murphy, G., Rose, J., Cooper, V.,	**Abstract:** Recent COVID-19 lockdown restrictions resulted in reduced access to educational, professional, and social support systems for children with intellectual disabilities and their carers. The aim of this study was to gain insight into the ways

Langdon, P.E., Hiles, S., Clifford, C., & Willner, P. **The experiences of mothers of children and young people with intellectual disabilities during the first COVID-19 lockdown period.** *Journal of Applied Research in Intellectual Disabilities,* 2021, Mar, 23:10.1111/jar.12884. doi, 10.1111/jar.12884. Online ahead of print.	mothers of children with intellectual disabilities coped during the first 2020 lockdown period. Eight mothers of children with intellectual disabilities were interviewed. The recordings of these interviews were subjected to a thematic analysis. Three main themes were identified: carrying the burden; a time of stress; and embracing change and looking to the future. All mothers experienced increased burden and stress. However, some also described some positive impact of lockdown conditions on them as well as on their child's well-being and behaviour. These findings are discussed in the light of the (Journal of Applied Research in Intellectual Disabilities, 33, 2020, 1523) survey results on parental coping and suggestions for future service provision during pandemic conditions are proposed.
Rose, J., Willner, P., Cooper, V., Langdon, P. E., Murphy, G. H., & Stenfert Kroese, B. **The effect on and experience of families with a member who has intellectual and developmental disabilities of the COVID-19 pandemic in the UK: Developing an investigation.** *International Journal of Developmental Disabilities*, 2020. (on-line) https://doi.org/10.1080/20473869.2020.1764257	**Abstract:** [*none – extracted from text*] The COVID 19 pandemic is having an added and unprecedented impact upon families through the imposition of social distancing and isolation measures. It is most likely that these measures will impair the mental health of many people; this is of particular concern for family carers as many with a relative who has IDD are likely to have many additional burdens. Initial reports from clinical services and families about the impact of the pandemic are mixed. Some clinicians are reporting less challenging behavior in people with IDD, possibly as the result of fewer demands and a quieter lifestyle due to social isolation). Some families are also reporting that there can be benefits to living a less complex lifestyle, with more opportunities for positive interaction with their offspring. However, these benefits can quickly be offset by the intensity of the demands of continual caring, often with work commitments being managed alongside the support of their offspring required in the home. If restrictions are maintained with services and support reduced, it will be important to try to understand the impact of this on families over the course of the pandemic. Trying to understand how people adapt (or not) will provide valuable information as to how their needs can be both understood and responded to dynamically. If appropriate support can be provided it is likely to have a significant economic benefit by reducing the breakdown of family support, which could lead to more out-of-home residential placements. It is imperative that we devote resources and research effort to find out what is going on in families where there is a member with IDD over the course of the COVID 19 pandemic and how adaptations can be made to provide the most effective help.
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:** *[none - Extracted from text on PowerPoints]* 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.

https://www.nationalacademies.org/event/06-19-2020/best-practices-for-patient-clinician-communication-for-people-with-disabilities-in-the-era-of-covid-19-a-webinar [Presentations Archived]	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. **Disability, ethics, and health care in the COVID-19 pandemic** *American Journal of Public Health,* 2020, 110(10) (October 1, 2020), 1523-1527. https://doi.org/10.2105/AJPH.2020.305837	**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.
Sabatello, M., Landes, S.D., & McDonald, K.E. **People with disabilities in COVID-19: Fixing our priorities.** *American Journal of Bioethics,* 2020, 20(7), 187–190. Published online July 27. https://doi.org/10.1080/15265161.2020.1779396	**Abstract:** *[none - 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.
Scheffers, F., & Moonen, X. **Assessing the quality of support and discovering sources of resilience during COVID-19 measures in people with intellectual disabilities by professional carers.** *Research in Developmental Disabilities*, (In Press), Available online 28 January 2021, 103889 https://doi.org/10.1016/j.ridd.2021.103889	**Abstract:** During COVID-19 interactions using face-to-face contact is limited and professional carers must find other ways to support people with intellectual disabilities. COVID-19 measures can increase stress in people with intellectual disabilities, although some people may adapt to or grow from these uncertain situations. Resilience is the process of effectively negotiating, adapting to, or managing significant sources of stress and trauma. The current study aims to provide professional caregivers with new insights into how they can support people with intellectual disabilities. An online survey was shared through the social media and organizational newsletters of MEE ZHN (a non-governmental organization for people with disabilities). The resilience framework by Ungar (2019) was adapted to fit people with intellectual disabilities during COVID-19 measures. Statistical analyses were performed in SPSS statistics version 26. Results show that professional carers applied diverse and distal methods to maintain contact with people with intellectual disabilities during the COVID-19 measures. Professional carers reported a significant decrease in the quality of contact with clients with intellectual disabilities, but overall high levels of resilience in the same clients. Online methods of communication are possibly insufficient for professionals to cover all needs of people with intellectual disabilities. During this pandemic, professionals should be aware of stress but also of resilience in people with intellectual disabilities. Key findings include: (1) During COVID-19 measures professional caregivers used more diverse and distal methods to maintain contact with people with ID, (2) professionals reported that the quality of the contact with people with ID had significantly decreased during COVID-19 measures, and (3) people with ID seem to have access to multiple sources of resilience during COVID-19 measures.
Schuengel, C., Tummers, J., Embregts, P.J.C.M, & Leusink, G.L.	**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

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	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.
Scottish Commission for Learning Disability. **The impact of coronavirus on people with learning disabilities and their parents, carers and supporters.** The Scottish Commission for People with Learning Disabilities (Glasgow), 2020 (June). Retrieved from https://www.scld.org.uk/wp-content/uploads/2020/06/SCLD-Coronavirus-Report-FINAL.pdf. Published June 2020.	**Abstract:** SCLD, wanting to explore the impact of the crisis on people with learning/intellectual disabilities and their parents, carers and supporters, undertook two surveys (one for people with learning/intellectual disabilities and one for their parents, carers and supporters). The survey ran from April 14 to May 5, 2020. In total, 350 responses were received: 127 from people with learning/intellectual disabilities and 223 from their parents, carers and supporters. Our survey findings show that people with learning/intellectual disabilities and their parents, carers, and supporters are feeling the impact of the Coronavirus emergency. By far the most common concerns raised across two surveys were (1) the reduction or removal of support, increased social isolation, compounded by digital exclusion, and (2) the mental health impact this is having on people with learning/intellectual disabilities. Increased pressure on family carers, because of reductions in support from care providers or fears of accepting support due to the risks of Coronavirus; and pressure on paid carers, due to staff shortages, and changes to how support Is given were also key issues. While a small majority felt information about the Coronavirus emergency was relatively clear. Many carers felt there was a lack of clear guidance on specific issues. such as whether the person they were supporting should 'shield' and how often they could leave the house. The survey also found that people with learning/ intellectual disabilities were very worried about the health implications of Coronavirus on them and their loved ones. People also expressed feelings of anxiety and uncertainty about how long measures would last, and whether their usual support and activities would return once measures were lifted. Several less common, but no less important, issues were also uncovered, including: (a) insufficient Personal Protective Equipment and inconsistency of use, (b) concerns over medical decision making and access to routine health appointments, (c) difficulties accessing food supplies, and (d) lack of access to school hubs and/or Inadequate support available for children with

	learning/intellectual disabilities. Notable is that the survey findings are limited due to small sample size and that the survey was online.
Scully, J.L. **Disability, disablism, and COVID-19 pandemic triage** *Journal of Bioethical Inquiry*, 2020, 17, 601–605. https://doi.org/10.1007/s11673-020-10005-y	**Abstract:** Pandemics such as COVID-19 place everyone at risk, but certain kinds of risk are differentially severe for groups already made vulnerable by pre-existing forms of social injustice and discrimination. For people with disability, persisting and ubiquitous disablism is played out in a variety of ways in clinical and public health contexts. This paper examines the impact of disablism on pandemic triage guidance for allocation of critical care. It identifies three underlying disablist assumptions about disability and health status, quality of life, and social utility, that unjustly and potentially catastrophically disadvantage people with disability in COVID-19 and other global health emergencies.
Shakespeare, T., Ndagire, F., & Seketi, Q.E. **Triple jeopardy: disabled people and the COVID-19 pandemic** *The Lancet*, March 16, 2021 https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00625-5/fulltext	**Abstract:** [*none – extracted from text*] People with disabilities have been differentially affected by COVID-19 because of three factors: the increased risk of poor outcomes from the disease itself, reduced access to routine health care and rehabilitation, and the adverse social impacts of efforts to mitigate the pandemic. Cancellation or postponement of regular health care or rehabilitation will differentially impact those with additional health needs. When assistive technology is not prescribed, maintained, or repaired, people with disabilities are rendered dependent. When social care is put on hold, cancelled, or reduced, people with disabilities are thrown back on the support of families if they have them. When it is not possible to attend day centers or voluntary projects, people with disabilities may be left with no one to meet. When individuals are expected to use face masks and physically distance, people with hearing loss who cannot lip read or people with visual impairment who use guide dogs can find it difficult to follow these rules and as a result they might be stigmatized. Additionally, confinement in homes increases the risk of physical or sexual violence and abuse, to which children and adults with disabilities are additionally vulnerable. In a public health crisis such as the COVID-19 pandemic, clear information becomes more important than ever. In the UK, messages have been confused or complicated, which has been difficult for people with intellectual disabilities to understand. In other countries, there can be low confidence in public health messaging. Increased isolation and uncertainty or fear about the pandemic have also impacted the mental health of people with disabilities. People with mental illness can find isolation and fear particularly debilitating. People with physical impairments are also disproportionately at risk of mental health conditions.20 For many people, this pandemic has generally been bad for mental health. The COVID-19 pandemic has increased risks, compounded unmet health needs, and disproportionately affected the socioeconomic lives of people with disabilities around the world. As evidence evolves, strategic thinking is needed about how society, social inclusion,

	and public health can better reach the 15% of the global population1 who are disabled.
Sharpe, D., Rajabi, M., Chileshe, C., Joseph, S.M., Sesay, I., Williams, J., & Sait, S. **Mental health and wellbeing implications of the COVID-19 quarantine for disabled and disadvantaged children and young people: evidence from a cross-cultural study in Zambia and Sierra Leone.** *BMC Psychology*, 2021, May 15, 9(1), 79. doi: 10.1186/s40359-021-00583-w.	**Abstract:** The mental health impact of the COVID-19 pandemic and quarantining on children and young people (CYP) living in low- and middle-income countries (LMICs) has yet to be fully comprehended. CYP in LMICs are at utmost risk, given the COVID-19-related restrictions and social distancing measures, resulting in reduced access to school-based services for nutritional and mental health needs. This study examined mental health of CYP during the first COVID-19 lockdown in Zambia and Sierra Leone. A total of 468 disabled and disadvantaged CYP aged 12 to 25 completed a planning tool that comprised the short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS), as well as open-ended questions covering social connectedness, physical distancing, and educational challenges during the lockdown. The community coaches screened individuals and families who could be eligible to receive emergency aid and based on a convenience sample following distribution of aid, recipients were invited to complete the planning tool. The data showed that participants in the global south have increasing anxieties and fears centered on accessing offline educational resources and income loss in the family affecting food security and their ability to return to education. Mean (SD) SWEMWBS scores for all participants in Zambia and Sierra Leone, were 19.61 (3.45) and 21.65 (2.84), respectively. Mental well-being scores were lower in females, children aged 12-14 and participants with two or more disabilities. Factors significantly associated with poor mental wellbeing in the sample were: type of disability, nationality, peer relationships, connection to others during the pandemic, knowledge about COVID-19, worry about the long-term impact of COVID-19, and the types of self-isolating. The study shows that participants who self-reported low levels of COVID-19 health literacy also scored low on the mental wellbeing self-assessment. Yet, despite undoubted limited resources, these CYP are doing well in identifying their needs and maintaining hope in the face of the problems associated with COVID-19 in countries where stigma persists around mental ill-health.
Sheehan, R., Dalton-Locke, C., Ali, A., Totsika, V., San Juan, N. V., & Hassiotis, A. **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.** *medRxiv,* September 2, 2020 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. Most 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.** *ACCSES,* Washington DC, September 8, 2020. https://www.the-ntg.org/covid-19-resources	**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 lockdowns 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.
Smile, S.C. **Supporting children with autism spectrum disorder in the face of the COVID-19 pandemic** *CMAJ,* 2020, *May* 25, 192(21) E587; DOI: https://doi.org/10.1503/cmaj.75399	**Abstract:** *[no abstract – article text included]* The call for innovative approaches and the need to ensure continuity of care for those with chronic health issues during the pandemic cannot be overemphasized. A specific response is needed to address the mental distress of children who are quarantined. There needs to be greater emphasis on designing diverse, socioculturally appropriate programs to address mental distress and provide mental health care and psychosocial supports to mitigate the effects of prolonged isolation in children. Children and youth with autism spectrum disorder are

	vulnerable to the effects of prolonged isolation or quarantine, and may have difficulty adapting to this new norm, especially as inflexibility and insistence on sameness are hallmark characteristics of this disorder. The consequences of a pandemic and the measures put in place to decrease transmission of coronavirus disease 2019 (COVID-19) have the potential to adversely affect children and youth with autism spectrum disorder and their families, including siblings. Parental anxiety around job loss, economic uncertainty, lack of access to health care facilities and treatment centers, and extension of waitlists for early intervention programs may cripple a caregiver's or parent's ability to cope with the COVID-19 pandemic. Integration of varied levels of intervention cocreated within a pandemic response program specific to children and families is needed. Such programs may not require new initiatives and funding; the current pandemic instead challenges health care providers and institutions to reimagine service delivery using virtual care platforms. Delivery of programs that are easily implemented and meet the needs of children and their families is needed. Creation of a virtual helpline within pre-existing health communities, such as hospitals and treatment centers, supported by a multidisciplinary team to provide real-time supports and intermittent ongoing medical and behavioral support should be considered. The COVID-19 pandemic has given us the opportunity to expand and rethink service delivery to one of the most vulnerable populations, children and youth living with a disability and their families.
Spreat, S., Cox, R., & Davis, M. **COVID-19 case & mortality report – intellectual or developmental disabilities** *New York Alliance for Inclusion and Innovation*, 2020. https://www.ancor.org/sites/default/files/covid-19_case_and_mortality_report.pdf	**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 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 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
Rabin, R.C. **Developmental disabilities heighten risk of Covid death** *New York Times,* November 11, 2020. https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html?action=click&module=Top%20Stories&pgtype=Homepage	**Abstract:** (*none - Extracted from text*] Newspaper story on findings about the impact of COVID-19 on persons with developmental disabilities. Reporter notes that such findings raise complex questions about how to allocate new vaccines as they become available in limited supplies. She notes that "So far, guidelines for distributing vaccines have recommended prioritizing emergency workers, health care providers and other essential workers, as well as people at heightened risk for severe disease, including some older adults and those with certain chronic illnesses. The guidelines, which are still evolving, have not specifically emphasized the importance of prioritizing the vaccination of children and adults with intellectual disabilities like Down syndrome and developmental disorders." She cites a report from FAIR Health, an organization that hosts "the nation's largest private health insurance claims database" and reports that "FAIR Health set out to identify who is at greatest risk for dying of Covid-19 by reviewing health claims from nearly half a million Americans of all ages filed from April 1 through Aug. 31, and quoted a FAIR Health executive as noting that "What we find particularly new is the identification of developmental disorders and intellectual disabilities really surfacing to the top in terms of linkages between these categories of comorbidities and the risk of death," The executive further was quoted as saying, "As we move toward approval of a vaccine, we're identifying at-risk populations where you could either prioritize vaccine distribution or, prior to that, begin to give special attention to the care and treatment of these individuals knowing that they're particularly vulnerable. The reported noted also that as "Vaccination will play a broader role beyond preventing infections. It will be critical to resuming education and the full array of treatments and other services for those with intellectual disabilities and developmental disorders, whose lives have been disrupted by the pandemic."
Tapper, J. **Fury at 'do not resuscitate' notices given to Covid patients with learning disabilities**	**Abstract:** [*none - Extracted from text*] Newspaper report on a story that people with learning [intellectual] disabilities have been given do not resuscitate orders during the second wave of the pandemic, in spite of widespread condemnation of the practice last year and an urgent investigation by the care

The Guardian (London), February 13, 2021. https://www.theguardian.com/world/2021/feb/13/new-do-not-resuscitate-orders-imposed-on-covid-19-patients-with-learning-difficulties	watchdog. Mencap (an UK advocacy organization) said it had received reports in January 2021 from people with [intellectual] disabilities that they had been told they would not be resuscitated if they were taken ill with Covid-19. The Care Quality Commission said in December that inappropriate Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices had caused potentially avoidable deaths last year. The disclosure comes as campaigners put growing pressure on ministers to reconsider a decision not to give people with [intellectual] disabilities priority for vaccinations. There is growing evidence that even those with a mild disability are more likely to die if they contract the coronavirus. Although some people with [intellectual] disabilities such as Down syndrome were in one of four groups set by the Joint Committee on Vaccination and Immunization (JCVI) which the government promised would be offered the vaccine by tomorrow, many were classified lower categories of need and are still waiting. Dr Keri-Michèle Lodge, a consultant in learning disability psychiatry in Leeds. Was quoted as saying: "A lack of badgering is part of the reason why people with learning disabilities may be more likely to die from Covid-19 than the rest of the population… Doctors often don't understand that someone with learning disabilities may not be able to communicate their symptoms… Carers are sometimes not listened to – you might notice something is wrong, but that is often written off as part of their behavior." An analysis by the Office for National Statistics last week showed that six in 10 Covid deaths were of people with a disability. NHS figures released last week show that in the five weeks since the third lockdown began, Covid-19 accounted for 65% of deaths of people with [intellectual] disabilities. Figures from the Office for National Statistics show that the rate for the general population was 39%, although the two statistics are drawn from different measurements. Younger people with [intellectual] disabilities aged 18 to 34 are 30 times more likely to die of Covid than others the same age, according to Public Health England. Professor Martin Green, Care England's chief executive, said: "As the largest representative body for independent providers for adult social care, Care England remains concerned that the government has not given individuals with a learning disability a higher level of priority for the Covid vaccine... We urge the government to remove the arbitrary distinction between prioritizing those with a severe or profound learning disability and those with a mild or moderate learning disability and prioritize all those with a learning disability in priority group four… People with learning disabilities must not be overlooked at any time." A spokes-person from the Department of Health and Social Care said: "It is completely unacceptable for 'do not attempt CPR' decisions to be applied in a blanket fashion to any group of people. This has never been policy and we have taken action to prevent this from happening."

Taquet, M., Luciano, S., Geddes, J.R., Harrison, P.J. **Bidirectional associations between COVID-19 and psychiatric disorder: Retrospective cohort studies of 62 354 COVID-19 cases in the USA** *The Lancet Psychiatry*, 2021, 8(2), 130-140. Published November 9,2020; DOI:https://doi.org/10.1016/S2215-0366(20)30462-4 ***NOTE: This report does not directly focus on intellectual disability but is of value as it refers to the residual effects of COVID-19 and can be applied to adults with intellectual disability.***	**Abstract:** Adverse mental health consequences of COVID-19, including anxiety and depression, have been widely predicted but not yet accurately measured. There are a range of physical health risk factors for COVID-19, but it is not known if there are also psychiatric risk factors. In this electronic health record network cohort study using data from 69 million individuals, 62 354 of whom had a diagnosis of COVID-19, we assessed whether a diagnosis of COVID-19 (compared with other health events) was associated with increased rates of subsequent psychiatric diagnoses, and whether patients with a history of psychiatric illness are at a higher risk of being diagnosed with COVID-19. We used the TriNetX Analytics Network, a global federated network that captures anonymized data from electronic health records in 54 health-care organizations in the USA, totaling 69·8 million patients. TriNetX included 62 354 patients diagnosed with COVID-19 between Jan 20, and Aug 1, 2020. We created cohorts of patients who had been diagnosed with COVID-19 or a range of other health events. We used propensity score matching to control for confounding by risk factors for COVID-19 and for severity of illness. We measured the incidence of and hazard ratios (HRs) for psychiatric disorders, dementia, and insomnia, during the first 14 to 90 days after a diagnosis of COVID-19. In patients with no previous psychiatric history, a diagnosis of COVID-19 was associated with increased incidence of a first psychiatric diagnosis in the following 14 to 90 days compared with six other health events (HR 2.1, 95% CI 1.8–2.5 vs influenza; 1·7, 1·5–1·9 vs other respiratory tract infections; 1.6, 1.4–1.9 vs skin infection; 1.6, 1.3–1.9 vs cholelithiasis; 2.2, 1.9–2.6 vs urolithiasis, and 2.1, 1.9–2.5 vs fracture of a large bone; all p<0.0001). The HR was greatest for anxiety disorders, insomnia, and dementia. We observed similar findings, although with smaller HRs, when relapses and new diagnoses were measured. The incidence of any psychiatric diagnosis in the 14 to 90 days after COVID-19 diagnosis was 18.1% (95% CI 17.6–18.6), including 5·8% (5.2–6.4) that were a first diagnosis. The incidence of a first diagnosis of dementia in the 14 to 90 days after COVID-19 diagnosis was 1.6% (95% CI 1.2–2.1) in people older than 65 years. A psychiatric diagnosis in the previous year was associated with a higher incidence of COVID-19 diagnosis (relative risk 1.65, 95% CI 1.59–1.71; p<0.0001). This risk was independent of known physical health risk factors for COVID-19, but we cannot exclude possible residual confounding by socioeconomic factors. Survivors of COVID-19 appear to be at increased risk of psychiatric sequelae, and a psychiatric diagnosis might be an independent risk factor for COVID-19. Although preliminary, our findings have implications for clinical services, and prospective cohort studies are warranted.
Taquet, M., Geddes, J.R., Husian, M., Luciano, S., & Harrison, P.J. **6-month neurological and psychiatric outcomes in 236 379 survivors of COVID-19:**	**Abstract:** Neurological and psychiatric sequelae of COVID-19 have been reported, but more data are needed to adequately assess the effects of COVID-19 on brain health. We aimed to provide robust estimates of incidence rates and relative risks of neurological and psychiatric diagnoses in patients in the 6

A retrospective cohort study using electronic health records The Lancet Psychiatry, 2021, 8(5), 416-427. Published:April 06, 2021DOI:https://doi.org/10.1016/S2215-**0366(21)00084-5** ***NOTE: This report does not directly focus on intellectual disability but is of value as it refers to the residual effects of COVID-19 and can be applied to adults with intellectual disability.***	months following a COVID-19 diagnosis. For this retrospective cohort study and time-to-event analysis, we used data obtained from the TriNetX electronic health records network (with over 81 million patients). Our primary cohort comprised patients who had a COVID-19 diagnosis; one matched control cohort included patients diagnosed with influenza, and the other matched control cohort included patients diagnosed with any respiratory tract infection including influenza in the same period. Patients with a diagnosis of COVID-19 or a positive test for SARS-CoV-2 were excluded from the control cohorts. All cohorts included patients older than 10 years who had an index event on or after Jan 20, 2020, and who were still alive on Dec 13, 2020. We estimated the incidence of 14 neurological and psychiatric outcomes in the 6 months after a confirmed diagnosis of COVID-19: intracranial hemorrhage; ischemic stroke; parkinsonism; Guillain-Barré syndrome; nerve, nerve root, and plexus disorders; myoneural junction and muscle disease; encephalitis; dementia; psychotic, mood, and anxiety disorders (grouped and separately); substance use disorder; and insomnia. Using a Cox model, we compared incidences with those in propensity score-matched cohorts of patients with influenza or other respiratory tract infections. We investigated how these estimates were affected by COVID-19 severity, as proxied by hospitalization, intensive therapy unit (ITU) admission, and encephalopathy (delirium and related disorders). We assessed the robustness of the differences in outcomes between cohorts by repeating the analysis in different scenarios. To provide benchmarking for the incidence and risk of neurological and psychiatric sequelae, we compared our primary cohort with four cohorts of patients diagnosed in the same period with additional index events: skin infection, urolithiasis, fracture of a large bone, and pulmonary embolism. Among 236 379 patients diagnosed with COVID-19, the estimated incidence of a neurological or psychiatric diagnosis in the following 6 months was 33.62% (95% CI 33.17–34.07), with 12.84% (12.36–13.33) receiving their first such diagnosis. For patients who had been admitted to an ITU, the estimated incidence of a diagnosis was 46.42% (44.78–48.09) and for a first diagnosis was 25.79% (23.50–28.25). Regarding individual diagnoses of the study outcomes, the whole COVID-19 cohort had estimated incidences of 0.56% (0.50–0.63) for intracranial hemorrhage, 2.10% (1.97–2.23) for ischemic stroke, 0.11% (0.08–0.14) for parkinsonism, 0.67% (0.59–0.75) for dementia, 17.39% (17.04–17.74) for anxiety disorder, and 1.40% (1.30–1.51) for psychotic disorder, among others. In the group with ITU admission, estimated incidences were 2.66% (2.24–3.16) for intracranial hemorrhage, 6.92% (6.17–7.76) for ischemic stroke, 0.26% (0.15–0.45) for parkinsonism, 1.74% (1.31–2.30) for dementia, 19.15% (17.90–20.48) for anxiety disorder, and 2.77% (2.31–3.33) for psychotic disorder. Most diagnostic categories were more common in patients who had COVID-19 than in those who had influenza (hazard ratio [HR] 1.44, 95% CI 1.40–1.47, for any diagnosis; 1.78, 1.68–1.89, for any first

	diagnosis) and those who had other respiratory tract infections (1.16, 1.14–1.17, for any diagnosis; 1.32, 1.27–1.36, for any first diagnosis). As with incidences, HRs were higher in patients who had more severe COVID-19 (e.g., those admitted to ITU compared with those who were not: 1.58, 1.50–1.67, for any diagnosis; 2.87, 2.45–3.35, for any first diagnosis). Results were robust to various sensitivity analyses and benchmarking against the four additional index health events. Our study provides evidence for substantial neurological and psychiatric morbidity in the 6 months after COVID-19 infection. Risks were greatest in, but not limited to, patients who had severe COVID-19. This information could help in service planning and identification of research priorities. Complementary study designs, including prospective cohorts, are needed to corroborate and explain these findings.
Tennebaum, A., Glasbauer, D., & Wexler, I.D. **Coronavirus and people with intellectual disability: A special perspective** *Israel Medical Association Journal*, 2021, Jan, 23, 5-6.	**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. *[Extract of 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.

Theis, N., Campbell, N., De Leeuw, J., Owen, M., & Schenke, K.C. **The effects of COVID-19 restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities.** *Disability and Health Journal*, 2021, published online Jan 22, 2021. https://doi.org/10.1016/j.dhjo.2021.101064	**Abstract:** COVID-19 has caused unprecedented restrictions, significantly affecting the most vulnerable groups in society, such as those with a disability. The aim of the study was to investigate the effects of COVID-19 lockdown restrictions on physical activity and mental health of children and young adults with physical and/or intellectual disabilities. The study was a cross-sectional design. Parents/carers completed an electronic survey in the UK between June–July 2020 on behalf of their child. Through Likert scales and free-text questions, the survey asked about physical activity levels and mental health during lockdown compared to before, access to specialist facilities and equipment to aid with physical activity, and the short- and long-term concerns around ongoing lockdown restrictions. Generally, respondents reported negative effects of lockdown restrictions, with 61% reporting a reduction in physical activity levels and over 90% reporting a negative impact on mental health (including poorer behavior, mood, fitness and social and learning regression). Many respondents cited a lack of access to specialist facilities, therapies, and equipment as reasons for this, and raised concerns about the long-term effects of this lack of access on their child's mental health and physical activity levels. The survey highlighted the negative impact of the COVID-19 lockdown on the physical activity levels and mental health of children and young adults with disabilities and highlights the importance of addressing the needs of the disabled community as restrictions are eased.
Thomas, R. **'Unprecedented number of DNR orders for learning disabilities patients** *Health Services Journal*, 24 April 2020, https://www.hsj.co.uk/coronavirus/unprecedented-number-of-dnr-orders-for-learning-disabilities-patients/7027480.article	**Abstract:** *(none - Extracted from text]* An agency in the UK which provides supported living and residential care for people with learning [intellectual] disabilities, has raised concerns that it has received 13 "unlawful" do not attempt cardio-pulmonary resuscitation or do not resuscitate orders from hospital specialists and GPs since the beginning of April 2020, half of which came in the last week. The provider which operates facilities across the UK, plans on challenging the lawfulness of the orders received this month, which it said appear to have been carried out without consultation with patients or their families. The orders have come despite NHS England telling all primary care, community trust, and acute CEOs on 3 April that any decisions on a treatment for people with learning [intellectual] disability and or autism should be made on an individual basis. The agency's CEO has noted that "We are seeing DNR orders that have not been discussed with the person themselves, the staff who support and care for them, or their families. This is very concerning as it may potentially lead to people being denied life-saving treatment that other patients would be granted."
Thompson, J.R., & Nygren, M.A. **COVID-19 and the field of intellectual and developmental disabilities: Where have we been? Where are we? Where do we go?** *Intellectual and Developmental Disabilities.* (2020), Aug 1, 58(4), 257-261. doi:	**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 of field of IDD during the pandemic, and (b) place the IDD community in a strong position when the health threats

10.1352/1934-956-58.4.257. PMID: 32750709	associated with the pandemic abate and post-pandemic social and policy structures are formed.
Tromans, S., Chester, V., Harrison, H., Pankhania, P., Booth, H., & Chakraborty, N. **Patterns of use of secondary mental health services before and during COVID-19 lockdown: observational study** *BJPsych Open,* 2020 (November), 6(6), e117 DOI: https://doi.org/10.1192/bjo.2020.104	**Abstract:** The coronavirus disease 2019 (COVID-19) pandemic has had a profound impact on both the physical and mental well-being of the global population. Relatively few studies have measured the impact of lockdown on utilization of secondary mental health services in England. They aimed to describe secondary mental health service utilization pre-lockdown and during lockdown within Leicestershire, UK, and the numbers of serious incidents during this time frame. Data pertaining to mental health referral and hospital admissions to adult mental health, child and adolescent mental health, intellectual disability and mental health services for older people were collated retrospectively from electronic records for both 8 weeks pre-lockdown and the first 8 weeks of lockdown in England. Serious incidents during this time frame were also analyzed. Significantly ($P < 0.05$) reduced referrals to a diverse range of mental health services were observed during lockdown, including child and adolescent, adult, older people, and intellectual disability services. Although admissions remained relatively stable before and during lockdown for several services, admissions to both acute adult and mental health services for older people were significantly ($P < 0.05$) reduced during lockdown. Numbers of serious incidents in the pre-lockdown and lockdown periods were similar, with 23 incidents pre-lockdown, compared with 20 incidents in lockdown. To the best of our knowledge, this is the first UK-based study reporting patterns of use of mental health services immediately prior to and during COVID-19 lockdown. Overall numbers of referrals and admissions were reduced following commencement of COVID-19 lockdown. Potential reasons for these observations are discussed.
Tromans, S., Kinney, M., Chester, V., Alexander, R., Roy, A., Sander, J. W., Dudson, H., & Shankar, R. **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 has 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. https://onlinelibrary.wiley.com/doi/full/10.1111/jir.12730	**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. **Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis.** *Disability and Health Journal,* 2020, Jul, 13(3), 100942. doi:10.1016/j.dhjo.2020.100942. Epub 2020 May 24. PMID: 32473875	**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%, without IDD, 20.7%. Authors note that though of concern for all individuals, COVID-19 appears to present a greater risk to people with IDD, especially at younger ages. Future research should seek to document COVID-19 trends among people with IDD, with particular attention to age related trends.
University of Bristol **Deaths of people with learning disabilities from COVID-19** The Learning Disabilities Mortality Review (LeDeR) Programme, University of Bristol (UK), 42 pp. https://www.bristol.ac.uk/media-library/sites/sps/leder/Deaths%20of%20people%20with%20learning%20disabilities%20from%20COVID-19.pdf	**Abstract**: [*none – extracted from 'Summary'*] This report describes the circumstances leading to death for a representative sample of 206 adults with intellectual (learning) disabilities. The majority of the 206 deaths (79%, n=163) were attributable to COVID-19: 27% of the total number of COVID-19 deaths notified to the LeDeR program from 2nd March 2020 – 9th June 2020. Forty-three (21%) of the 206 deaths were attributed to other causes and are included as a comparator group – 6% of the total deaths from other causes occurring during this period. Key findings are as follows. • There is a striking difference in age at death between COVID-19 deaths in the general population compared with people with learning disabilities. • A third (35%) of those who died from COVID-19 lived in residential care homes, rising to almost half of those with Down syndrome. • People who died from COVID-19 were more frequently reported to have respiratory conditions (72%), compared to those who died from other conditions (60%). • Of those who died from COVID-19, 37% had all three symptoms of cough, fever or difficulty breathing; 39% had two of the symptoms and 21% had one of these symptoms. • Access to healthcare that was problematic for some people who died from COVID-19. • Just over half (56%) of people who died from COVID-19 received care that was graded as meeting or exceeding good practice. • Concerns were raised about the absence of tools (and the specific equipment required for these, such as oxygen saturation monitors) that can be used to detect acute deterioration in a person's health, particularly in primary care and community settings. • At least seven people acquired the virus during a previous hospital admission, suggesting a need to strengthen infection control and safe hospital discharges. • It was noted that frailty or 'learning disabilities' were given as rationales for a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decision for people who had died from COVID-19, yet this was not the case for people who had died from other causes. • Several recommendations were made in relation to preventing deaths from COVID-19.
Van Beusekom, M. **Intellectual disability, obesity tied to COVID-19 hospitalization, death**	**Abstract:** [*none – extracted from text*] Intellectual disability is second only to old age as a risk factor for COVID-19 death, and obesity is linked to coronavirus-related hospitalization and

CIDRAP News, Center for Infectious Disease Research and Policy, March 8, 2021, https://www.cidrap.umn.edu/news-perspective/2021/03/intellectual-disability-obesity-tied-covid-19-hospitalization-death	death, two new studies find. Deadlier than heart, kidney, lung disease. The first study, led by researchers from Jefferson Health in Philadelphia and published late last week as a commentary in the New England Journal of Medicine Catalyst, involved analyzing the medical records of 558,672 US COVID-19 patients from January 2019 to November 2020. Patients with intellectual disabilities had higher rates of coronavirus infection than those without those limitations (3.1% vs 0.9%). In unadjusted analysis, compared with the 431,669 patients without intellectual disabilities, the 127,003 patients with intellectual disabilities were more susceptible to hospitalization (63.1% vs. 29.1%), intensive care unit (ICU) admission (14.5% vs. 6.3%), and death (8.2% vs. 3.8%). Intellectual impairments were the strongest predictor of death other than older age. "The chances of dying from COVID-19 are higher for those with intellectual disability than they are for people with congestive heart failure, kidney disease or lung disease," lead study author Jonathan Gleason, MD, said in a Thomas Jefferson University news release. COVID-19 patients with intellectual disabilities were more likely to be established patients of the health system where they sought care; 22% were new patients, compared with 44% of those without intellectual disabilities. They were also more likely to be younger than those without these limitations, with only 1% older than 80 years and 18% aged 60 to 80, versus 5% and 25%, respectively.
Vetri, L., Elia, M., Aurelio Vitello, G., Greco, D., Gagliano, C., Costanzo, M.C., Romeo, G., & Musumeci, S.A. **Impact of daytime routine modifications on people with severe intellectual disability amid COVID-19 pandemic** Perspectives of Psychiatric Care, 2021, May 245, doi: 10.1111/ppc.12696	**Abstract:** [*no abstract – text extracted]* Increasing evidence has shown that a holistic approach considering the well-being and overall life satisfaction of people with mental health issues is the most effective and worthwhile approach. The Oasi Research Institute provides specialized services including diagnostic work-ups and physical and cognitive rehabilitation for inpatients and outpatients with intellectual disability and its comorbidities. The implications of COVID-19 infection in individuals with severe intellectual disability, and the frequent involvement of multiple organs and systems due to genetic or acquired etiologies, are difficult to predict. The authors report on three adult patients with severe intellectual disability and a recent COVID-19 infection. As they were transferred to a COVID-center hospital; abruptly interrupting their affective relationships, treatments, and the daytime routines of their long-term residential treatment program, they developed food rejection behaviors. We find it compelling to underline how these patients developed behavioral and adaptive disorders after their COVID-19 infection-related hospitalization, similar to previous literature data showing that people with intellectual disability have acutely poor hospital experiences. Returning to their familiar daily routine and restoring affective relationships allowed them to resolve or limit these anomalies, underlining the critical importance of a safe emotional and affective balance for the health and well-being of people with severe intellectual disability. Stress, anxiety, depression, and withdrawal are triggered by routine changes, especially in people with cognitive impairment and psychiatric disorders.

	These feelings have heterogeneous effects on food intake, which are often stimulatory but sometimes cause prolonged cessation of eating and anorexia. Interestingly, there is evidence that aversive environments often produce short-term anorexia, along with freezing behaviors. Authors conclude that feelings of well-being, participation in enjoyable occupational activities, autonomy, and a sense of belonging are crucial elements in the management of intellectual disability. Health workers should never neglect these factors, especially in states of health emergency.
Vieta, E., & Arango, C. **Psychiatry in the aftermath of COVID-19** *Revista de Psiquiatría y Salud Mental,* 2020 (April-June), 13(2), 105-110	**Abstract:** At the time of the writing of this article, a substantial part of the world population is in partial or total lockdown due to the pandemic caused by the SARS CoV-2 virus. This health emergency, which has hit our country of Spain hard, has transformed and will continue to transform our social customs, our economy, and, obviously, our health care system in ways that are difficult to predict. This article aims to anticipate some of the changes that are coming in the field of mental health and care for people with mental disorders (including autism spectrum disorders or intellectual disability), as well as the specialty that deals with it: psychiatry. Psychiatry, in its broad sense, also includes aspects of medical psychology and prevention and health promotion that are undoubtedly part of the specialty's doctrine**.**
Villani, E.R., Carfì, A., Di Paola, A., Palmieri, L., Donfrancesco, C., Lo Noce C., Taruscio, D., Meli, P., Salerno, P., Kodra, Y., Pricci, F., Tamburo de Bella, M., Floridia, M., Onder, G., & Italian National Institute of Health CoVID-19 Mortality Group **Clinical characteristics of individuals with Down syndrome deceased with CoVID-19 in Italy - A case series**. *American Journal of Medical Genetics Part A.,* 2020, Dec, 182(12), 2964-2970. doi: 10.1002/ajmg.a.61867. Epub 2020 Sep 12.	**Abstract:** Persons with Down syndrome (DS) are presumed to be at high risk of severe CoVID-19, due to immune dysregulation and often compromised cardiopulmonary function. Aim of the present study is to assess epidemiological and clinical characteristics of individuals with DS deceased in Italian hospitals with CoVID-19. We used a nationwide database of 3,438 patients deceased with RT-PCR-confirmed SARS-CoV-2 infection in Italy (10.4% of all deaths with CoVID-19 in the country at the time of analysis). Data on demographics, pre-existing comorbidities and in-hospital complications leading to death were extracted from medical charts obtained from hospitals. Data on individuals with DS deceased with CoVID-19 were obtained from this sample. Sixteen cases of death in individuals with DS (0.5% of all charts analyzed) were identified. Acute respiratory distress syndrome occurred in all 16 cases. Compared with individuals without DS, those with DS deceased with CoVID-19 were younger (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 were similar in both groups (25 vs. 18.8%, p = .129). Individuals with DS deceased with CoVID-19 are younger than individuals without DS. Comorbidity burden and increased risk of complications (i.e., bacterial superinfections) can influence CoVID-19 prognosis in individuals with DS. Specific strategies to prevent and mitigate the effects of CoVID-19 in the population with DS are needed.

Villani, E.R., Vetrano, D.L., Damiano, C., Di Paola, A.D., Ulgiati, A.M., Martin, L., Hirdes, J.P., Fratiglioni, L., Bernabei, R., Onder, G., & Carfi, A. **Impact of COVID-19-related lockdown on psychosocial, cognitive, and functional well-being in adults with Down syndrome.** *Frontiers in Psychiatry,* 2020, (Oct. 28), 11:578686, https://doi.org/10.3389/fpsyt.2020.578686	**Abstract:** People with Down syndrome (DS) have a high prevalence of physical and psychiatric comorbidities and experience early-onset dementia. With the outbreak of CoVID-19 pandemic, strict social isolation measures have been necessary to prevent the spreading of the disease. Effects of this lockdown period on behavior, mood, and cognition in people with DS have not been assessed so far. In the present clinical study, we investigated the impact of CoVID-19-related lockdown on psychosocial, cognitive, and functional well-being in a sample population of 46 adults with DS. The interRAI Intellectual Disability standardized assessment instrument, which includes measures of social withdrawal, functional impairment, aggressive behavior, and depressive symptoms, was used to perform a three time-point evaluation (two pre-lockdown and one post-lockdown) in 37 subjects of the study sample, and a two-time point evaluation (one pre- and one post-lockdown) in 9 subjects. Two mixed linear regression models – one before and one after the lockdown – have been fitted for each scale so as to investigate the change in the time-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 (β = 0.55; 95% CI 0.34; 0.76). In the post-lockdown period, a significant worsening in social withdrawal (β = 3.05, 95% CI 0.39; 5.70), instrumental activities of daily living (β = 1.13, 95% CI 0.08; 2.18) and depression rating (β = 1.65, 95% CI 0.33; 2.97) scales scores was observed, as was a significant improvement in aggressive behavior (β = −1.40, 95% 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. On the opposite, aggressive behavior was reduced after the lockdown period. Authors note that 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.
Vindegaard, N., & Benros, M.E. **COVID-19 pandemic and mental health consequences: Systematic review of the current evidence** Brain, Behavior, and Immunity, 2020, Oct., 89, 531–542. Published online 2020 May 30. doi: 10.1016/j.bbi.2020.05.048 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7260522/	**Abstract:** During the COVID-19 pandemic general medical complications have received the most attention, whereas only a few studies address the potential direct effect on mental health of SARS-CoV-2 and the neurotropic potential. Furthermore, the indirect effects of the pandemic on general mental health are of increasing concern, particularly since the SARS-CoV-1 epidemic (2002–2003) was associated with psychiatric complications. Authors systematically searched the database PubMed including studies measuring psychiatric symptoms or morbidities associated with COVID-19 among infected patients and among noninfected groups the latter divided in psychiatric patients, health care workers and non-health care workers. A total of 43 studies were included. Out of these, only two studies evaluated patients with confirmed COVID-19 infection, whereas 41 evaluated the indirect effect of the pandemic (2 on patients with preexisting psychiatric

	disorders, 20 on medical health care workers, and 19 on the general public). 18 of the studies were case-control studies/compared to norm, while 25 of the studies had no control groups. The two studies investigating COVID-19 patients found a high level of post-traumatic stress symptoms (PTSS) (96.2%) and significantly higher level of depressive symptoms (p = 0.016). Patients with preexisting psychiatric disorders reported worsening of psychiatric symptoms. Studies investigating health care workers found increased depression/depressive symptoms, anxiety, psychological distress, and poor sleep quality. Studies of the general public revealed lower psychological well-being and higher scores of anxiety and depression compared to before COVID-19, while no difference when comparing these symptoms in the initial phase of the outbreak to four weeks later. A variety of factors were associated with higher risk of psychiatric symptoms and/or low psychological well-being including female gender, poor-self-related health, and relatives with COVID-19. Research evaluating the direct neuropsychiatric consequences and the indirect effects on mental health is highly needed to improve treatment, mental health care planning and for preventive measures during potential subsequent
Vita, S., Di Bari, V., Corpolongo, A., Palmieri, F., Nicastri, E., on behalf of INMI COVID-19 study groups **Down Syndrome patients with COVID-19 pneumonia: A high-risk category for unfavourable outcome** *International Journal of Infectious Diseases,* published: November 30, 2020. DOI: https://doi.org/10.1016/j.ijid.2020.11.188	**Abstract:** We report two cases of Corona Virus Disease-19 (COVID-19) in patients with Down Syndrome (DS) and describe the identification, diagnosis, clinical course, and management of the infection. Down Syndrome, which is caused by trisomy 21, is characterized by immune dysregulation, anatomical differences in the upper respiratory tract and higher rate of comorbidities. All these risk factors can contribute to more severe clinical presentations of COVID-19 in this population. It is essential to raise awareness of the clinical relevance of SARS-COV-2 infection in DS patients, as well as in other most vulnerable patients, to improve their management and treatment and to encourage vaccinating these individuals early, once a vaccination is available. Authors note that (1) pro-inflammatory factors play a central role in COVID-19 severity and mortality, (2) Down syndrome is characterized by immune dysregulation and respiratory infections, and (3) Down syndrome patients with COVID-19 are at high risk of an unfavorable outcome.
Wadman, M. **COVID-19 is 10 times deadlier for people with Down syndrome, raising calls for early vaccination** *ScienceMag.org*, December 15, 2020. https://www.sciencemag.org/news/2020/12/covid-19-10-times-deadlier-people-down-syndrome-raising-calls-early-vaccination doi:10.1126/science.abg1795	**Abstract:** [*none - news article – extracted from text*] 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

Updated NOTE regarding CDC recognizing Down syndrome as an at-risk group. Source: Diament, M, January 7, 2021, *Disability Scoop*, "CDC Adds Down syndrome to COVID-19 'Increased Risk' List, https://www.disabilityscoop.com/2021/01/07/cdc-adds-down-syndrome-to-covid-19-increased-risk-list/29140/ See also: CDC, December 29, 2020, COVID-19: People with certain medical conditions. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html	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 Down syndrome are at increased risk of severe illness from COVID-19." *NOTE: Disability Scoop on January 7, 2021, reported that The Centers for Disease Control and Prevention is acknowledging for the first time that COVID-19 poses an especially high risk for people with Down syndrome. The federal agency updated its list of conditions that carry an "increased risk of severe illness from the virus that causes COVID-19" in late December to include Down syndrome. "Severe illness from COVID-19 is defined as hospitalization, admission to the ICU, intubation or mechanical ventilation, or death," the CDC said.*
Wadman, M. **People with Down syndrome face high risk from coronavirus** *Science,* 2020, Dec 18, 370(6523), 1384-1385. doi: 10.1126/science.370.6523.1384.	No abstract – taken from text: 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 2020. Other recent studies back up the high risk. 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. Hippisley-Cox and her colleagues analyzed a database of 8.26 million people in the United Kingdom for their paper, published in the Annals of Internal Medicine. The extraordinary risk they found emerged

	even after they corrected for many other factors including obesity, heart disease, diabetes, and living in a group home. Another recent preprint that includes findings from a large international survey found that people with DS hospitalized with COVID-19 who are 40 and older bear most of the increased risk, with a mortality of 51% versus 7% for those under 40.
Wang, QQ., Davis, P.B., Gurney, M.E., & Xu, R. **COVID-19 and dementia: Analyses of risk, disparity, and outcomes from electronic health records in the US** *Alzheimer's & Dementia*, 2021, 17(1), 1-10. DOI: 10.1002/alz.12296	**Abstract:** [Note – *this article does not relate specifically to intellectual disability but was included as it addresses dementia and its findings have application to ID*] At present, there is limited data on the risks, disparity, and outcomes for COVID-19 in patients with dementia in the United States. This is a retrospective case-control analysis of patient electronic health records (EHRs) of 61.9 million adult and senior patients (age ≥ 18 years) in the United States up to August 21, 2020. Patients with dementia were at increased risk for COVID-19 compared to patients without dementia (adjusted odds ratio [AOR]: 2.00 [95% confidence interval (CI), 1.94–2.06], P < .001), with the strongest effect for vascular dementia (AOR: 3.17 [95% CI, 2.97–3.37], P < .001), followed by presenile dementia (AOR: 2.62 [95% CI, 2.28–3.00], P < .001), Alzheimer's disease (AOR: 1.86 [95% CI, 1.77–1.96], P < .001), senile dementia (AOR: 1.99 [95% CI, 1.86–2.13], P < .001) and post-traumatic dementia (AOR: 1.67 [95% CI, 1.51–1.86] P < .001). Blacks with dementia had higher risk of COVID-19 than Whites (AOR: 2.86 [95% CI, 2.67–3.06], P < .001). The 6-month mortality and hospitalization risks in patients with dementia and COVID-19 were 20.99% and 59.26%, respectively. These findings highlight the need to protect patients with dementia as part of the strategy to control the COVID-19 pandemic.
Wieting, J., Eberlein, C., Bleich, S., Frieling, H., & Deest, M. **Behavioural change in Prader–Willi syndrome during COVID-19 pandemic.** *Journal of Intellectual Disability Research,* 2021 [on-line version: 22 March 2021] https://doi.org/10.1111/jir.12831	**Abstract:** Prader–Willi syndrome (PWS) is a rare genetic disorder that in many cases is associated with intellectual disability or mental health disorders, in addition to characteristic symptoms such as hyperphagia. The current Sars-CoV-2 coronavirus pandemic has led to massive restrictions in health care and social life worldwide. People with PWS represent a particularly vulnerable population group to these restrictions, with unknown impact on their mental health. We conducted an online questionnaire to assess the impact of the restrictions associated with the COVID-19 pandemic on the mental health of people with PWS. One hundred and eight caregivers completed the survey about individuals with PWS. Individuals with PWS > 6 years (n = 89) were included for evaluation about psychopathological change. Respondents frequently reported an increase in psychopathological symptoms associated with PWS during the lockdown, with 51.7% reporting increased temper outbursts, 43.8% showing signs of sadness, 38.2% being anxious, 55.0% more irritable, and 39.3% showing more food seeking behavior. Adjusted for the type of accommodation food seeking behavior and irritability is increased to a significantly lesser extent in people with PWS accommodated in specialized care facilities compared with those living in their family home. No significant

	difference could be found between the sexes. The COVID-19 pandemic has had a significant effect on the mental health of individuals with PWS, evidenced by an increase in behaviors associated with PWS, including temper outbursts, food-seeking, and irritability, which again underlines their need for specialized care. Individuals living with their families were particularly vulnerable, indicating that they and their families are in special need of support.
Williams, Nicole **Family begged to have sister with Down syndrome vaccinated sooner. Now she's on a ventilator with COVID-19** *CBC News,* Posted: May 20, 2021 https://www.cbc.ca/news/canada/ottawa/down-syndrome-covid-19-vaccine-1.6031801	**Abstract:** [none - news article – extracted from text] Toula Zouzoulas, 44, who has Down syndrome, has spent the last year terrified of catching COVID-19, according to her sister Olga Zouzoulas. Now, Toula is on a ventilator, fighting for her life in the ICU of Montfort Hospital in Ottawa after testing positive. Zouzoulas said she feels all this could have been avoided if her sister had been vaccinated, arguing that Toula and others with Down syndrome should have qualified sooner. Under Ontario's vaccine rollout program, those with intellectual or developmental disabilities are considered high-risk under Phase 2, but didn't become eligible until May 3 — too late for Toula who contracted COVID-19 a week earlier. "The government didn't see them as the highest risk, and they failed. They failed my sister," said Zouzoulas. "She deserves to be protected ... and she wasn't." Toula lives in a COVID-19 hotspot in Ottawa with her elderly parents, one of whom is considered high-risk and requires home care services. The parents qualified for a vaccine in March, as did Olga, who is her mother's caregiver. But Toula had to wait. Given these circumstances and the fact that Toula has Down syndrome, Zouzoulas tried repeatedly to have her vaccinated as early as possible but said every request was denied by Ottawa Public Health (OPH), who told her Toula didn't yet qualify. In mid-April, Toula developed a stomach ulcer that required surgery. Complications after the surgery kept her in hospital longer. Then in late April, Toula tested positive for COVID-19 while in hospital and is now in the ICU on a ventilator. "It's horrible. She should not be in this situation. She needs to be home," Zouzoulas said. There have been campaigns across Canada, from both organizations and families, to get people with Down syndrome vaccinated sooner. Yona Lunsky, professor at the University of Toronto, who specializes in developmental disabilities and health care, says it is a good thing that Ontario named people with Down syndrome and other developmental disabilities as a priority — even if vaccinations are still too late for some. Not every province in the country has done so. OPH said it couldn't comment on any particular case, but that it's "obligated to follow" the order of vaccination priority laid out by the province. In a statement, it said only "in select, rare situations where the provincial guidance is not explicit or not yet determined" does the city's taskforce provide interpretation or recommendations on eligible populations. Ontario's Ministry of Health has not replied to a request for comment from CBC News. Zouzoulas is still left wanting answers — and a change if anything like this should ever happen again in the future. "The

	Down syndrome population, they can't be put [in the queue] where they were this time and they need to be protected.... She may not matter to them, but she matters to us."
Willner, P., Rose, J., Stenfert Kroese, B., Murphy, G.H., Langdon, P.E., Clifford, C., Hutchings, H., Watkins, A., Hiles, S., & Cooper, V. **Effect of the COVID-19 pandemic on the mental health of carers of people with intellectual disabilities.** *Journal of Applied Research in Intellectual Disabilities*, 2020, Nov, 33(6), 1523-1533. doi: 10.1111/jar.12811. PMID: 32885897	**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.
Wos, K., Kamecka-Antczak, C., & Szafrański, M. **Remote support for adults with intellectual disability during COVID-19: From a caregiver's perspective** *Journal of Policy and Practice in Intellectual Disabilities,* 2021, June 15, https://doi.org/10.1111/jppi.12385	**Abstract:** The reality of people with ID changed during the pandemic COVID-19. Most institutions supporting people with ID switched to remote work. This required some major adaptation to these individuals' new realities, their immediate families, and facility staff. Supporting and monitoring the quality of life of individuals with disabilities and their family members during a crisis is an essential topic of current research. This research project undertaken in Poland aimed to explore the experiences of parents of adults with ID in relation to remote support provided by public support agencies. In a qualitative study, the authors used semi-structured individual interviews with caregivers of people with ID. Data analysis distinguished the following categories: parents as therapists, organization difficulties, material problems, lack of social contacts, positive solutions, and difficult behavior. The results show the difficulties of parents in balancing professional, domestic, and supporting tasks. The study was the first in Poland to report on the qualitative assessment of remote support for people with ID during COVID-19. Further, more extensive research is needed to search for solutions that respect the rights of people with disabilities to professional support.
World Health Organization (WHO). **Disability considerations during the COVID-19 outbreak.** *WHO* (2020). https://www.who.int/publications/i/item/WHO-2019-nCoV-Disability-2020-1	**Abstract:** [*none – text from webpage*]. Why are additional considerations needed for people with disabilities during the COVID-19 outbreak? Actions need to be taken to ensure that people with disabilities 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 disabilities 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.
Wright, C., Steinway, C., & Jan, S. **The crisis close at hand: How COVID-19 challenges long-term care planning for adults with intellectual disability** *Health Equity,* 2020 (Dec), 4(1), 247-248 Published online 9 Jun 2020 https://doi.org/10.1089/heq.2020.0020	**Abstract:** Whether cared for in the community or in a facility, adults with intellectual disability are among the most vulnerable individuals in the United States. Families caring for these individuals face financial, social, and emotional stress as they navigate long-term care choices for their loved ones. COVID-19 has stressed an already overwhelmed and disparate system. Emergency placement is defined as unexpectedly needing residential long-term care in a nursing home or facility. Planning helps avoid this emergent need by carefully working with and then supporting a family's strategy for future care. This may include community or residential living and depend on siblings or unrelated guardians. Widespread knowledge on how to navigate these decisions simply does not exist. Add an unexpected crisis such as COVID-19 and you have the perfect storm of yesterday—caregivers and patients in potential danger as they shelter in place, caregivers unable to work, and family members with intellectual disability left alone at home without any support and unable to use the myriad of virtual touchpoints that allow connections between those not physically together. Each state has a different way of supporting these individuals and their families, and funding is highly disparate across the country; so too has the response been to families who live in this current crisis. And what about those individuals with intellectual disability who already reside in a group home or facility? They and their families are not immune to a stressed system. In fact, group homes and facilities began and continue to be hotbeds of COVID-19 infection. For several weeks, residential dwellings have limited visitors, volunteers, and vendors while promoting social distancing and struggling to keep an infection-free staff. In Delaware, yesterday's executive order by the governor focused on long-term care facilities and their ability to cohort staff and patients with COVID-19 to prevent spread. As dynamic plans

	are implemented that involve potential moves of residents to a hospital or another facility, the inability to visit or even communicate with busy staff has left many families without any information on the status of their loved ones.
Yarci-Carrión, A., Esparcia-Pinedo, L., Mateo-Jiménez, G., Alfranca, A., Real de Asúa, D., Gutiérrez-Cobos, A., **Effect of a SARS-CoV-2 booster vaccine dose on the immune response of adults with Down syndrome** *Journal of Infection,* 2022, doi: https://doi.org/10.1016/j.jinf.2022.11.014	Adults with Down syndrome are a high-risk population for hospitalization and death due to COVID-19, and have been frequently compared to other immunocompromised populations. Their worse prognosis has been attributed to a higher prevalence of comorbidities and to a congenital immune dysregulation, which impairs the generation of a protective immunity after vaccination. Though adults with DS develop an effective immune response after receiving a two-dose regime of SARS-CoV-2 vaccination [3], SARS-COV-2-specific IgG titers wane over time, especially in adults over 40 years of age, and the duration of vaccine-elicited protection is unknown. A third vaccine dose (booster dose) has been recommended for adults with DS, but its impact on the immune response of this population has not been studied. Following an initial study on a cohort of adults with DS one to three (V1) and six (V2) months after a two-dose SARS-CoV-2 vaccination regime [3], the authors found that even though immune protection granted by COVID-19 vaccines wanes over time, a booster COVID-19 vaccine dose promotes a renewed, effective cellular and humoral immune response in adults with DS, akin to that seen in the general population. This finding was especially evident among adults over 40 years of age.
Young, E., Milligan, K., Henze, M., & Johnson, S. **Caregiver burnout, gaps in care, and COVID-19 effects on families of youth with autism and intellectual disability.** *Canadian Family Physician*, 2021, 67, 506-508. DOI: 10.46747/cfp.6707506	Abstract: *[no abstract – text summarization*] The coronavirus disease 2019 pandemic is exacerbating the stresses on patients with autism and intellectual disability, as well as on their families and caregivers. Acknowledging and validating caregiver burnout is a critical part of care for this population that needs to be prioritized in routine care. Respite care should be considered an essential service for this population, particularly during pandemics and other types of emergencies, owing to the complexity of care needs. Greater capacity needs to be built into the care system to address the needs of people with autism and intellectual disability as they age into the adult system. Caregiver capacity and well-being must be kept at the forefront of developmental care, with a continued focus on family rather than only individuals. There is an urgent need for family physicians, pediatricians, allied health practitioners, and therapists to actively inquire about, recognize, and validate burnout in caregivers of youth with autism and intellectual disability. By normalizing this experience, offering support, and reinforcing help-seeking, physicians and allied health professionals can strengthen their relationship with caregivers of children with autism and intellectual disability, providing a therapeutic space for caregivers that is nonjudgmental, builds trust, and promotes selfcare. Interprofessional communication is critical for effective service navigation and engagement. Family physicians and pediatricians can collaborate to document the experiences of these families, their strengths and successes, challenges faced, and strategies

	employed. This documentation can play a critical role in crisis planning and informing how best to support youth and their families so that they can plan and prepare for accessing emergency care
Zaagsma, M., Volkers, K. M., Swart, E.A.K., Schippers, A. P., & Van Hove, G. **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	**Abstract:** During the COVID-19 outbreak, service providers in the Netherlands had to switch towards providing remote support for people with intellectual disability living independently. 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. *1-6-2023*

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