

Washington University School of Medicine

Digital Commons@Becker

2020-Current year OA Pubs

Open Access Publications

7-1-2022

Impact of the COVID-19 pandemic on daily life, mood, and behavior of adults with Down syndrome

Sigan L Hartley

University of Wisconsin-Madison

Beau M Ances

Washington University School of Medicine in St. Louis

et al.

Follow this and additional works at: https://digitalcommons.wustl.edu/oa_4



Part of the [Medicine and Health Sciences Commons](#)

Please let us know how this document benefits you.

Recommended Citation

Hartley, Sigal L; Ances, Beau M; and et al., "Impact of the COVID-19 pandemic on daily life, mood, and behavior of adults with Down syndrome." *Disability and Health Journal*. 15, 3. 101278 (2022).

https://digitalcommons.wustl.edu/oa_4/1698

This Open Access Publication is brought to you for free and open access by the Open Access Publications at Digital Commons@Becker. It has been accepted for inclusion in 2020-Current year OA Pubs by an authorized administrator of Digital Commons@Becker. For more information, please contact vanam@wustl.edu.



ELSEVIER

Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

Original Article

Impact of the COVID-19 pandemic on daily life, mood, and behavior of adults with Down syndrome



Sigan L. Hartley, PhD ^{a, b, *}, Victoria Fleming, MS ^{a, b}, Brianna Piro-Gambetti, MS ^{a, b}, Annie Cohen, PhD ^c, Beau M. Ances, MD, PhD ^d, Michael A. Yassa, PhD ^e, Adam M. Brickman, PhD ^f, Benjamin L. Handen, PhD ^c, Elizabeth Head, PhD ^g, Mark Mapstone, PhD ^h, Bradley T. Christian, PhD ^a, Ira T. Lott, MD ^m, Eric Doran, MS ⁱ, Shahid Zaman, MD, PhD ^{j, n}, Sharon Krinsky-McHale, PhD ^k, Fredrick A. Schmitt, PhD ^l, Christy Hom, PhD ⁱ, Nicole Schupf, PhD ^f, the ABC-DS Group

^a Waisman Center, University of Wisconsin-Madison, 1500 Highland Ave, Madison, WI 53706, USA

^b School of Human Ecology, University of Wisconsin-Madison, 1300 Linden Dr, Madison, WI 53706, USA

^c University of Pittsburgh, Department of Psychiatry, 3811 O'Hara Street, Pittsburgh, PA, 15213, USA

^d Washington University St. Louis, Department of Neurology, 660 Euclid Ave, St. Louis, MO 631100, USA

^e University of California, Irvine, Neurobiology and Behavior, 213 Qureshey Research Lab, Irvine, CA 92697, USA

^f Columbia University, Department of Neurology, 710 W 168th Street, New York, NY 10033, USA

^g University of California, Irvine, Department of Pathology and Laboratory medicine, 1111 Gillespie Neuroscience Research Facility, Irvine, CA 92697, USA

^h University of California, Irvine, Clinical Neurology, 839 Health Sciences road, Irvine, CA, 92697, USA

ⁱ University of California Irvine, Department of Pediatrics, Bldg 2 34d Floor Rt81, 101 The City Drive, Orange, CA 92668, USA

^j Cambridge Intellectual & Developmental Disabilities Research Group (CIDDRG), University of Cambridge, Department of Psychiatry, Addenbrooke's Hospital, Box 189, Level E4, Hills Road, Cambridge, CB2 0QQ, UK

^k New York Institute for Basic Research in Developmental Disabilities, Department of Psychology, 1050 Forest Hill Rd, Staten Island, NY 10314, USA

^l University of Kentucky, Department of Neurosurgery, 740 S. Limestone, Lexington, KY 40536, USA

^m University of California, Irvine, Department of Psychiatry and Human Behavior, Irvine, CA 92697, USA

ⁿ Cambridgeshire & Peterborough NHS Foundation Trust (CPFT), Elizabeth House, Fulbourn Hospital, Cambridge Road, Cambridge, CB21 5EF, UK

ARTICLE INFO

Article history:

Received 6 June 2021

Received in revised form

3 February 2022

Accepted 4 February 2022

Keywords:

COVID-19

Down syndrome

Coronavirus

Pandemic

Daily life

Mood

ABSTRACT

Background: The Down syndrome population has been disproportionately affected by Coronavirus 2019 (COVID-19) in terms of experiencing severe illness and death. Societal efforts to curb the spread of COVID-19 may also have taken a heavy toll on the daily lives of individuals with Down syndrome.

Objective/hypothesis: The goal of the study was to understand how the COVID-19 pandemic has altered daily life (including residence, employment, and participation in adult disability day programs) and influenced the mood and behavior of adults with Down syndrome.

Methods: Between September 2020 and February 2021, caregivers of 171 adults with Down syndrome (aged 22–66 years) located across the United States and in the United Kingdom enrolled in the Alzheimer's Biomarker Research Consortium on Down Syndrome (ABC-DS) completed a survey.

Results: The residence of 17% of individuals was altered, and 89% of those who had been employed stopped working during the pandemic. One-third (33%) of individuals were reported to be more irritable or easily angered, 52% were reported to be more anxious, and 41% were reported to be more sad/depressed/unhappy relative to prepandemic. The majority of changes in mood and behavior were of modest severity.

Conclusions: The COVID-19 pandemic has had widespread effects on the daily life and mood and behavior of adults with Down syndrome. In the short term, caregivers and providers should be prepared

* Corresponding author. , 100 Women Chair in Human Ecology, Associate Professor, Human Development and Family Studies, School of Human Ecology, Waisman Center Investigator, UW-Madison, 4101 Nancy Nicholas Hall|1300 Linden Dr., Madison, WI 53706.

E-mail address: slhartley@wisc.edu (S.L. Hartley).

to help adults with Down syndrome with changes in daily routines, residence, employment, or adult disability day programs as society shifts away from COVID-19 safety protocols.

© 2022 The Authors. Published by Elsevier Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

The world has experienced unprecedented challenges following the outbreak of a novel coronavirus named Coronavirus 2019 (COVID-19). COVID-19 is highly contagious and often leads to a severe respiratory condition with risk of morbidity and mortality. COVID-19 was declared a pandemic by the World Health Organization in March 2020. By summer 2021, 219 million individuals worldwide had contracted COVID-19 and 4.5 million had died from the virus.¹ Societal efforts to curb the spread of the virus have led to vast changes in daily life and taken a tremendous emotional toll on society.^{2,3} Some groups, including adults with Down syndrome (DS), have been disproportionately affected by COVID-19. DS is the leading genetic cause of intellectual disability (1 in 1000 worldwide) and is due to full or partial third copy of chromosome 21.⁴ Relative to the general population, adults with DS are more likely to have severe illness and die from COVID-19.^{5,6} Societal efforts to curb the spread of COVID-19 may also have taken a particularly heavy toll on the daily lives of adults with DS, given reliance on disability services and the cognitive and behavioral phenotypes of DS. The goal of the current study was to understand how the COVID-19 pandemic altered daily life and influenced the mood and behavior of adults with DS.

Adults with DS are vulnerable to COVID-19. Adults with DS over the age of 40 years are four times more likely to be hospitalized and ten times more likely to die from COVID-19 than same-aged adults in the general population.^{2,3} In part, this heightened risk for severe illness from COVID-19 in DS is thought to be caused by immune dysregulation associated with trisomy 21, which may exacerbate the consequences of severe respiratory illnesses.⁷ Adults with DS are also thought to be at high risk for severe illness from COVID-19 because of co-occurring medical conditions,⁸ including obesity, cardiovascular conditions, diabetes, endocrine conditions, obstructive sleep apnea, and Alzheimer's disease,^{9,10} all of which are themselves associated with severe illness and death from COVID-19.^{11,12,13}

Adults with DS, as well as those with other types of intellectual and developmental disabilities, are faced with unique challenges above and beyond those of adults in the general population from societal efforts to curb the spread of COVID-19. For example, federal and state mandates for quarantining and social distancing likely led to reductions in disability programs that adults with DS normally rely on. Moreover, adults with DS are often not able to benefit from telehealth or virtual services to the same extent as their non-DS peers given communication, sensory, and cognitive difficulties or reduced access to technology.^{14,15} Employment common for adults with DS, such as janitorial work, filing/shredding, and assembly work¹⁶ cannot easily be done remotely, which may have led to temporary or permanent layoffs. In addition, not all adults with DS can adhere to COVID-19 safety procedures, including wearing masks, due to medical or sensory issues, further reducing opportunities to be in the community and interact socially. For adults with DS who could wear them, masks may have contributed to communication problems (e.g., muffled speech and obscured lip reading), as expressive language and pronunciation are areas of relative weakness in DS.¹⁷ Moreover, hearing deficits occur in up to 80–90% of individuals with DS¹⁸ which may make it difficult to understand conversational partners who wear masks. Adding to challenges, there is a 90% lifetime risk of Alzheimer's disease in DS,¹⁹ with declines in memory, attention, and executive functioning

beginning in middle adulthood (40s and 50s).^{20,21} These declines may add to the difficulty of adjusting to pandemic-related changes.

Daily-life changes caused by the COVID-19 pandemic as well as new stressors brought on by the pandemic may have consequences for the mood and behavior of adults with DS. As a group, adults with DS have a high prevalence of mood and behavior problems,^{22,23} with depressive and anxiety symptoms especially common.^{24,25} The pandemic may have led to new worries (e.g., concerns about oneself or loved ones contracting the virus), stressors (e.g., moving, new routines, and distressing news), as well as sadness from losing loved ones from the virus. The pandemic may also have reduced activities important for mood and behavior regulation and overall health including exercise and time spent outdoors, given that these activities are often fostered by disability programs.²⁶

The goal of the present study was to determine how the COVID-19 pandemic has affected daily life and the mood and behavior of adults with DS. In total, caregivers of 171 adults with DS (aged 27–66 years) in the United States and the United Kingdom completed a survey to report changes in residence, employment, and adult disability programs, as well as daily activities (e.g., time outside and physical activity). Caregivers also reported on changes in mood and behavior since the pandemic began. This information will help caregivers and providers identify interventions and services to address pandemic-related negative impacts in the short term and to consider their consequences for the longer-term aging of this population.

Methods

Between September 2020 and February 2021, caregivers of adults with DS enrolled in the Alzheimer's Biomarker Research Consortium on Down Syndrome (ABC-DS; <https://www.nia.nih.gov/research/abc-ds>) completed a survey online or by telephone (10–20 min). The ABC-DS is an ongoing multisite longitudinal research study aimed at examining the transition to Alzheimer's disease in DS. Caregivers were asked to report on daily life, mood, and behavior changes for the adult with DS since March 2020. Study procedures were in accordance with institutional and national ethical standards of the responsible conduct of human research and the Helsinki Declaration of 1975 (revised in 2000).

Participants

Seven of the eight recruiting ABC-DS sites approached a convenience sample of caregivers about the survey. Sites were spread throughout the United States and included the United Kingdom. Caregivers of 173 adults of DS consented and completed the survey ($n = 138$ [81%] online and $n = 35$ [20%] by telephone). Caregivers of adults with DS known to have died of COVID-19 ($n = 4$) or who had a major health condition (COVID-19 or other) were not approached. Two surveys had missing data on >80% of items and were removed from analyses, resulting in 171 completed surveys. This selected sample represents 55% of the ABC-DS sample ($n = 312$). These adults with DS were younger ($t(170) = 2.13, p < .001$) and less likely to have a clinical status of Alzheimer's disease ($\chi^2 = 12.57, p = .002$) pre-pandemic than those in the larger ABC-DS sample, but did not significantly differ in race/ethnicity ($\chi^2 = 2.93, p = .233$), biological

sex ($\chi^2 = 0.69$, $p = .405$), premorbid intellectual disability level ($\chi^2 = 2.92$, $p = .234$), prepandemic residence ($\chi^2 = 2.29$, $p = .318$), or the number of physical health conditions ($t(170) = 1.09$, $p = .278$).

Survey

Sociodemographics. Caregivers reported on the age (years), biological sex (males = 1, females = 2), and race/ethnicity (white/non-Hispanic, Hispanic, African-American, Asian, Pacific Islander, Native American, and multiple race/ethnicity) of adults with DS. Caregivers also rated the amount of time they spent with the adults with DS (<1 h/week, 1–5 h/week, 6–10 h/week, 11–20 h/week, and 21+ hours/week) and their relationship (parent, sibling or other family, paid caregiver, or other). Remaining sociodemographics were collected from the ABC-DS study during a visit that occurred an average of 11 months ($SD = 6.21$, range: 4–19 months) prior to the current study. Level of intellectual disability of the adult with DS was coded as mild, moderate, or severe based on IQ tests²⁷ or medical records. If the adult with DS had dementia, their IQ prior to the onset of dementia (premorbid) was used. Information on the health of adults with DS included caregiver-reported presence of hypertension or hypotension, thyroid condition, obstructive sleep apnea, and psychiatric conditions requiring medication. Body mass index was calculated from the weight in kilograms divided by height in meters squared.

Clinical status related to Alzheimer's disease was also obtained from the previous ABC-DS visit. This involved review of caregiver-reported and directly administered measures of cognition and adaptive behavior and consideration of intellectual disability level, psychiatric and medical conditions, and life events. This process has been described elsewhere.²⁸ Categories were a) *cognitively stable*; b) *mild cognitive impairment-DS*, indicating mild cognitive declines limited in scope; c) *dementia*, indicating marked cognitive and adaptive behavior decline; and d) *unable to determine* (Table 1).

CoRonavirus Health Impact Survey. An adapted and shortened version of the CoRonavirus Health Impact Survey (CRISIS V0.3; crisissurvey.org) survey was completed by caregivers. This measure assesses the extent and impact of life changes induced by the COVID-19 pandemic. Items related to COVID-19 status (e.g., tested positive for COVID-19 virus or antibodies), residence, employment, daily activities, and emotions/worries and behavior were completed. Item wording was modified when needed to reflect the lives of adults with DS (e.g., day programs in addition to employment). Response options varied and included option menus, dichotomous options and 5-point Likert-type scales. Item wording and response options are provided in Figs. 1–5.

Pittsburgh Sleep Quality Index²⁹. Caregivers completed nine questions from the Pittsburgh Sleep Quality Index (PSQI) to evaluate sleep quality over the past month. Items asked about sleep habits, quality of sleep, and daytime tiredness. Items were rated from 0 to 3 points (0 = no difficulty to 3 = severe difficulty). The PSQI has good reliability and validity in general population adult samples as well as in adults with high rates of sleep problems, including those with intellectual and developmental disabilities.³⁰

Data analysis plan

Items were screened for outliers (>3 standard deviations from mean), normal distribution of data (Skew: –1 and 1; Kurtosis: –2 and 2), and homoscedasticity. All data were within normal limits by these criteria. Descriptive statistics (frequencies, means, and standard deviations) were used to understand how common daily-life impacts and changes in mood and behavior were in our sample.

Results

Sociodemographics

Approximately half of the adults with DS were female ($n = 86$, 50%) and the majority ($n = 139$, 81%) were Caucasian, non-Hispanic. Adults with DS aged 27–66 years ($M = 41.58$, $SD = 9.13$), and 46% ($n = 79$) had mild intellectual disability. The majority of caregivers were family ($n = 150$, 88%) and interacted with the adult with DS at least 10 h per week ($n = 148$, 87%). Prior to the pandemic, adults most commonly lived with family ($n = 80$, 47%) or in a group home ($n = 61$, 36%). The majority of adults with DS ($n = 120$, 70%) were cognitively stable, whereas 9 (5%) had mild cognitive impairment and 8 (5%) had dementia, and the clinical status was unknown for 34 (20%) adults. Sixty-seven adults had been diagnosed with obstructive sleep apnea (39%), 59 (35%) had a thyroid condition, and 17 (10%) had hypertension or hypotension. Thirty-eight (22%) were on an antipsychotic or mood stabilizer for a psychiatric condition, and 76 (44%) were obese.

COVID-19 status

Four adults with DS (2%) had tested positive for COVID-19, 2 (1%) tested positive for COVID-19 antibodies, and 7 (4%) were suspected of having COVID-19 but had not been tested. The remaining 160 (94%) adults had not had COVID-19 to the caregiver's knowledge.

Residence

As a result of the pandemic, 14 (8%) adults with DS moved to a different residence; all involved leaving a group home or independent living situation to live with family. Another 15 (9%) experienced change in who was living in their residence, most often involving roommates moving out of the group home or apartment (Fig. 1a). Remaining adults ($n = 142$, 83%) had not experienced a residence change. As shown in Fig. 1b, change in family, staff, or household contacts due to the pandemic was reported to be 'slightly' or 'moderately' stressful for 94 (54%) adults with DS and 'very' to 'extremely' stressful for 27 (16%) adults with DS.

Employment and adult disability day programming

Forty-four (26%) adults with DS were not employed prior to the pandemic, and this did not change during the pandemic. Of the 127 adults employed prior to the pandemic, 14 (8%) continued to work and 113 (89%) stopped working. Of those who stopped work, 62 (49%) reported this was a temporary break, whereas 11 (9%) reported this was a permanent job loss, and the remaining 40 (31%) were not sure if it was a temporary break or permanent loss (Fig. 2a). Of the 82 adults who attended an adult disability day program prior to the pandemic, 13 (16%) continued to attend and 69 (84%) stopped attending for at least a period of time (Fig. 2b). Change in employment or in participation in adult disability day programs due to the pandemic was reported to be 'slightly' to 'moderately' stressful for 87 (51%) adults and 'very' to 'extremely' stressful to 35 (20%) of the adults (Fig. 2c).

Exercise and time outside of the home

The majority of adults with DS were reported to engage in exercise that elevated heart rate and breathing for at least 30 min 3 days a week or more ($n = 94$, 55%). More than one-third of adults either engaged in no exercise ($n = 35$; 20%) or exercised only 1–2 days ($n = 40$, 23%) a week (Fig. 3a). Less than one-fifth ($n = 39$, 23%)

Table 1
Participant sociodemographics (N = 171).

Participant site, No. (%)	
Northeast, United States	34 (20%)
COVID-19 Incidence: 100-499	
Midwest, United States	65(38%)
COVID-19 Incidence: 100-499	
Southeast, United States	24 (14%)
COVID-19 Incidence: 100-750+	
Southwest, United States	34 (20%)
COVID-19 Incidence: 100-499	
United Kingdom	14 (8%)
COVID-19 Incidence: 100-750+	
Female, No. (%)	86 (50%)
Unknown	3 (2%)
Chronological age in years, M (SD)	41.58 (9.13)
Intellectual disability level, No. (%)	
Mild	79 (46%)
Moderate	61 (36%)
Severe	8 (5%)
Unknown	23 (13%)
Race/ethnicity, No. (%)	
Latina/o	6 (4%)
African American	2 (1%)
Asian	3 (2%)
Caucasian, non-Hispanic	139 (81%)
Unknown	21 (12%)
Alzheimer's clinical status, No. (%)	
Cognitively Stable	120 (70%)
MCI	9 (5%)
Alzheimer's disease	8 (5%)
Unknown	34 (20%)
Residence prior to pandemic, No. (%)	
With family	80 (47%)
Group home	61 (36%)
Independent	14 (8%)
Facility	2 (1%)
Unknown	14 (8%)
Health, No. (%)	
Obstructive sleep apnea	67 (39%)
Thyroid condition	59 (35%)
Hypertension or hypotension	17 (10%)
Obesity	76 (44%)
Antipsychotic or mood stabilizer medication	38 (22%)
Unknown	24 (14%)
Caregiver relationship, No. (%)	
Paid caregiver	16 (9%)
Parent	128 (75%)
Sibling or other family	22 (13%)
Missing	5 (3%)
Caregiver contact, No. (%)	
Less than 1 h/week	3 (2%)
1-5 h/week	9 (7%)
6-10 h/week	11 (6%)
11-20 h/week	17 (10%)
More than 20 h/week	131 (77%)

Note. COVID-19 incidence rate is based on 7 days per 100,000 for region from August 2020 to February 2021. Obesity is defined as body mass index >30.0 kg/m².

of adults were reported to spend time outside daily. The remaining adults spent time outside on no days (n = 30, 18%), 1-2 days (n = 43, 25%), 3-4 days (n = 31, 18%), or 5-6 days (n = 24, 14%) per week (Fig. 3b).

Mood and behavior

Compared with prior to the pandemic, 50 (29%) adults with DS were reported to be 'slightly' or 'somewhat' more irritable or easily angered and an additional 4% (n = 7) were 'a lot' or 'extremely more' irritable or easily angered (Fig. 4a). The majority of adults were reported to have had no change in irritability (n = 106, 62%). Compared with prior to the pandemic, 76 (44% adults experienced 'slightly' or 'somewhat' more anxiety) and 12 (8%) experienced 'a lot' to 'extremely' more anxiety relative to prepandemic. The other

half (n = 74, 43%) experienced no global change in anxiety, or increases in anxious were not known (n = 9, 5%) (Fig. 4b). Compared with prior to the pandemic, 70 (41%) adults were reported to be 'slightly' to 'a lot' more sad/depressed/unhappy during the pandemic (Fig. 4c). In contrast, 19 (12%) adults were reported to be 'slightly' to 'a lot' more cheerful/happy relative to prepandemic. Remaining adults (n = 78, 46%) had no change in mood (happiness vs. sadness) since the pandemic began. Changes in daily routines related to COVID-19 safety (e.g., masks and staying six feet apart) caused 'slight' or 'moderate' anxiety and stress in half (n = 87; 51%) of the adults and 'very' or 'extreme' anxiety in 19 (11%) adults (Fig. 4d).

Sleep

During the past month, 20 (11%) adults with DS were reported to have 'fairly bad' to 'very bad' quality of sleep. Remaining adults had 'fairly good' (n = 66, 39%) to 'very good' (n = 79, 46%) quality of sleep. Nineteen (11%) adults had taken medication to help them sleep at least once in the past month. About one-fourth (n = 42, 24%) had trouble staying awake while being driven, eating meals, or during social interactions at least once in the past month. Overall, 70 (41%) adults were reported to have problems getting enough enthusiasm to get things done, with most indicating this was 'only a very slight problem' or 'somewhat of a problem' (n = 64, 37%) as opposed to 'very big problem' (n = 6, 4%).

Discussion

Adults with DS have been disproportionately affected by the COVID-19 virus in terms of experiencing severe illness and death at a younger age compared to the non-DS population.^{2,5,6} The current study sought to understand how the COVID-19 pandemic and societal efforts to curb the spread of the virus also affected the daily life and mood and behavior of adults with DS. This information is critical for informing interventions to address pandemic-related effects in the short term and to anticipate longer-term effects on aging in DS in the years to come.

Overall, the COVID-19 pandemic has had widespread consequences for the living situation, employment, and adult day programs of adults with DS. The pandemic necessitated a change in residence or in housemates for 17% of our sample. There is an important need to develop plans for eventually transitioning this subset of adults back to prepandemic residential situations or to identify new permanent residences. Similarly, the majority of adults with DS will need assistance in the transition back to employment, as 89% of those who had been employed prior to the pandemic stopped working. This was reported to be a permanent job loss for 9% of adults, and 31% were not sure if this was a temporary break or permanent loss. Breaks in employment (temporary or permanent) are likely to necessitate job retraining and assistance with job placements in the coming months to years.

There will similarly be a need to assist adults with DS in transitions back to adult disability day programs, which may also require retraining and increased staffing. Of the adults with DS who had been involved in adult day programs, 84% stopped attending during the pandemic. Changes in employment or adult disability day programs due to the pandemic were reported to be 'slightly' to 'moderately' stressful for 51% of adults with DS and 'very' to 'extremely' stressful for 21% of adults. If these interruptions are prolonged, there could be a heavy toll on the mental health of adults with DS. Work and adult day programs have documented benefits including providing cognitive stimulation and social interaction and by increasing self-confidence, sense of community belonging, and quality of life.³¹

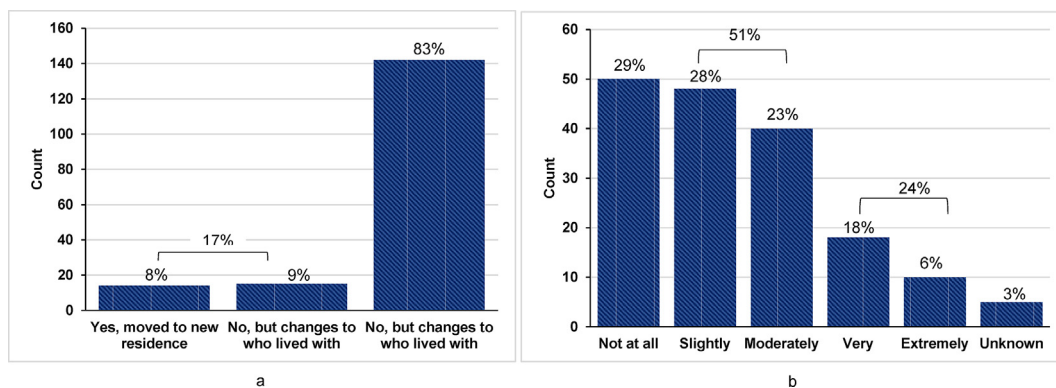


Fig. 1. a. Did the adult with Down syndrome experience a change in residence because of the COVID-19 pandemic (N = 171)? b. How stressful have changes in family, staff, or household contacts been for the adult with Down syndrome since the COVID-19 pandemic began (N = 171)?

There are likely both short- and long-term consequences of the altered daily life caused by the pandemic for the health of adults with DS. During the pandemic, 43% of the adults with DS engaged in no exercise or exercised on only one or two days a week. Moreover, 42% of the adults with DS spent time outside on either no days or only one or two days per week. We do not know if this low level of exercise and limited time outdoors reflects a pandemic-related shift or was also true prepandemic. However, it does suggest that physical inactivity may add to comorbid health conditions such as obesity, sleep apnea, and endocrine and cardiovascular conditions.^{32,33} Moreover, there is evidence that high sedentary behavior and low moderate to vigorous activity are related to mental health problems and poor cognitive performance in DS.^{34,35} Thus, by maintaining or

possibly exacerbating low levels of physical activity and staying indoors, the pandemic could have lasting impacts on aging in DS. The longer the pandemic, the greater the need to address these challenges.

Mood and behavior problems are already elevated in DS,³⁶ and our findings suggest that these problems grew during the pandemic. One-third of adults with DS (33%) were reported to be more irritable or easily angered, about half (52%) were more anxious, and two-fifths (41%) were more sad/depressed/unhappy relative to prepandemic. These findings are consistent with previous reports from studies of caregivers of adults with intellectual disability due to a variety of etiologies that the majority of adults experienced new stress and anxiety.³⁷ These changes were at a slight or moderate level in most cases but severe for a marked

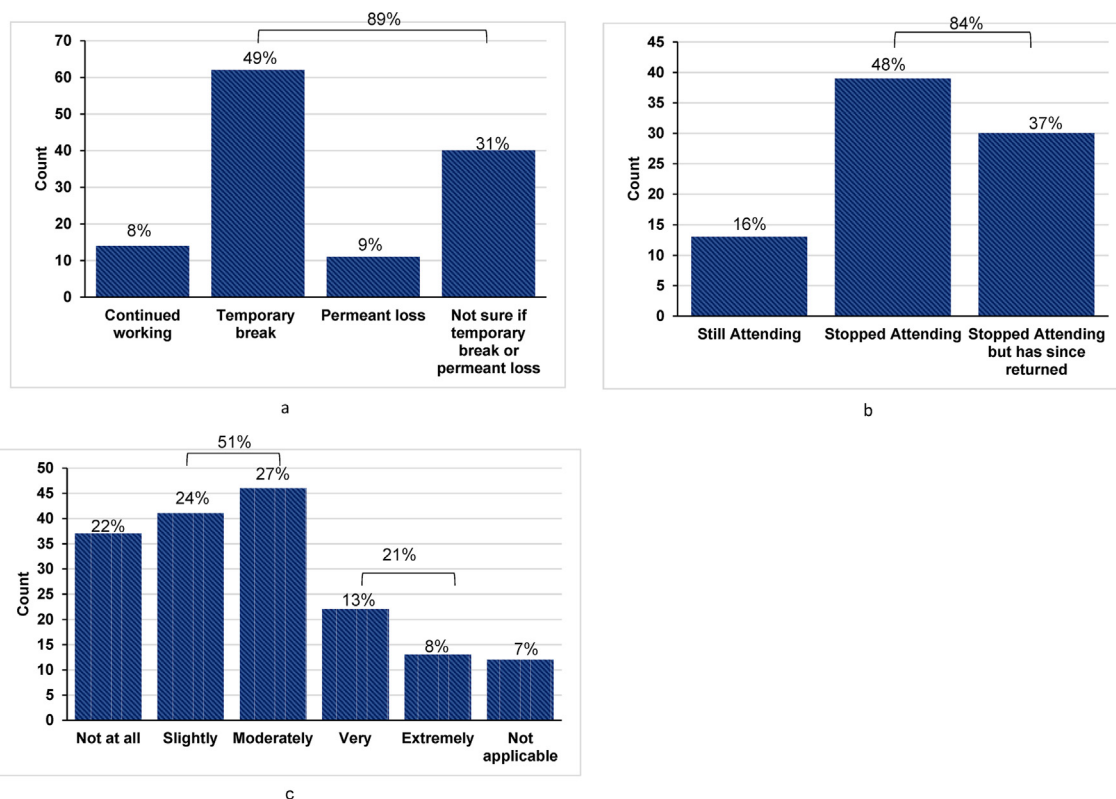


Fig. 2. a. For adults with Down syndrome employed prior to the pandemic (N = 127), have they continued to work during the pandemic? b. For adults with Down syndrome who attended an adult disability day program (N = 82) prior to the pandemic, have they continued to attend during the pandemic? c. How stressful have changes in employment or adult disability day program related to the pandemic been for the adult with Down syndrome (N = 171)?

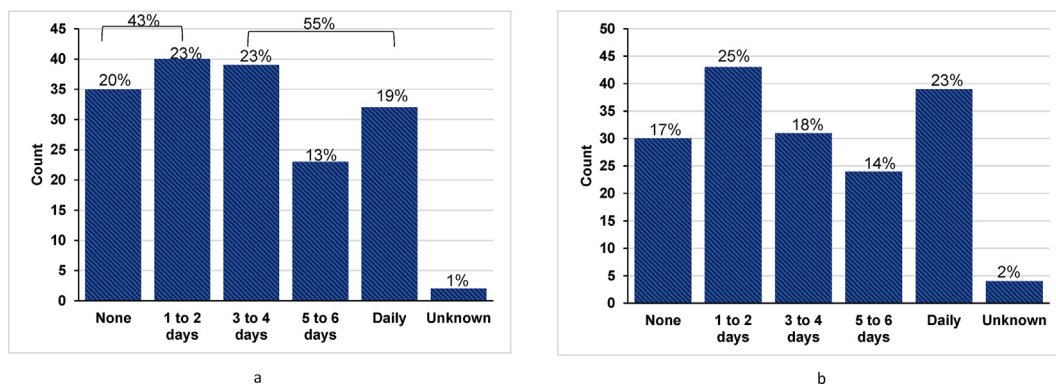


Fig. 3. a. How many days per week does the adult with Down syndrome engage in exercise for at least 30 min that elevates heart rate and breathing (N = 171). b. How many days per week does the adult with Down syndrome spent time outside (N = 171)?

subset (3–8%). This is concerning given the already high level of mood and behavior problems in adults with DS and because this population is underserved by the mental health system.³⁸ Increases in mood and behavior problems could interfere with the ability of adults with DS to integrate back into employment and adult disability day programs.³⁹ Moreover, these increased problems could contribute to caregiver burnout, especially given that caregivers have little respite from caregiving during the pandemic due to loss of employment and adult day programs for the adult with DS.³⁷ Thus, it is important to ensure caregiver mental health is addressed. Changes in daily routines related to COVID-19 safety caused slight to moderate anxiety and stress in half (51%) of adults and severe increases in stress and anxiety in 11% of adults. The changing nature of COVID-19 (e.g., new variants) may mean that

these originally acute stressors are now chronic and will increasingly tax the mental health of adults with DS.

During the pandemic, a subset of adults with DS were reported to have experienced sleep problems, including poor sleep quality (11%), taking sleep medication (11%), trouble staying awake during the day (24%), and difficulty having enough enthusiasm to get things done (41%), possibly because of the lack of structure or cognitive stimulation or increased anxiety and/or depression. More than one-third (39%) of these adults with DS had previously been diagnosed with obstructive sleep apnea. This high prevalence of sleep problems has important implications because sleep disruptions have been found to be related to early Alzheimer's disease pathology (i.e., biomarkers of amyloid-β) and lower memory, attention, and executive functioning performance in adults with

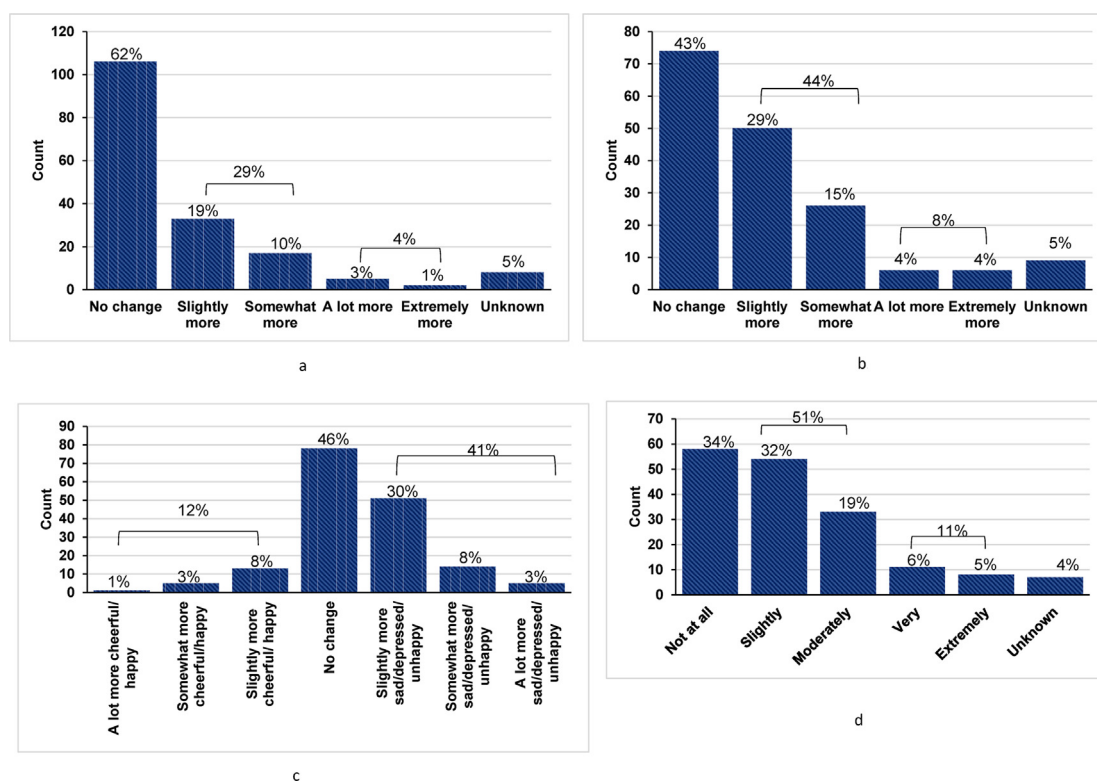


Fig. 4. a. Compared to prior to the pandemic, how irritable or easy to anger is the adult with Down syndrome (N = 171)? b. Compared to prior to the pandemic, how anxious or nervous is the adult with Down syndrome (N = 171)? c. Compared to prior to the pandemic, how happy vs. sad is the adult with Down syndrome (N = 171)? d. Have changes in daily routine related to COVID-19 safety (e.g., wearing masks and staying six feet apart) caused anxiety or stress for the adult with Down syndrome (N = 171)?

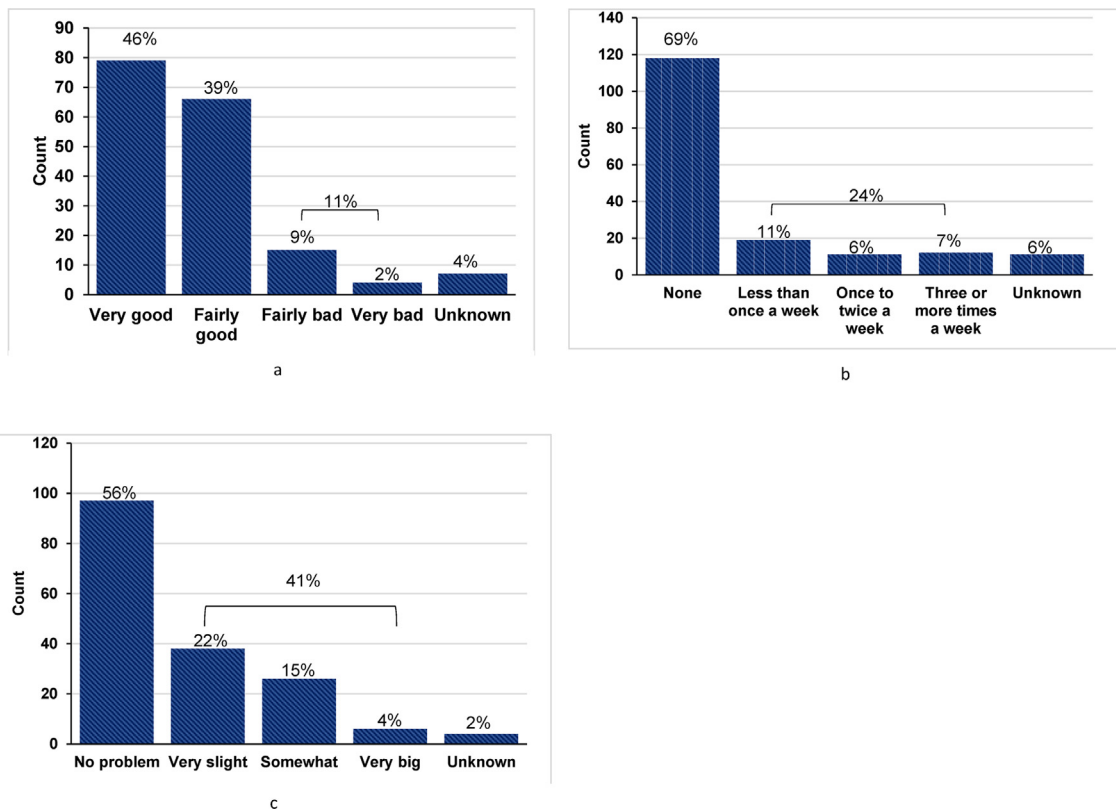


Fig. 5. a. During the past month, how would you rate the quality of sleep of the adult with Down syndrome overall (N = 171)? b. During the past month, how often has the adult with Down syndrome had trouble staying awake while driving, eating meals, or engaging in social activity (N = 171)? c. During the past month, how much of a problem has it been for the adult with Down syndrome to keep up enough enthusiasm to get things done (N = 171)?

DS.⁴⁰ Thus, future longitudinal studies should evaluate whether pandemic-related changes in sleep are tied to the timing of Alzheimer’s disease in DS in the coming years.

There was evidence of ‘silver linings’ from the pandemic. A subset (13%) of adults with DS were reported to be ‘slightly’ to ‘a lot’ more cheerful or happy relative to before the pandemic. Open-ended caregiver comments indicated that increases in positive mood were related to time away from employment or disability day program stressors and/or breaks from roommates. Caregivers also reported benefits from spending more time with family during the pandemic, which has also been reported in interviews of caregivers of adults with other types of intellectual and developmental disabilities³⁷

The current study had strengths and limitations. The study included adults with DS from across the US and the United Kingdom. Caregivers reported on face-valid questions that had a clear time anchor (e.g., March 2020) for the pandemic. That said, the study used a convenience sample from the ABC-DS and is not representative of adults with DS not willing/able to participate in longitudinal research. This convenience sample was younger and less likely to have a clinical status of Alzheimer’s disease than what was true for the full ABC-DS cohort. Moreover, few adults with DS had tested positive for COVID-19. Shifts in daily life, mood, and behavior may have been more severe for older adults and adults with dementia with DS and/or those who contracted the virus. The study is also limited in that caregivers responded to questions about behaviors and mood ‘on average’ across several months. This strategy captured global COVID-19 effects but obscured severe temporary changes. Indeed, in an open-ended question asking for any additional comments, several caregivers reported that increases

in worrying, stress, and anxiety were greatest in spring of 2020 and fluctuated in response to risk level, news, and vaccine rollout. Our discussion of results often focused on the prevalence of adults with DS affected (grouped: ‘slightly’ and ‘moderately’) and very affected (grouped: ‘a lot’ and ‘extremely’). This strategy may minimize differences among the grouped response options and/or exaggerate differences between groupings. Finally, the clinical status and physical health of adults with DS was from a previous ABC-DS study visit and could have changed (average interim 11 months) between that visit and current study.

In conclusion, the COVID-19 pandemic has altered the daily life, mood, and behavior of adults with DS. In the short term, adults with DS need assistance managing changes in their daily routines, residence, employment, and adult disability day programs and to prepare for further transitions in these domains when society shifts out of the pandemic. Interventions are needed to alleviate increases in stress, anxiety, irritability/anger, and sadness/depression from the pandemic in adults with DS. There is also a need to support caregivers. Strategies for promoting exercise, time outside, and good sleep are needed given longstanding concerns in these areas, which may have been exacerbated by the pandemic. In the long term, researchers should monitor how the pandemic alters aging in DS, including consequences for physical and mental health and Alzheimer’s disease. The ABC-DS cohort provides a unique opportunity in this regard. Future research should leverage the current dataset to determine if specific subgroups of adults with DS were particularly taxed by the pandemic and to identify the changes in daily life (e.g., loss of employment) predictive of mood and behavior problems. Future research should assess pandemic effects from the perspective of adults with DS.

Acknowledgments

The authors thank the adults with Down syndrome volunteering as participants in this study for their invaluable contributions to this work, along with their service providers and families.

Presentation

This work was presented at the Alzheimer's Disease Biomarker Consortium on Down Syndrome (ABC-DS) annual meeting.

Funding

This project was supported by the Alzheimer's Biomarker Consortium on Down Syndrome (ABC-DS) and the researcher and investigator time was funded by the National Institutes of Health (U01 AG051406, U01 AG051412, U19AG06854, HDR01064993, P30 AG028383, T32AG057461 and U54HD090256).

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of funding agencies.

Conflicts of interest

The authors do not have any conflicts of interest to report.

References

- World Health Organization. *Coronavirus Disease (COVID-19) Global Epidemiological Situation*. 2021.
- Cliff AK, Coupland CAC, Keogh RH, Hemingway H, Hippisley-Cox J. COVID-19 mortality risk in Down Syndrome: results from a cohort study of 8 million adults. *Ann Intern Med*. 2020;174(4):572–576. <https://doi.org/10.7326/M20-4986>. M20-4986.
- Hüls A, Costa ACS, Dierssen M, et al. T21RS COVID-19 Initiative. Medical vulnerability of individuals with Down syndrome to severe COVID-19—data from the Trisomy 21 Research Society and the UK ISARIC4C survey. *EClinicalMedicine*. 2021;33:100769. <https://doi.org/10.1016/j.eclinm.2021.100769>.
- World Health Organization. Genomic Resource Centre: Genes and human disease. <http://www.who.int/genomics/public/geneticdiseases/en/index1.html>; 2017.
- De Cauwer H, Spaepen A. Are patients with Down syndrome vulnerable to life-threatening COVID-19? *Acta Neurol Belg*. 2020;1(3). <https://doi.org/10.1007/s13760-020-01373-8>.
- Malle L, Gao C, Hur C, et al. Individuals with Down syndrome hospitalized with COVID-19 have more severe disease. *Genet Med*. 2020;23(3). <https://doi.org/10.1038/s41436-020-01004-w>.
- Espinosa JM. Down syndrome and COVID-19: a Perfect Storm? *Cell Reports Medicine*. 2020;1(2):100016. <https://doi.org/10.1016/j.xcrm.2020.100019>. <https://doi.org/10.1016/j.xcrm.2020.100019>.
- 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. *Innovations in Care Delivery*. 2021;5:1–12. <https://doi.org/10.1056/CAT.21.0051>.
- Capone GT, Chicoine B, Bulova P, et al. Down Syndrome Medical Interest Group DSMIG-USA Adult Health Care Workgroup. Co-occurring medical conditions in adults with Down syndrome: a systematic review toward the development of health care guidelines. *Am J Med Genet*. 2018;176(1):116–133. <https://doi.org/10.1002/ajmg.a.38512>.
- Tsou AY, Bulova P, Capone G, et al. Global down syndrome Foundation medical care guidelines for adults with down syndrome Workgroup. Medical care of adults with down syndrome: a clinical guideline. *JAMA*. 2020;324(15):1543–1556. <https://doi.org/10.1001/jama.2020.17024>.
- Cade BE, Dashti HS, Hassan SM, Redline S, Karlson EW. Sleep apnea and COVID-19 mortality and hospitalization. *Am J Respir Crit Care Med*. 2020;202(10):1462–1463. <https://doi.org/10.1164/rccm.202006-2252LE>.
- Dietz W, Santos-Burgoa C. Obesity and its implications for COVID-19 mortality. *Obesity*. 2020;28(6):1005. <https://doi.org/10.1002/oby.22818>.
- Illouz T, Biragyn A, Frenkel-Morgenstern M, et al. Specific Susceptibility to COVID-19 in adults with down syndrome. *NeuroMolecular Med*. 2021;12:1–11. <https://doi.org/10.1007/s12017-021-08651-5>.
- Annaswamy TM, Verdusco-Gutierrez M, Frieden L. Telemedicine barriers and challenges for persons with disabilities: COVID-19 and beyond. *Disability and Health Journal*. 2020;13:1–8. <https://doi.org/10.1016/j.dhjo.2020.100973>. Elsevier Inc.
- Krysta K, Romańczyk M, Diefenbacher A, Krzysztanek M. Telemedicine treatment and care for patients with intellectual disability. *Int J Environ Res Publ Health*. 2021;18:1–12. <https://doi.org/10.3390/ijerph18041746>.
- Kumin L, Schoenbrodt L. Employment in adults with down syndrome in the United States: results from a national survey. *J Appl Res Intellect Disabil*. 2016;29(4):1–9. <https://doi.org/10.1111/jar.12182>.
- Roberts JE, Malkin C. Language and communication development in Down syndrome. *Ment Retard Dev Disabil Res Rev*. 2007;13:26–35. <https://doi.org/10.1002/mrdd.20136>.
- McCarron M, McCallion P, Reilly E, Dunne P, Carroll R, Mulryan N. A prospective 20-year longitudinal follow-up of dementia in persons with Down syndrome. *Journal of Intellectual Disability Research*. 2017;61:843–852.
- Raut P, Sriram B, Yeoh A, Hee KY, Lim SB, Daniel ML. High prevalence of hearing loss in Down syndrome at first year of life. *Annals of the Academy of Medicine*. 2011;40(11):493–498.
- Hartley SL, Handen BL, Devenny D, et al. Cognitive indicators of transition to preclinical and prodromal stages of Alzheimer's disease in Down syndrome. *Alzheimer's Dementia: Diagnosis, Assessment and Disease Monitoring*. 2020;12(1). <https://doi.org/10.1002/dad2.12096>.
- Krinsky-McHale SJ, Zigman WB, Lee JH, et al. Promising outcome measures of early Alzheimer's dementia in adults with Down syndrome. *Alzheimer's Dementia: Diagnosis, Assessment & Disease Monitoring*. 2020;12(1). <https://doi.org/10.1002/dad2.12044>.
- Dykens EM. Psychiatric and behavioral disorders in persons with down syndrome. *Ment Retard Dev Disabil Res Rev*. 2007;13(3):272–278. <https://doi.org/10.1002/mrdd.20159>.
- Straccia C, Baggio S, Barisnikov K. Mental illness, behavior problems, and social behavior in adults with down syndrome. *Journal of Mental Health Research in Intellectual Disabilities*. 2014;7(1):74–90. <https://doi.org/10.1080/19315864.2012.741660>.
- Tassé MJ, Navas Macho P, Haverkamp SM, et al. Psychiatric conditions prevalent among adults with Down Syndrome. *J Pol Pract Intellect Disabil*. 2016;13(2):173–180. <https://doi.org/10.1111/jppi.12156>.
- Vicari S, Pontillo M, Armando M. Neurodevelopmental and psychiatric issues in down's syndrome: Assessment and intervention. *Psychiatr Genet*. 2013;23(3):95–107. <https://doi.org/10.1097/YPG.0b013e32835fe426>.
- Rubenstein E, DuBois L, Sadowsky M, et al. Evaluating the potential for special olympics fitness models as a health interention for adults with intellectual disabilities. *Disability and Health Journal*. 2020;13:10–15. <https://doi.org/10.1016/j.dhjo.2019.100850>.
- Roid GH. *Stanford Binet Intelligence Scales*. Itasca, IL: Riverside Pub; 2003.
- Handen BL, Lott IT, Christian BT, et al. The Alzheimer's biomarker Consortium-down syndrome: Rationale and methodology. *Alzheimer's & Dementia:Diagnosis, Assessment and DiseaseMonitoring*. 2020;12:45–50. <https://doi.org/10.1002/dad2.12065>.
- Buysse DJ, Reynolds CF, Monk TH, Berman SR, Kupfer DJ. The Pittsburgh Sleep Quality Index: a new instrument for psychiatric practice and research. *Psychiatr Res*. 28(2), 193–213. doi: 10.1016/0165-1781(89)90047-4.
- Baker EK, Richdale AL. Sleep patterns in adults with a diagnosis of high-functioning autism spectrum disorder. *Sleep*. 2015;38(11):1765–1774. <https://doi.org/10.5665/sleep.5160>.
- Lindsay S, Cabliostro E, Albarico M, Mortaji N, Karon L. A systematic review of the benefits of hiring people with disabilities. *J Occup Rehabil*. 2018;28:634–655. <https://doi.org/10.1007/s10926-018-9756-z>.
- Baraona F, Gurvitz M, Landzberg MJ, Opatowsky AR. Hospitalizations and mortality in the United States for adults with Down syndrome and congenital heart disease. *Am J Cardiol*. 2013;111(7):1046–1051. <https://doi.org/10.1016/j.amjcard.2012.12.025>.
- Pikora TJ, Bourke J, Bathgate K, Foley K-R, Lennox N, Leonard H. Health conditions and their impact among adolescents and young adults with down syndrome. *PLoS One*. 2014;9(5):e96868. <https://doi.org/10.1371/journal.pone.0096868>.
- Pape SE, Baksh RA, Startin C, Hamburg S, Hithersay R, Strydom A. The association between physical activity and CAMDEX-DS changes prior to the onset of alzheimer's disease in Down syndrome. *J Clin Med*. 2021;10:1882–1893. doi: 3390/jcm10091882.
- Ptomey LT, Szabo AN, Willis EA, et al. Changes in cognitive function after a 12-week exercise intervention in adults with Down syndrome. *Disability and Health Journal*. 2018;11(3):486–490. <https://doi.org/10.1016/j.dhjo.2018.02.003.29501470>.
- Dykens EM, Shah B, Davis B, Baker C, Fife T, Fitzpatrick J. Psychiatric disorders in adolescents and young adults with Down syndrome and other intellectual disabilities. *J Neurodev Disord*. 2015;7(1). <https://doi.org/10.1186/s11689-015-9101-1>.
- Doody O, Keenan PM. The reported effects of the COVID-19 pandemic on people with intellectual disability and their carers: a scoping review. *Annals of Medicine*. 2021;53:786–804. <https://doi.org/10.1080/07853890.2021.1922743>.
- Whittle EL, Fisher KR, Reppermund S, Lenroot R, Troller J. Barriers and enablers to access mental health services for people with intellectual disability: a scoping review. *Journal of Mental Health Research in Intellectual Disabilities*. 2018;11:69–102. <https://doi.org/10.1080/19315864.2017.1408724>.
- Tomaszewski B, Fidler D, Talapatra D, Riley K. Adaptive behaviour, executive function and employment in adults with Down syndrome. *J Intellect Disabil Res*. 2018;62(1):41–52. <https://doi.org/10.1111/jir.12450>.
- Cody KA, Piro-Gambetti B, Zammit MD, et al. Association of sleep with cognition and beta amyloid accumulation in adults with Down syndrome. *Neurobiol Aging*. 2020;93:44–51. <https://doi.org/10.1016/j.neurobiolaging.2020.04.018>.