American Journal on Intellectual and Developmental Disabilities

Healthcare and behavior changes for adults with Down syndrome 1-year into COVID-19

--Manuscript Draft--

Manuscript Number:	AJIDD-D-22-00007R1
Article Type:	Research Report
Keywords:	down syndrome, COVID-19, caregiver
Corresponding Author:	Eric Rubenstein, PhD Boston University School of Public Health Boston, Massachusetts UNITED STATES
First Author:	Eric Rubenstein, PhD
Order of Authors:	Eric Rubenstein, PhD
	Nichole Kyprianou, BS
	Prisha Sujin Kumar, BS
	Anna-Mariya Kirova, MSW
	Alexis Sokoloff
	Hampus Hillerstrom, MBA, MS
	James Hendrix, PhD
Manuscript Region of Origin:	UNITED STATES
Abstract:	Individuals with Down syndrome (DS) have been disproportionately harmed by the COVID-19 pandemic and may have been more likely to have sacrificed opportunity and activity to avoid potential exposures. Our objective was to describe the experience one to one and half years into the COVID-19 pandemic for adults with DS, as reported by their caregivers in an online survey conducted between April and September of 2021. In our sample of 438 adults with DS, caregivers reported that adults with DS lost activities, struggled with employment, had negative behavioral changes, lost skills, and developed more mental health conditions. For adults with DS, one in five caregivers reported less healthcare usage, one in four reported delayed routine care, and 86.5% reported lost activities. As the pandemic continues, targeted support for adults with DS is needed to prevent further skill loss and mental health conditions.

Healthcare and behavior changes for adults with Down syndrome 1-year into COVID-19

Abstract

Individuals with Down syndrome (DS) have been disproportionately harmed by the COVID-19 pandemic and may have been more likely to have sacrificed opportunity and activity to avoid potential exposures. Our objective was to describe the experience one to one and half years into the COVID-19 pandemic for adults with DS, as reported by their caregivers in an online survey conducted between April and September of 2021. In our sample of 438 adults with DS, caregivers reported that adults with DS lost activities, struggled with employment, had negative behavioral changes, lost skills, and developed more mental health conditions. For adults with DS, one in five caregivers reported less healthcare usage, one in four reported delayed routine care, and 86.5% reported lost activities. As the pandemic continues, targeted support for adults with DS is needed to prevent further skill loss and mental health conditions.

Keywords: Down syndrome, COVID-19, employment, health care, health services

Individuals with Down syndrome (DS) have been disproportionately harmed by the COVID-19 pandemic. In data from 2020, studies found that people with DS had 3.5 to 10 times the mortality rate compared to people without DS (Clift, Coupland, Keogh, Hemingway, & Hippisley-Cox, 2021; Huls et al., 2021). People with DS may be at higher risk of COVID-19 infection and poor outcomes because of immune dysregulation, pulmonary hypertension, congenital heart disease, and Alzheimer's disease (Illouz et al., 2021). Further, people with intellectual disabilities (which includes DS), experienced staggering case mortality rates and were deeply impacted by outbreaks at assisted living facilities (Landes, Turk, Formica, McDonald, & Stevens, 2020; Turk, Landes, Formica, & Goss, 2020). With the increased understanding of COVID-19 and availability of effective vaccines, the landscape has changed since the end of 2020. However, the social ramifications of the pandemic may still affect health and health care for adults with DS.

People with DS are considered 'high-risk' for COVID-19, so they may have been more likely to have sacrificed opportunity and activity to avoid potential exposures. Likely, many lost opportunity and activity due to shuttered programs and lack of funding for direct care staff. Disruption of routine and life changes can be especially difficult for people with DS (Murphy et al., 2017) and may lead to more mental health issues like anxiety and depression (Walker, Dosen, Buitelaar, & Janzing, 2011). COVID-19 related disturbances of daily living have not been described amongst adults with DS during this period and these data are critically needed to understand gaps in care and to plan for future public health crises.

Further, there may be large age effects when assessing COVID-19 behavioral outcomes for adults with DS. Starting at age 40, most people with DS exhibit biological signs of Alzheimer's disease (Zigman & Lott, 2007) with more than 60% having Alzheimer's disease diagnosed by 55 years (Rubenstein, Hartley, & Bishop, 2020). Therefore, older adults likely have other employment, living, and caregiving situations (Kumin & Schoenbrodt, 2016; Stancliffe et al., 2012), which may impact pandemic related changes. Regardless of DS status, people with Alzheimer's disease were affected by the pandemic, as they were at higher risk for acquiring COVID-19 and lost opportunities for critical therapies and treatments (Mok et al., 2020). Therefore, older adults with DS who may be experiencing cognitive decline may have a starkly different pandemic experience compared to a young adult with DS.

With limited information about outcomes for adults with DS during the COVID-19 pandemic, our objective was to describe the experience one to one and half years into the COVID-19 pandemic for adults with DS, as reported by their caregivers. We conducted quantitative and qualitative analyses to assess occurrence of COVID-19, changes in health care and activities, and behavioral change. We examined differences by age groups as we hypothesized that older adults may experience poorer outcomes compared to younger adults.

Methods

Caregiver survey

Data were from a survey of caregivers of individuals with DS co-led by researchers at REDACTED and the REDACTED. The goal of the survey was to describe and understand the challenges and barriers for caregivers and individuals with DS, while also characterizing the health and employment status of the individual with DS. Design of the survey began in January 2021 with input from researchers, DS non-profit executives, caregivers, advocates, and representatives for pharmaceutical companies. The final survey was hosted on Qualtrics and was comprised of 115 questions (including yes/no, fill-in, Likert scale, and open-ended questions). The survey took approximately 1 hour to complete and had six sections: background on the individual with DS, employment of the individual with DS, classifying your caregiver journey, healthcare access and satisfaction for the individual with DS, history and perceived willingness for the individual with DS to participate in research studies, and caregiver background. COVID-19 questions were included in all but the clinical trial participation section. The survey and recruitment materials were approved by the REDACTED Institutional Review Board.

Recruitment

The survey was opened in April 2021. Participants were eligible if they identified as a caregiver of an adult with DS≥ 18 years of age, they themselves were ≥18 years of age, and they could respond to the survey in English. Participants were recruited through REDACTED and National Down Syndrome Society email listservs, social media pages, and post-card mailers. Upon enrollment, participants were eligible for a raffle for three $50 Amazon gift cards. The survey was closed in September 2021 when the recruitment goal of n=500 consented to participate in the survey.

COVID-19 questions

Because of the timing of the survey, it was prudent to ask questions about the occurrence of COVID-19 and how the pandemic has affected the lives of people with DS. Since the survey was implemented after a year of the pandemic, we asked whether the individual with DS was ever diagnosed with COVID-19 by a medical professional and whether the caregiver believed the individual ever had COVID-19; this approach accounts for the time period where COVID-19 testing was not readily available. We asked a series of questions about whether the pandemic resulted in work and activity changes, and changes in health care usage and delivery (e.g., telehealth). We asked caregivers ‘Have you noticed any changes in behavior or mental health [in the person you care for with DS] potentially related to the COVID-19 pandemic and resulting quarantine?’ If they answered ‘yes’ they were asked to describe in an open-ended text field. There was no limit to the length of answer they could provide for open ended questions. All COVID-19 related questions from the survey are listed in Supplement 1.

Other variables

Demographics for the individual with DS and the caregiver were reported by the caregiver. For some variables, we collapsed categories to prevent sparse data (e.g., for caregiver relationship combining ‘brother’ and ‘sister’ to sibling). We categorized age of the individual with DS as 18-39, 40-54, and ≥55. We chose this parameterization to align with dementia studies, since dementia is a major age-related change that could impact our findings with little incidence before 40 years of age and high incidence after 55 (Rubenstein et al., 2020).

Analysis

First, we removed participants who completed <20% of the survey. We selected the 20% threshold since it indicates completion of at least 1 of the 6 survey sections. We then excluded responses where the individual with DS was <18 years of age or age was missing. We calculated descriptive statistics for demographic variables and for our COVID-19 questions. We compared responses for COVID-19 questions by age group using chi-square tests. As an exploratory analysis, we looked at differences by gender. While we recruited a large sample, the survey was open for a long period of times and responses may have been different for those that answered in April compared to August. We ran a sensitivity analysis stratified by month of survey completion.

For our qualitative question on behavior change, two researchers independently identified themes from the responses then compared theme sets. Themes were identified using an inductive approach (Thomas, 2016). After resolution and alignment, a final theme set was created. Then, each reviewer assigned responses to themes. Reviewers discussed discordance and worked together to resolve any disagreement. A response could contain multiple themes.. We present representative responses for each theme, number of responses for each theme and then within each age group and provide representative responses.

Results

Demographics

Of 500 survey responses, we excluded 30 who had completed <20% of the survey and 32 who cared for an individual with DS <18 years of age. Our final analytic sample was N=438. A large majority of adults with DS were white, lived in the US, and were non-Hispanic (Table 1). By age, 75% of adults with DS were 18-39 years of age (N=329), 19% were 40-54 (N=84), and 6% were ≥55 (N=25). Most caregivers were mothers of the individual with DS, were highly educated, and were older than 55 years old.

COVID-19 incidence

In our sample, only 24 caregivers (5.5%) reported a clinician confirmed COVID-19 case in the individual with DS they care for (Table 2). The percentage was slightly higher when including those with suspected COVID-19 (8.8%). Only 12% of individuals with DS retained the same level of employment from pre-pandemic to mid 2021, with the most common experience being not being employed before or during the pandemic (44%). Most lost activities due to the pandemic. Nearly half had a reported behavioral change.

Healthcare change

Caregivers reported change in the amount and type of healthcare received for the individual with DS they care for (Table 2). Telemedicine use became common (31.9%), but 1/5 reported less healthcare usage and ¼ reported delayed routine care. Less than two percent reported that state disability agencies were more helpful. One third reported no change in healthcare.

By age group

By age group, we saw no statistical differences between groups for COVID-19 outcomes, employment changes, and healthcare use. There was little difference comparing the younger age groups (18-39 and 40-54). The sample size of older adults (≥55) was small which may have led to non-informative percentages and reduction in precision of statistical tests. In exploratory analyses, males with DS were less likely to use telemedicine (22.0% of males used telemedicine compared to 32.7% of females; p=0.01) and received less healthcare than pre-pandemic (58.8% of males received less healthcare compared to 41.3% of females; p=0.05) compared to females. There were no other meaningful changes by gender by age group, we saw no statistical differences between groups for COVID-19 outcomes, employment changes, and healthcare use. There was little difference comparing the younger age groups (18-39 and 40-54). There were no other meaningful changes by gender (Data not shown). In a sensitivity analysis stratifying by month of survey completion (April / May, June, July / August). Those that responded in June were less likely to report loss of activities (80% in June compared to 89% in April / May or July / August, p=0.04). There were no other meaningful differences by month.

Behavior change

From the responses of those that indicated behavioral change, we identified 8 themes from the open-ended responses: anxiety, depression, anger, fear, skill loss (including regression and disintegration disorder, boredom/ isolation, memory loss, and obsessive-compulsive disorder (Table 3). Anxiety and depression were the most common reported mental health change (27.7% and 26.2% respectively; Figure 3). Boredom was common (30.6%) and 1 in 4 of those with reported behavioral change had a regression or loss of skill. We saw few differences by age.

Discussion

People with DS are especially vulnerable to COVID-19 due to biological and social factors. Through a survey of caregivers, we were able to describe how the pandemic has affected health, healthcare use, and behavior for adults with DS. Adults with DS lost activities, had negative behavioral change, and struggled with employment, with many being unemployed pre-pandemic.

Pre-pandemic, adults with DS faced various challenges in regard to employment and health care. For example, many individuals with DS cannot access DS-specific care because specialty clinicians are rare (King, Remington, & Berger, 2022). Additionally, employment rates among adults with DS have historically been low; in a study published in 2016, only 13% of adults with DS had >20 hours of weekly employment (Kumin & Schoenbrodt, 2016). In our survey, we found that healthcare and employment opportunities declined below retrospectively reported pre-pandemic levels. Since our survey captured a single point in time, we could not assess temporality, but with the loss of employment and health care, it is not a surprise that caregivers reported that the individuals they care for showed an increase in anxiety, depression, and isolation. While issues with employment for people with DS are systemic (Kumin & Schoenbrodt, 2016), and the continued risk of COVID-19 prevents a return to work or increase in employment opportunities, more targeted mental health outreach is important to treat mental health issues. State agencies that serve adults with disabilities can be a key resource for individuals with DS; however, <2% of our survey respondents found state agencies to be helpful during the pandemic. Improving how these agencies provide services is an important area for focus that can lead to improved outcomes.

We saw little difference in change in healthcare use and activity when comparing by age. Because of the dementia associated with older age, we hypothesized that there would be a greater change for older adults with DS. However, because adults with DS are at high risk for COVID-19 regardless of age, it is likely that loss in health care use and activities would affect all adults with DS. Nevertheless, a larger sample of older adults with DS is needed to better understand a population experiencing rapid cognitive decline.

Our qualitative analysis identified eight important themes of behavior change for the ~50% of adults with DS who had reported behavior change. Not surprisingly, isolation and boredom was common. Prior to the pandemic, people with disabilities reported higher social isolation, lower social support, and more loneliness as compared to peers without disabilities (Emerson, Fortune, Llewellyn, & Stancliffe, 2021). The loss of activities and need to be extra cautious in public settings likely increased social isolation beyond an already high level. Interestingly, loss of skills and regression was commonly reported, likely also tied to the lack of activities and stimulation.

Responses reflected the caregiver's perception and may not agree with an individual's self-perception. Too few studies directly ask individuals with intellectual disability about themselves (Santoro, Donelan, & Constantine, 2022), and they are the experts in their experiences. Both caregiver and the individual with DS observations are important to give the full context of health and well-being for individuals with DS and more work is needed to capture the lived experiences of adults with DS during the pandemic. The caregivers' experiences are also influencing their reporting; many are older adults who are at high risk for poor COVID-19 outcomes (Ruksakulpiwat et al., 2021), which may impact their behavior and their assessment of other's behavior. There is additionally stress of being a caretaker, especially during a pandemic, that may impact reporting (Dhiman et al., 2020).

Our study was limited by a lack of a non-DS intellectual disability comparison group. With such a comparison group, we could have evaluated whether the pandemic related changes were unique to DS or whether changes were attributable to the pandemic, both which might inform intervention. Data were collected at one point in time which prevent us from assessing causal mechanisms that may link outcomes (e.g., loss of employment and depression). We had a small number of caregivers reporting on older adults which limited our statistical power. Older adults with DS are an important population and presenting results in this group is important despite the small sample size. Because of our convenience sampling and English-only survey, our sample is not generalizable to the wider DS population. In addition, our respondents were overwhelmingly white, well educated, and high-income. The study needs to be replicated in more low income and non-English speaking settings. Self-selection into surveys may lead to selection bias (Rubenstein & Furnier, 2021); however, because our survey did not advertise as a ‘COVID-19’ survey, we do not believe that there was differential response by COVID-19 status. Because of our focus on caregivers, we did not have direct responses from individuals with DS.

Conclusion

Studies consistently find adults with DS are at greater risk for severe COVID-19 illness and mortality, and we have described how the pandemic has affected opportunity, access to health, and behavior. The loss of activity, health care, and increase in mental health conditions may have long lasting impacts on people with DS. As the pandemic continues, targeted support for adults with DS is needed to prevent further skill loss and exacerbation of mental health conditions.

REFERENCES

Clift, A. K., Coupland, C. A. C., Keogh, R. H., Hemingway, H., & Hippisley-Cox, J. (2021). COVID-19 mortality risk in down syndrome: results from a cohort study of 8 million adults. *Ann Intern Med, 174*(4), 572-576. doi:10.7326/M20-4986

Dhiman, S., Sahu, P. K., Reed, W. R., Ganesh, G. S., Goyal, R. K., & Jain, S. (2020). Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. *Res Dev Disabil, 107*, 103790. doi:10.1016/j.ridd.2020.103790

Emerson, E., Fortune, N., Llewellyn, G., & Stancliffe, R. (2021). Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: Cross-sectional study. *Disabil Health J, 14*(1), 100965. doi:10.1016/j.dhjo.2020.100965

Huls, A., Costa, A. C. S., Dierssen, M., Baksh, R. A., Bargagna, S., Baumer, N. T., . . . Initiative, T. R. C.-. (2021). Medical vulnerability of individuals with Down syndrome to severe COVID-19-data from the Trisomy 21 Research Society and the UK ISARIC4C survey. *EClinicalMedicine, 33*, 100769. doi:10.1016/j.eclinm.2021.100769

Illouz, T., Biragyn, A., Frenkel-Morgenstern, M., Weissberg, O., Gorohovski, A., Merzon, E., . . . Okun, E. (2021). Specific susceptibility to COVID-19 in adults with down syndrome. *Neuromolecular Med, 23*(4), 561-571. doi:10.1007/s12017-021-08651-5

King, E., Remington, M., & Berger, H. (2022). Family perspectives on gaps in health care for people with Down syndrome. *Am J Med Genet A, 188*(4), 1160-1169. doi:10.1002/ajmg.a.62635

Kumin, L., & Schoenbrodt, L. (2016). Employment in adults with down syndrome in the United States: results from a national survey. *Journal of Applied Research in Intellectual Disabilities, 29*(4), 330-345. doi:https://doi.org/10.1111/jar.12182

Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disabil Health J, 13*(4), 100969. doi:10.1016/j.dhjo.2020.100969

Mok, V. C. T., Pendlebury, S., Wong, A., Alladi, S., Au, L., Bath, P. M., . . . Scheltens, P. (2020). Tackling challenges in care of Alzheimer's disease and other dementias amid the COVID-19 pandemic, now and in the future. *Alzheimers Dement, 16*(11), 1571-1581. doi:10.1002/alz.12143

Murphy, N., Epstein, A., Leonard, H., Davis, E., Reddihough, D., Whitehouse, A., . . . Downs, J. (2017). Qualitative analysis of parental observations on quality of life in Australian children with down Syndrome. *J Dev Behav Pediatr, 38*(2), 161-168. doi:10.1097/DBP.0000000000000385

Rubenstein, E., & Furnier, S. (2021). #Bias: The opportunities and challenges of surveys that recruit and collect data of autistic adults online. *Autism Adulthood, 3*(2), 120-128. doi:10.1089/aut.2020.0031

Rubenstein, E., Hartley, S., & Bishop, L. (2020). Epidemiology of dementia and Alzheimer disease in individuals With down syndrome. *JAMA Neurol, 77*(2), 262-264. doi:10.1001/jamaneurol.2019.3666

Ruksakulpiwat, S., Zhou, W., Phianhasin, L., Benjasirisan, C., Fan, Y., Su, T., & Chiaranai, C. (2021). The experience of caregivers of chronically ill patients during the COVID-19: A Systematic Review. *Chronic Illn*, 17423953211064854. doi:10.1177/17423953211064854

Santoro, S. L., Donelan, K., & Constantine, M. (2022). Proxy-report in individuals with intellectual disability: A scoping review. *Journal of Applied Research in Intellectual Disabilities*. doi:10.1111/jar.13013

Stancliffe, R. J., Lakin, K. C., Larson, S. A., Engler, J., Taub, S., Fortune, J., & Bershadsky, J. (2012). Demographic characteristics, health conditions, and residential service use in adults with Down syndrome in 25 U.S. states. *Intellect Dev Disabil, 50*(2), 92-108. doi:10.1352/1934-9556-50.2.92

Thomas, D. R. (2016). A general inductive approach for analyzing qualitative evaluation data. *American Journal of Evaluation, 27*(2), 237-246. doi:10.1177/1098214005283748

Turk, M. A., Landes, S. D., Formica, M. K., & Goss, K. D. (2020). Intellectual and developmental disability and COVID-19 case-fatality trends: TriNetX analysis. *Disabil Health J, 13*(3), 100942. doi:10.1016/j.dhjo.2020.100942

Walker, J. C., Dosen, A., Buitelaar, J. K., & Janzing, J. G. (2011). Depression in down syndrome: a review of the literature. *Res Dev Disabil, 32*(5), 1432-1440. doi:10.1016/j.ridd.2011.02.010

Zigman, W. B., & Lott, I. T. (2007). Alzheimer's disease in Down syndrome: neurobiology and risk. *Ment Retard Dev Disabil Res Rev, 13*(3), 237-246. doi:10.1002/mrdd.20163

Table 1 Demographic characteristics of adults with Down syndrome and their caregivers

Characteristics of adults with Down syndrome **N=438**	**N (%)**	**Caregiver characteristics** **N=438**	**N (%)**
Age (years)		**Caregiver Age** (years)	
18-39	329 (75.1)	18-44	17 (4.5)
40-54	84 (19.1)	45-54	64 (17.0)
55+	25 (5.8)	55-64	158 (42.0)
Mean (SD)	32.9 (11.1)	65-74	112 (29.8)
Median (range)	30 (44)	75+	25 (6.7)
		Missing	62
Gender			
Male	214 (48.9)	**Caregiver type**	
Female	223 (50.9)	Primary Caregiver	277 (70.4)
Missing	1 (0.23)	Equally share responsibilities	89 (22.6)
		Other	27 (6.9)
		Missing	15
Race			
White	391 (89.3)	**Caregiver relationship**	
Black/African American	10 (2.6)	Mother	304 (74.5)
Mixed race / American Indian	19 (4.3)	Father	15 (3.7)
Missing / Prefer not to say	18 (4.1)	Sister	52 (12.7)
		Other family member	21 (5.1)
Ethnic Group		Paid caregiver	16 (3.9)
Hispanic	21 (4.8)	Missing	30
Non-Hispanic	417 (95.2)		
		Caregiver education	
Physical Health conditions*		High school graduate or less	18 (4.1)
Attention Deficit Hyperactivity Disorder	35 (8.0)	Some college / Associates degree	93 (21.3)
Autism	40 (9.1)	Bachelor’s degree	138 (31.5)
Alzheimer’s Disease	48 (11.0)	Graduate degree	113 (25.8)
Epilepsy	25 (5.7)	Missing	62
Cardiovascular conditions	168 (38.4)		
Obesity/Overweight	212 (48.4)	**Income (USD)**	
Sleep Apnea	179 (40.9)	<20,000	76 (22.8)
Thyroid conditions	252 (57.5)	50,000-79,999	69 (20.2)
		80,000-99,000	49 (14.4)
Mental health conditions*		100,0000-149,999	76 (22.9)
Anxiety disorders	117 (26.7)	>150,000	71 (20.8)
Behavioral challenges	113 (25.8)	Missing	97
Depression / depressive disorders	70 (15.9)		
Obsessive Compulsive Disorder	80 (18.3)		
Country			
United States	416 (95.0)		
Other	22 (5.0)		
Living Situation			
In a group home	17 (3.9)		
In caregiver's home with paid support	102 (23.3)		
In caregiver's home with unpaid family support	240 (54.8)		
Independent/Alone	10 (2.3)		
Other	68 (15.5)		

*Individuals can have multiple conditions

Table 2 COVID-19 related outcomes for adults with Down syndrome, 2021

	Total N=438		Age 18-39 N=329		Age 40-54 N=84		Age ≥55 N=25			
	N	%	N	%	N	%	N	%	X^2	p
Clinician confirmed COVID										
Yes	24	5.5	20	6.8	4	5.7	0	0	1.7	0.4
No	362	94.5	273	93.2	66	94.3	23	100		
Missing	52		36		14					
Suspected COVID										
Yes	37	8.8	29	9.2	7	8.8	1	4.0	0.8	0.7
No	384	91.2	287	90.8	73	91.3	24	96.0		
Missing/ Do not know	17		13		4					
Work disruption										
Less hours	117	28.6	90	29.4	23	28.4	0	0.0	9.7	0.1
Loss of employment	61	14.9	50	16.3	11	13.6	4	22.2		
Retained same level of employment	49	12.0	44	14.4	17	21.0	4	22.2		
Not employed prior or during COVID	182	44.5	122	39.9	30	37.0	14	77.8		
Missing / Do not know	29		23		3		3			
Loss of activities										
Yes	379	86.5	288	87.5	72	85.7	19	79.2	2.1	0.3
No	59	13.5	41	12.5	12	14.3	6	25.0		
Healthcare changes*										
Telemedicine visits	119	31.9	87	31.0	24	35.8	8	32.0	0.4	0.8
Less use	79	21.2	59	21.0	13	19.4	7	28.0	2.0	0.4
More use	10	2.7	6	2.1	3	4.5	1	4.0	1.2	0.5
Harder to schedule	70	18.8	54	19.2	10	14.9	6	24.0	2.2	0.3
State agencies more helpful	7	1.9	6	2.1	1	1.5	0	0.0	0.6	0.7
Delayed routine care	94	25.2	73	26.0	14	20.9	7	28.0	1.9	0.4
No change	120	32.2	91	32.4	24	35.8	5	20.0	0.8	0.7
Pandemic related behavioral change										
Yes	206	48.1	159	49.2	36	43.4	11	50.0	6.0	0.2
No	222	51.9	164	50.8	47	56.6	11	50.0		
Missing / Do not know	10		6		1		2			

Table 3. Themes identified and example responses for each theme from qualitative question reporting behavioral change in adults with Down Syndrome one year into the COVID-19 pandemic.

Theme	**Example**
Anxiety	*'Increase in anxiety and concern for political arena'*
Depression	*'Depression from loss of social contact and loss of work opportunities'*
Agitation	*'More easily agitated; seeks non available social interaction'*
Memory loss	*'Rapid descent into dementia'*
Boredom	*'Complains of being bored and stuck in the house with "the old people" (his parents)!'*
Skill loss	*'Loss of independence and skills'*
Fear	*'Decrease in social activity because scared to go out even following guidelines'*
Obsessive compulsive disorder	*'Increased OCD patterns, reduced language/interactions in person'*

Figure 1. Behavior changes reported by caregivers for individuals with Down syndrome 12 to 18 months into the COVID-19 pandemic, by age of individual with Down syndrome

‘Any change’ includes those that indicated a change but did not specify the behavior.

OCD- obsessive compulsive disorder