



# Early Pandemic Experiences of Autistic Adults: Predictors of Psychological Distress

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The COVID-19 pandemic has disrupted lives around the world. Autistic adults are at higher risk for co-occurring medical and psychiatric conditions and may be more prone to difficulties adapting to pandemic-related changes and social distancing mandates and coping with ongoing uncertainties. On the other hand, the pandemic may lead to greater understanding and acceptance of accommodations in the broader community that may facilitate supports for autistic adults beyond the pandemic. To learn more about their early pandemic experiences, online surveys were sent to independent adults enrolled in the Simons Powering Autism Research Knowledge (SPARK). The first survey was open from March 30 to April 19, 2020; a follow-up survey sent to original responders was open from May 27 to June 6, yielding 396 participants with data for both surveys. We found that adults who were female, younger, had prior diagnoses of a mental health condition, personal COVID-19 experience (i.e., knowing someone who had symptoms or tested positive) or less frequent hope for the future reported the greatest negative impacts. Decrease in feelings of hopefulness over time predicted greater psychological distress at T2, accounting for T1 impact and distress levels and increases in total COVID-19 impact. Less perceived benefit of online services also predicted later distress. Although there tends to be a focus on coping with negative effects of the pandemic, mental health providers may consider approaches that focus on positives, such as fostering hope and understanding factors that facilitate benefit from online services. *Autism Res* 2021, 14: 1209–1219. © 2021 The Authors. *Autism Research* published by International Society for Autism Research published by Wiley Periodicals LLC.

**Lay Summary:** Autistic adults may be at risk for psychological distress during the COVID-19 pandemic. The current study suggests that autistic adults who were younger, female, had a mental health diagnosis before the pandemic and knew someone who showed symptoms or tested positive for COVID-19 reported more areas negatively impacted by COVID-19 and greater difficulty coping with those effects. Decreases in hope over time were associated with greater psychological distress. Less perceived benefit from online services also predicted distress 2 months later. These results suggest important areas to further explore as we develop supports for autistic adults during the pandemic.

**Keywords:** adults; co-morbid conditions; gender/female ASD; COVID-19 pandemic; hope; loneliness

## Introduction

The COVID-19 pandemic has resulted in widespread disruption to daily life. Community transmission in the U.S. began in February 2020, and within a month there were reported cases in all 50 states [CDC Covid-19 Response Team, 2020]. On March 11, the World Health Organization declared a global pandemic [WHO, 2020]. By early April, Americans faced numerous impacts and challenges as many more states issued sweeping restrictions, including stay-at-home directives and closure of non-essential businesses. In addition to effects on daily lives, uncertainty plagues many people, as they face job

loss and increasing concern for their own health and well-being and that of their loved ones.

Autistic adults have multiple factors that put them at risk for adverse effects of the pandemic [den Houting, 2020]. They have increased rates of chronic illness and medical conditions [Croen et al., 2015; Kohane et al., 2012] that may increase their risk of serious complications of COVID-19. Many individuals with autism already have difficulty accessing healthcare under non-pandemic conditions [Nicolaidis et al., 2015; Raymaker et al., 2017]. Finding accessible care in an overburdened healthcare system, often with additional procedures and restrictions due to COVID-19, is likely to exacerbate

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already existing disparities for autistic adults. In addition, some have expressed concerns about whether autistic people might be seen as a lower priority for life-saving care if resources are limited [den Houting, 2020]. Each of these disparities not only puts autistic adults at higher physical risk, but likely also adds additional stress and anxiety.

There are widespread concerns about the current and longer-term mental health effects of the pandemic. In a general population survey of adults conducted from March 10th to 16th, 10.7% reported a moderate or severe level of distress [Holingue et al., 2020a]. In April 2020, 13.6% of US adults reported serious psychological distress, an increase from 3.9% in April 2018 [McGinty, Presskreischer, Han, & Barry, 2020]. Pre-existing psychiatric conditions are a risk factor for greater distress during disaster-related traumas, emphasizing the need for increased support during quarantine for this at-risk population [Brooks et al., 2020]. Autistic adults are more likely than non-autistic adults to be diagnosed with co-occurring psychiatric conditions such as depression and anxiety than non-autistic adults [Croen et al., 2015; Hollocks, Lerh, Magiati, Meiser-Stedman, & Brugha, 2019], putting them at increased risk for exacerbation of symptoms and mental health crisis. While many individuals are faced with disruptions to routine, adapting to changes may be particularly difficult for autistic adults in the face of uncertainty and a loss of or absence of supports [Cassidy et al., 2020]. Social distancing likely decreases social interactions (i.e., due to workplace and school closures, group gathering restrictions) and limit access to both formal services and informal supports.

Some might assume that autistic adults would feel less impacted by social distancing orders, as studies have suggested that they may be less likely to engage in in-person social activities than neurotypical peers [Stacey, Froude, Trollor, & Foley, 2019] and more likely to be involved with and receiving support from online communities [Jordan, 2010]. Notably, however, den Houting [2020] reminds us that such social isolation may have arisen out of need to protect themselves from negative experiences (e.g., discrimination) or inaccessible environments, rather than preference-driven. Nonetheless, as people around the world face the challenges of social distancing, there is hope that they may be more empathetic to the experiences of autistic adults and understanding of accommodations that increase accessibility for some autistic adults, such as online delivery of services or working remotely. This may lead to greater acceptance of these practices beyond the pandemic [Cassidy et al., 2020; den Houting, 2020]. Thus, it may be that a “silver lining” of awareness, understanding and acceptance could inspire autistic adults to feel more hopeful about the future. Hope is associated with the

ability to cope in the face of natural disasters [Hackbarth, Pavkov, Wetchler, & Flannery, 2012] and may a potential protective factor against psychological distress following such traumatic events [Glass, Flory, Hankin, Kloos, & Turecki, 2009].

Parents report that their autistic child’s behavioral challenges are more intense and frequent than before the pandemic, suggesting adverse effects on their mental health [Colizzi et al., 2020]. Several papers have also provided personal and professional perspectives on the pandemic’s impact on autistic adults [Cassidy et al., 2020; den Houting, 2020]. To our knowledge, however, there has not yet been systematic description of autistic adults’ experiences of the pandemic. The studies reporting the pandemic’s negative impact on those in the general population [e.g., Holingue et al., 2020a, 2020b; Kirzinger et al., 2020] are important to increase awareness that will hopefully contribute to expansion and continued reimbursement for telehealth [Holingue et al., 2020b]. Thus, it is important to investigate how autistic adults have been affected by the pandemic to ensure that their needs are considered as we move forward; assumptions that stay-at-home-orders may be perceived as “ideal” or that the pandemic will result in little change for them [den Houting, 2020] put them at risk for being overlooked. In this study, we provide an overview of the impact of the COVID-19 pandemic on autistic adults enrolled in the Simons Powering Autism Research for Knowledge (SPARK) research study. We surveyed autistic adults online to explore the relationship between individual characteristics (e.g. demographics, location, previous mental health diagnosis) and experiences during the COVID-19 pandemic with self-reported negative impact and coping. We also sought to identify the specific risk and protective factors predictive of psychological distress in the early months of the pandemic. We hypothesized that personal experience with COVID-19, such as having a household member with symptoms or knowing someone who tested positive for COVID-19, and job loss or pay reduction would be associated with higher levels of psychological distress as the pandemic persisted but that more frequent feelings of hopefulness about the future would be protective.

## Method

### *Procedure*

The SPARK study is a US-wide autism research cohort enrolling children and adults with autism [The SPARK Consortium, 2018]. Inclusion is based on self-report of a professional ASD diagnosis (including age of diagnosis and specification of diagnostician’s profession); because many participants are recruited from university-based autism programs, the majority of diagnoses are assumed

to be valid [The SPARK Consortium; 2018]. All participants who consent to join the SPARK study agree to be contacted to complete additional SPARK questionnaires. Independent adults ( $N = 3,133$ ) previously enrolled in the SPARK study were invited to complete a brief online survey about their experiences during the COVID-19 pandemic. Surveys were emailed on March 30th and remained open through April 10, 2020, with reminders sent on day 3 and day 9 after the invitation. Survey respondents were sent a second survey on May 27th, which remained open until June 6th. Online consent was obtained at the start of each survey. All procedures were approved by the Western Institutional Review Board (WIRB).

### Measures

**COVID-19 impact survey.** The COVID-19 Impact survey for this study was developed by the authors (LCW, JKL, PF, WKC) and SPARK team to assess the impact of COVID-19 on the autism community (survey available upon request). Autistic members of the SPARK Community Advisor Council gave feedback to improve the questions and responses and inform subsequent survey topics. Both surveys focused on three broad domains related to COVID-19: 1) areas of their lives impacted, 2) emotional and mental health impact, and 3) their personal experiences of COVID-19. The following provides more detail regarding the survey items used for the present analyses.

**Demographics.** Date of birth, sex, race, ethnicity and zip code were self-reported. Age was calculated based on submission date; participants were divided by T1 age: transition age (18–24); young adult (25–39); middle age and older (40+). Small subgroups precluded analyses by individual racial groups; therefore, White Non-Hispanic participants were compared to participants who self-identified as another race/ethnicity. Zip code was used to group participants by census region (US Census Bureau, 2019) and as “rural” or “urban” using the National Center for Health Statistics Urban–Rural classification scheme [Ingram, & Franco, 2014].

**Psychological Distress.** Participants were asked six questions from a standard COVID-19 item set developed by JHSPH COVID-19 Mental Health Measurement Working Group. Items assessed the frequency of feeling anxious, depressed, lonely, hopeful about the future and physical reactions when thinking about COVID-19 in the past week (rated from 1: “rarely or none of the time (less than 1 day)” to 4: “most or all of the time (5–7 days)”) and whether a doctor or healthcare provider had ever told them they had a mental health condition. Anxiety, depression, loneliness and physical symptoms items were summed to yield an index of “Psychological Distress” ranging from 4 (no symptoms) to 12 (all four

symptoms rated as most/all of the time), with scores of 4–6 “minimal-to-none,” 7–9 “mild,” 10–12 “moderate,” 13–16 “severe.” The content and classifications were chosen for comparability to measures used in general population studies [e.g., Hologue et al., 2020a, 2020b]. Cronbach’s alpha for the four-item scale was 0.74. Participants were also grouped by frequency of hopefulness (2 or fewer days vs. 3 or more days) as a possible protective factor.

**Self-reported Impact of COVID-19.** For T1, participants were asked to indicate which of seven areas (school, employment, services/therapies, social life, home life, financial and “none”) had been changed due to COVID-19 in the past week. For each area endorsed, follow up questions queried the extent that area had been negatively impacted due to COVID-19 (0 = “not at all” to 3 = “significantly”) and how well they were coping with changes in that area (0 = “completely” to 3 = “not at all”). For comparison to T2, T1 impact and coping were considered “0” for any area not endorsed. At T2, the first step of asking participants to mark, which areas were disrupted, was omitted, therefore all participants were asked to rate current impact (0–3) for each area. If impact was rated as “0-not at all,” coping was not asked. All participants were also asked about their pre-pandemic (January/February 2020) school and employment status and what services they received. School status was categorized as full-time, part-time/other, or not a student. Employment status was categorized as full-time, part-time, self-employed/other or unemployed. Service status reflected number of services/therapies being received at least once per month. Pre-pandemic quality of home and social life and financial security were rated from 1 = “Excellent” to 5 = “Poor.”

Impact was quantified in four ways: (1) “number of disrupted areas” (sum of the number of areas endorsed as disrupted) ranging from 0–6; (2) “total impact” (sum of severity ratings for each area) ranging from 0 “not at all” to 18 “severely” in all 6 domains; (3) “total coping” (sum of coping ratings for each area) ranging from 0 to 18 “not at all;” (4) “resilient” if they reported “minimal-to-mild” (4–9) psychological distress and moderate-to-severe impact in two or more areas.

**Personal experience.** Participants were asked if anyone in their household had COVID-19 symptoms or had tested positive for COVID-19, whether anyone they knew personally (outside of household) had tested positive, been hospitalized, or died. “Personal COVID-19 experience” was classified based on endorsement of any of those items. Small sample sizes precluded individual consideration of the impact of COVID-19 related hospitalization or deaths.

**Online services.** Participants were asked if they were currently receiving online or remote delivery of services/therapies. If yes, they were asked if they were benefitting (0 = “significantly” to 3 = “not at all”).

*Employment changes.* At T2 only, participants were asked to indicate which employment changes they were experiencing due to COVID-19. For analysis, participants were grouped as: continuing to work with high risk of COVID-19 exposure; working from home or paid furlough; laid-off or unpaid furloughed or reduced hours; other situations.

### Statistical Analyses

T-Tests and One-Way ANOVAs were conducted to explore bivariate associations between participant characteristics [demographics (sex, age, minority status), location (region, urban/rural), previous mental health diagnosis (MHDx)], putative risk/protective factors (personal experience, job loss/pay reduction, hopefulness) and T1 impact (number of disrupted areas; areas disrupted; total negative impact), total coping and psychological distress (symptom total). T1 characteristics and T2 employment change was also explored in relation to change in impact, coping and distress. No significant differences emerged between racial/ethnic minority or location groups; therefore, results are not reported and these factors were not included in subsequent models. Participant characteristics, impact and other risk/protective factors were entered into linear regression models to identify predictors of T2 psychological distress. Subsequent models explored the effect of T1 online services and perceived benefit of online services on T2 distress. Logistic regression was used to identify T1 predictors of T2 “resilience.”

Consistent with recommendations to reduce false positives and improve research reproducibility [Benjamin et al., 2018], alpha threshold for significance was set at  $P < 0.005$ .

## Results

### Response Rate

Of 3,133 independent adults invited to participate in April, 782 indicated interest and 685 accessed the survey. Participants who did not complete the entire survey were excluded ( $n = 49$ ), leaving 636 participants with T1 data (20.3% overall response; 81.3% of those who responded to the invitation). Of participants who completed T1, 402 responded and 396 completed the T2 survey (62.3%). Time between responses ranged from 48–69 days ( $M = 57.92$ ,  $SD = 3.51$ ). T2 responders were older ( $M = 37.38$ ,  $SD = 13.36$ ) than non-responders ( $M = 33.37$ ,  $SD = 12.30$ ;  $t(634) = -3.78$ ,  $P < 0.001$ ). Groups did not significantly differ on other demographic characteristics, number of areas impacted, average impact, coping or distress levels.

The present analyses focus on 396 adults, ages 18–74 years ( $M = 37.38$ ,  $SD = 13.36$ ) with completed T1

and T2 surveys (Table 1). Participants were predominantly White (87.4%), Non-Hispanic (94.4%), living in urban areas (76.8%) and evenly distributed across the four regions (18.7% Northeast to 28.0% South). Only 19.7% ( $n = 78$ ) were students in January/February 2020 (full-time = 11.8%; part-time/other = 7.9%); transition-age (47.7%) were more likely to report being in school than young (16.7%) or older (9.2%) adults. Two-thirds ( $n = 263$ ) reported being employed (full-time = 34.8%; part-time = 22.0%; self-employed/other = 9.6%) and 70.5% ( $n = 279$ ) endorsed receiving at least one service regularly in January/February 2020. Quality of social life, home life and financial security prior to the pandemic were rated positively for the majority (Table 1).

### T1 COVID-19 Impact, Coping and Distress and Associations with Participant Characteristics

Most participants (92.9%) reported negative impact in at least one area. While 56.6% endorsed moderate-to-severe impact in two or more areas, only 19% rated minimal-to-

**Table 1. Sample characteristics**

Sample characteristics	
Age (years)	
<25	18.9%
25–39	45.5%
40+	35.6%
Living with	
Spouse	34.3%
Parents/other family	31.0%
Alone	26.3%
Other	8.3%
Pre-pandemic status	
Previous mental health diagnosis	83.8%
Receiving mental health services	52.5%
Quality social life	
Good to excellent	58.6%
Financial status	
Good to excellent	70.2%
Home life status	
Good to excellent	83.9%
Pre-pandemic characteristics <sup>a</sup>	
Dx before 18 years	42.2%
Education	
High school, GED	13.1%
Some college	36.4%
College	22.0%
Graduate degree	14.4%
Household income	
<\$20,000	33.1%
\$21,000–\$35,000	13.1%
\$36,000–80,000	23.8%
\$81,000+	15.9%
Relationship status	
Single	52.6%
Married/partner	35.1%

<sup>a</sup>Drawn from SPARK enrollment 1–2 years before T1 survey; missing  $n = 49$ .

no-coping in two or more areas. In contrast, 45% endorsed levels of psychological distress that fell in the “moderate”-to-“severe” range. Approximately half (53.8%) reported experiencing two or more symptoms at least 3 days in the previous week (see Fig. 1).

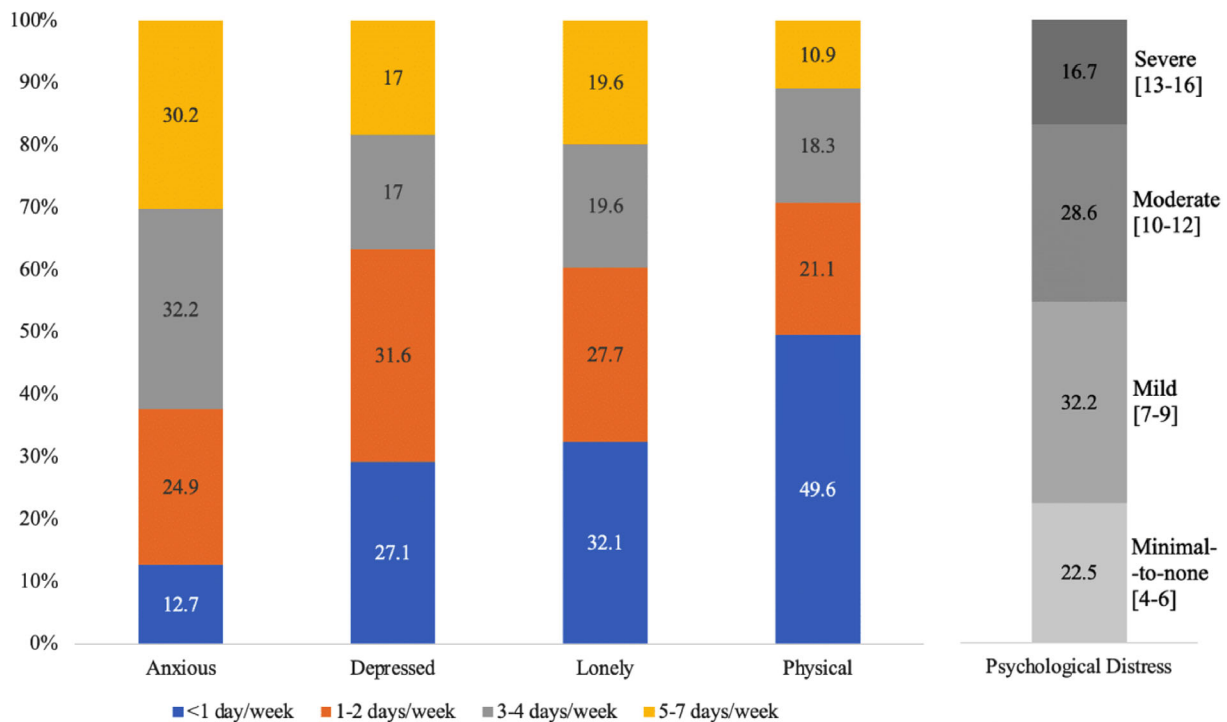
Females (Table S1) reported more areas impacted ( $t(394) = -4.28, P < 0.001$ ), higher average impact ( $t(394) = -4.55, P < 0.001$ ), poorer coping ( $t(696) = -4.88; P < 0.001$ ) and higher psychological distress ( $t(393) = -5.18, P < 0.001$ ), relative to males. Age (Table S1) was also associated with number of areas impacted ( $F(2, 393) = 7.23, P = 0.001$ ), reflecting more transition age adults (88.6%) endorsing school disruptions than young adults (63.3%) or older individuals (30.8%;  $X^2(2) = 15.66, P < 0.001$ ). Middle aged or older adults reported less total impact than both other groups ( $F(2, 393) = 11.40, P < 0.001$ ) and lower psychological distress ( $F(2, 392) = 11.03, P < 0.001$ ) but no differences in coping ( $F(2, 189) = 3.29, P = 0.04$ ). MHDx (Table S1) was associated with poorer overall coping ( $t(390) = -3.02, P = 0.003, d = -0.42$ ) and higher distress ( $t(390) = -3.40, P = 0.001$ ) but not number of disrupted areas ( $P = 0.007$ ) or total impact ( $P = 0.006$ ).

As shown in Table 2, 27.8% endorsed personal COVID-19 experience at T1. Of these, 10.4% reported experiences within their household and 21.0% endorsed knowing someone outside their household who tested positive. Few participants knew anyone hospitalized ( $n = 33$ ) or who had died of COVID-19 ( $n = 13$ ). Personal experience

was associated with more areas disrupted ( $M = 3.05, SD = 1.32$  vs. No experience  $M = 2.41, SD = 1.43; t(392) = -4.10, P < 0.001$ ), more severe total impact ( $t(392) = -3.91, P < 0.001$ ), poorer overall coping ( $t(392) = -4.50, P < 0.001$ ) and higher psychological distress ( $t(392) = -3.74, P < 0.001$ ).

Only 37.2% of participants endorsed feeling hopeful about the future 3 or more days in the past week at T1 (Table 2). Frequency of hopefulness did not differ by sex ( $X^2(1) = 4.68, P = 0.03$ ) or age ( $X^2(2) = 2.14, P = 0.34$ ). Those who reported more frequent hopefulness endorsed lower impact ( $t(391) = -2.65, P = 0.005$ , better coping ( $t(391) = -5.13, P < 0.001$ ) and lower distress ( $t(391) = -6.55, P < 0.001$ ) than those who indicated less hopefulness. Groups did not differ on number of areas disrupted ( $t(391) = -0.63, P = 0.53$ ).

**T1 impact and coping by area.** As shown in Table 3, employment was the most frequently impacted area, followed by school and social life. Employment impact was lower for those who reported full-time ( $M = 1.47, SD = 1.15$ ) compared to part-time, self-employed or other ( $M = 1.90, SD = 1.13$ ) employment before the pandemic ( $t(261) = -3.13, P = 0.002$ ). Social impact did not differ based on quality of pre-pandemic social life ( $P = 0.27$ ). Of 148 reporting impact to services, 66% were receiving online services. Most (74.5%) reported moderate or significant benefit.



**Figure 1.** T1 levels of psychological distress levels and frequency of distress symptoms.

**Table 2. Psychological Distress, Total Impact and Coping by Participant Characteristics and T1 Predictors Over Time**

		Overall sample		Personal experience				Hopeful about future			
		N = 396		Yes (n = 110)		No (n = 284)		3+ days (n = 146)		≤2 days (n = 247)	
		Mean	SD	Mean	SD	Mean	SD	Mean	SD	Mean	SD
Psychological distress [range = 4–16]	T1	9.27	(3.16)	10.22	(3.32) <sup>a</sup>	8.91	(3.02) <sup>a</sup>	7.99	(2.70) <sup>b</sup>	10.04	(3.17) <sup>b</sup>
	T2	9.10	(3.24)	9.81	(3.41)	8.86	(3.13)	8.21	(3.03) <sup>b</sup>	9.65	(3.24) <sup>b</sup>
	T2 – T1 <i>d</i>	–0.06		–0.16		–0.02		0.08		–0.15	
Total impact [range = 0–18]	T1	5.18	(3.66)	6.34	(3.68) <sup>a</sup>	4.76	(3.56) <sup>a</sup>	4.57	(3.14) <sup>b</sup>	5.57	(3.88) <sup>b</sup>
	T2	7.04	(3.58)	7.64	(3.50)	6.83	(3.59)	6.66	(3.52)	7.27	(3.59)
	T2 – T1 <i>d</i>	<b>0.55</b>		<b>0.39</b>		<b>0.61</b>		<b>0.63</b>		<b>0.49</b>	
Total coping [range = 0–18]	T1	2.92	(2.82)	3.94	(3.37) <sup>a</sup>	2.55	(2.47) <sup>a</sup>	2.01	(1.93) <sup>b</sup>	3.48	(3.11) <sup>b</sup>
	T2	3.95	(3.11)	4.67	(3.43)	3.69	(2.94)	3.06	(2.57) <sup>b</sup>	4.50	(3.29) <sup>b</sup>
	T2 – T1 <i>d</i>	<b>0.40</b>		<b>0.29</b>		<b>0.45</b>		<b>0.47</b>		<b>0.37</b>	

Note. Bold emphasis represents within group change over time  $P < 0.005$ ; same lettered superscripts indicate group difference within time point  $P \leq 0.005$ .

Females (60.6%) were more likely than males (40.4%) to endorse COVID-19 related disruptions in services ( $X^2(1) = 10.67, P = 0.001$ ) and financial security (41.6% vs. 27.6%;  $X^2(1) = 8.20, P = 0.004$ ). Females endorsed greater impact and difficulty coping with services, home and financial security (Fig. S1). Age was associated with level of impact on school ( $F(2, 75) = 8.30, P = 0.001$ ) and employment ( $F(2, 260) = 6.35, P = 0.002$ ); older adults endorsed less severe impact compared to transition age adults in both areas; young adults did not differ from either group. MHDx was not associated with impact or coping in any area ( $P_s > 0.005$ ).

Individuals with personal COVID-19 experience were more likely to report disruptions to social life (79.1% vs. 60.6%;  $X^2(1) = 12.08, P = 0.001$ ), home life (61.8% vs. 44.7%;  $X^2(1) = 9.28, P = 0.002$ ) and financial security (53.6% vs. 29.2%;  $X^2(1) = 20.50, P < 0.001$ ) and more severe impact and poorer coping in several areas (Fig. S2). Hope was associated with less severe school impact and better coping in all areas (Fig. S3).

#### Change in Impact, Coping and Psychological Distress

Participants reported an increase in the number of areas disrupted by COVID-19 at T2 ( $t(395) = 11.93, P < 0.001, d = 0.60$ ). As shown in Table 2, total impact ( $t(395) = 10.90, P < 0.001$ ) and coping ( $t(395) = 8.04, P < 0.001$ ) also worsened. Despite changes in impact, levels of psychological distress remained stable ( $t(394) = -1.17, P = 0.243$ ). Effects were similar across groupings by demographics (Table S1), T1 personal experience and hope (Table 2).

A higher proportion of adults reported disruptions to services, social and home life and finances at T2; impact and coping also worsened in most areas (Table 3). At T2, a similar proportion reported personal experience (24.1%) and hope (42.7% reporting feeling hopeful three or more days).

**Table 3. Negative Impact and Coping by Area Endorsed as Negatively Impacted by COVID-19**

	Overall Sample N = 396				
	T1		T2		T2 – T1 <i>d</i>
	M	(SD)	M	(SD)	
School (% of n = 78)	69.2%		73.1%		
Impact	1.53	(1.22)	1.64	(1.15)	0.09
Coping	0.81	(0.90)	0.83	(0.85)	0.03
Employ (% of n = 263)	73.0%		77.2%		
Impact	1.38	(1.19)	1.67	(1.16)	<b>0.24</b>
Coping	0.70	(0.81)	0.78	(0.86)	0.09
Services (% of n = 279)	<b>53.0%</b>		<b>84.9%</b>		
Impact	1.09	(1.20)	1.75	(1.02)	<b>0.46</b>
Coping	0.55	(0.81)	0.88	(0.85)	<b>0.35</b>
Social (% of n = 396)	<b>65.7%</b>		<b>86.8%</b>		
Impact	1.41	(1.20)	1.85	(1.02)	<b>0.39</b>
Coping	0.78	(0.83)	1.00	(0.84)	<b>0.26</b>
Home (% of n = 396)	<b>49.2%</b>		<b>77.0%</b>		
Impact	0.87	(1.09)	1.34	(0.95)	<b>0.40</b>
Coping	0.56	(0.82)	0.86	(0.83)	<b>0.33</b>
Finances (% of n = 396)	<b>35.9%</b>		<b>64.1%</b>		
Impact	0.76	(1.14)	1.21	(1.10)	<b>0.38</b>
Coping	0.49	(0.86)	0.81	(0.93)	<b>0.35</b>
None (% of n = 396)	7.1%		1.8%		

Note. Bold emphasis represents within area change over time  $P \leq 0.005$ ; % reflect proportion endorsing negative impact in each area; significance corresponds to McNemar tests; higher values indicate more severe impact and poorer coping; significance corresponds to paired *T*-tests.

Of 263 employed pre-pandemic, 9.9% reported continuing to work with high risk of COVID-19 exposure, 34.2% working from home or paid furlough, 34.6% laid-off, unpaid furloughed or reduced hours and 11.4% other situations. Employment impact increased most for those who reported working with COVID-19 risk, but those with reduced hours or without pay reported the most

**Table 4. Linear Regression Models Predicting T2 Psychological Distress in the Full Sample ( $n = 396$ ) and Those Receiving T1 Online Services ( $n = 98$ )**

	Full sample ( $n = 396$ )				T1 online services ( $n = 98$ )				
	<i>B</i>	<i>SE B</i>	$\beta$	<i>P</i>	<i>B</i>	<i>SE B</i>	$\beta$	<i>P</i>	
Constant	1.09	0.62		0.077	Constant	0.64	1.40	0.649	
Female	-0.20	0.25	-0.03	0.424	Female	-0.18	0.49	-0.03	0.711
Age	0.01	0.01	0.06	0.138	Age	0.01	0.02	0.04	0.612
Previous MH dx	0.39	0.34	0.04	0.254	Previous MH dx	-0.85	0.83	-0.08	0.309
<b>T1 total impact</b>	<b>0.13</b>	<b>0.04</b>	<b>0.14</b>	<b>0.003</b>	T1 Total Impact	0.10	0.08	0.13	0.182
<b>T2 – T1 impact</b>	<b>0.22</b>	<b>0.04</b>	<b>0.23</b>	<b>0.000</b>	T2 – T1 Impact	0.19	0.08	0.21	0.021
T1 hope	0.38	0.16	0.12	0.016	T1 Hope	0.66	0.29	0.21	0.025
<b>T2 – T1 hope</b>	<b>0.47</b>	<b>0.14</b>	<b>0.15</b>	<b>0.001</b>	T2 – T1 Hope	0.43	0.27	0.14	0.112
T1 personal exp.	0.15	0.27	0.02	0.579	T1 Personal Exp.	0.54	0.49	0.09	0.271
<b>T1 distress</b>	<b>0.60</b>	<b>0.05</b>	<b>0.59</b>	<b>0.000</b>	<b>Distress</b>	<b>0.53</b>	<b>0.10</b>	<b>0.56</b>	<b>0.000</b>
					<b>Online benefit</b>	<b>0.77</b>	<b>0.26</b>	<b>0.23</b>	<b>0.003</b>
	Model $R^2 = 0.495$					Model $R^2 = 0.552$			

Note. Bold emphasis represents  $P \leq 0.005$ ; higher scores reflect more severe impact, less hope, more psychological distress and less perceived online benefit.

severe impact at both timepoints (Fig. S4). Distress did not vary by employment change.

#### Predictors of T2 Psychological Distress and Resilience

T1 impact, increases in impact and decreases in hope were significant predictors of T2 distress, controlling for T1 distress (Table 4). Online services did not significantly contribute (Table S2); however, T1 perceived benefit was a significant predictor of T2 distress for the subset of participants receiving online services.

While 36.1% met criteria for resilience at T2, 34.6% had two or more areas rated as moderate-to-severe impact and moderate-to-severe distress. Logistic regression indicated that more frequent T1 hope (5–7 days OR = 6.12 CI [1.90, 19.68] and 3–4 days OR = 4.68 [1.79, 12.24] relative to less than 1 day;  $P = 0.002$ ) and minimal-to-mild T1 distress (OR = 6.39 [2.57, 11.44]) predicted T2 resilience.

#### Discussion

Our results suggest that in April, relatively early on in the pandemic for the U.S., autistic adults were already feeling a mild-to-moderate impact on their lives. On average, they reported 2–3 areas of their lives disrupted, with social life (66%), employment (73%) and school (69%) most frequently endorsed at T1. Transition age adults reported greater employment impact than older age groups, consistent with trends observed in the general population [Montenovo et al., 2020]. They were also more likely to be enrolled in school before the pandemic and therefore more likely to report educational disruptions. Females reported more areas impacted, greater total impact and poorer overall coping, driven by more severe impacts and poorer coping with changes in services,

home life and financial security. While information regarding the specific disruptions in each area (e.g., type of service, dependent care) was not collected, this mirrors the disproportionate gender effects observed in the general public in China [Wang et al., 2020], which have been hypothesized to be due to females often carrying more primary caregiving responsibilities in families [Wenham, Smith, & Morgan, 2020].

At T1, a significant minority (45%) endorsed levels of psychological distress that fell in the “moderate-to-severe” range, with half (53.8%) reporting two or more symptoms at least 3 days in the previous week. Females, younger adults and those with personal COVID-19 experience reported higher levels of psychological distress. Notably, psychological distress was stable from T1 to T2. While increases in distress might be expected, particularly considering the increasing impact over the same period, relative stability might reflect that T1 distress was already relatively high. In general population samples surveyed in March using similar instruments, only 10.7% of the general population fell in the “moderate-to-severe” range [Holingue et al., 2020a] and 28% endorsed experiencing two or more (out of five) symptoms for three or more days [Holingue et al., 2020b]. Thus, a higher proportion of autistic adults in our sample endorsed concerning levels of distress from the outset of the study. While we do not know if T1 distress represents an increase from pre-pandemic levels, increases in impact and decreases in hope between T1 and T2 predicted T2 distress. This suggests that distress is associated with pandemic-related changes and underscores the importance of considering autistic adults’ needs during the pandemic.

Just over one-third (37%) of the sample reported feeling hopeful about the future 3 or more days in the past week. While those reporting more frequent hopefulness

did not differ on the number of areas disrupted or likelihood of disruption in any area, they reported less overall impact and distress at T1. Our examination of hope was limited to one item, leaving the directionality of this association unknown (i.e. hopefulness as a trait that influences perceptions of impact and ability to cope vs. less impact and better coping leading one to a more hopeful state of mind). That a decrease in frequency of hopefulness from T1 to T2 was a significant predictor of T2 psychological distress may be consistent with research proposing hope as a treatment target to reduce psychological symptoms [Cheavens, Feldman, Woodward, & Snyder, 2006]. On the other hand, T1 hope predicting T2 resilience (defined as minimal-to-mild psychological distress in spite of reporting moderate-to-severe impact in two or more areas) is consistent with research suggesting that trait hope has a moderating effect on the relationship between negative life events and depressive symptoms [Visser, Loess, Jeglic, & Hirsch, 2013]. While mitigating the negative impact of the pandemic on individual areas of one's life may be difficult, these results suggest that hopefulness may be a particularly important area to explore in supports for autistic adults.

While it might be hoped that engagement in online services would be associated with lower psychological distress, less impact or better coping, those with more distress and greater impact are also likely to be pursuing online services. While our survey did not ask participants to specify the specific services received online, the majority reported receiving mental health services prior to the pandemic, suggesting that psychological supports are likely to be at least part of the online services being utilized. Of 98 participants receiving online services at T1, 74% reported moderate-to-significant benefit. For this subset of participants, lower perceived benefit of online services at T1 predicted higher distress at T2, suggesting a need to better understand the nuances of what is experienced as a negative impact to services. In particular, understanding the facets of telehealth that are and are not beneficial, as well as for whom telehealth is particularly beneficial, will be an important consideration for future studies.

It is notable that psychological distress and COVID impact did not differ by racial/ethnic minority or geographic region. While the former is likely due to limited sample diversity, the latter may be attributed to timing of the survey. The first survey was distributed just as cases were rising and stay-at-home orders were being put into effect, whereas T2 was released just as many states were seeing declines in daily cases and beginning to loosen restrictions. Thus, variability in restrictions between states likely impeded our ability to detect broader regional effects and few participants from individual states limited power to detect effects that were noted in the general population when there were only a few states

with high case numbers in early March [Holingue et al., 2020a]. Job changes may also have been expected to have greater effects on distress. Our results may have been affected by a lack of information regarding timing of job changes and small subgroups reporting specific changes, which resulted in combining categories (e.g. laid-off, unpaid furlough and reduced hours).

It is important to acknowledge limitations to this study. First, these data were collected early in the early months of the pandemic and likely underestimate the negative impacts of the pandemic on autistic adults, as those most severely impacted are less likely to respond to a survey. Older adults (who tended to report less severe T1 impact) were more likely to respond to the T2 survey. Relatedly, a high number of participants endorsed T1 personal COVID-19 experience, perhaps evincing another sampling bias. In addition, this sample is limited in its racial and ethnic diversity and includes only legally independent adults who can self-report. Finally, we do not have baseline pre-pandemic distress levels or behavioral characteristics (e.g., autism symptoms or communicative ability). While SPARK has some information from prior surveys, variability in the timing and completeness precluded inclusion of such data in these analyses. That 57% were diagnosed as adults and 72.8% reported some college or more at the time of enrollment provides important context in which to interpret these findings.

## Conclusion

Nearly half of the present sample of autistic adults reported moderate-to-severe levels of psychological distress. Being female or younger, having previous mental health diagnoses or personal COVID-19 experience and reporting less frequent hope for the future was associated with greater T1 distress. Findings suggest hope may be a protective factor, even in the presence of high levels of perceived negative impact to daily life. Supports aimed at increasing hope may be particularly useful to mitigate psychological distress for autistic adults during the pandemic. Better understanding of factors influencing perceived benefit of online services is also needed to foster development of psychological services. That predictors of distress in autistic adults largely mirror those in the general population cautions against assumptions that autistic adults may be less impacted by social distancing orders and warrant attention to ensure that their needs are recognized and supported throughout this ongoing public health crisis.

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## Conflict of Interest

No authors have any conflicts to declare. Mustafa Sahin has received research funding from Novartis, Roche, Pfizer, Biogen, Ipsen, LAM Therapeutics, Astellas, Bridgebio and Quadrant Biosciences and has served on the Scientific Advisory Boards for Sage Therapeutics, Roche, Celgene, Aeovian, Regenxbio and Takeda. Robin Kochel has a contract with Yamo Pharmaceuticals, Inc., to consult on the design of clinical trials for individuals with ASD. Suma Jacobs has been an investigator in multi-site treatment trials by Roche and served on an autism advisory board for Roche.

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## Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Appendix S1:** Supplementary Information.