


ORIGINAL ARTICLE OPEN ACCESS

Negative and Positive Experiences During the COVID-19 Pandemic in Canadians With Developmental Disabilities: A One-Year Ontario-Based Survey

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Received: 25 January 2024 | **Revised:** 19 July 2024 | **Accepted:** 22 August 2024

Funding: This work was supported by Centre for Addiction and Mental Health Foundation.

Keywords: adults | autism | developmental disabilities | mental health | pandemic | physical health

ABSTRACT

Purpose: Understanding the experiences of people with developmental disabilities during the initial period of COVID-19 pandemic.

Methods: Individuals with developmental disabilities and their caregivers completed baseline and up to five follow-up online surveys using the CRISIS-AFAR measures, between July 2020 and September 2021. We used qualitative (thematic analysis) and quantitative (MANOVA) analytic methods.

Results: One hundred and eighteen participants (64 caregivers on individuals 6–62 years, 54 self-reporting individuals aged 17–55 years) completed baseline survey; 46 participants (23 caregivers, 23 self-reporting adults) completed ≥ 1 follow-up. Qualitative themes included uncertainty, and negative and positive influences on behaviours and routines, daily life and mental wellness. Those experiencing positive impacts did not stably perceive so longitudinally.

Conclusions: Despite both negative and positive influences on individuals with developmental disabilities and their families, the prolonged pandemic had wide-ranging repercussions. Emergency preparedness planning should consider the disruptive effects of public health measures on routine and support for this vulnerable population.

1 | Introduction

The COVID-19 pandemic and subsequent public health emergency measures has caused widespread disruptions to all aspects of life around the world. In Ontario, Canada's most populous province, mandatory lockdown measures began on 17 March

2020, resulting in closures across workplaces, schools, non-essential retail, and in-person medical, dental and other services. Although the scope and intensity of these lockdown measures varied across different regions of the province, Ontario experienced one of the longest lockdowns in North America, with several periods of restrictions easing up, then being re-implemented

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in quick succession (Government of Ontario 2021). Instituting lockdowns led to prolonged disruptions in the daily routines for many people, particularly for those with developmental disabilities. The structure and predictability of daily routines can be essential for the general maintenance of mental and physical wellbeing (Cai et al. 2017; Margraf et al. 2016), and may be especially important for people with disabilities and their families, who are already at increased risk for poor mental health, unemployment, social isolation and caregiver burnout (Cree et al. 2020; Lillie, Alvarado, and Stuart 2013; Repke and Ipsen 2020; Wolicki et al. 2021). Evidence from the onset of COVID-19 suggests that pandemic-related disruptions have led to a worsening of these circumstances for people with disabilities and their caregivers (Adams et al. 2021; Emerson et al. 2021; Levante et al. 2021; Okoro et al. 2021; Pettinicchio et al. 2021).

However, studies have found significant heterogeneity in pandemic-related stress and mental health trajectories in samples including people with developmental disabilities. For instance, a Canadian cross-sectional survey on the mental health impact of COVID-19 on 1013 children and adolescents with pre-existing psychiatric diagnoses found variability among the rates of mental health deterioration, with some experiencing improvements in depression, anxiety and irritability (Cost et al. 2022). Similarly, a recent descriptive analysis of self-reported wellbeing in 16,940 UK children ages 8–18 years found that 33% reported improved mental wellbeing during the first national lockdown (Soneson et al. 2023). Additionally, a longitudinal study in 1639 UK and US children and adolescents identified differences in mood symptoms, by subgroups based on socio-economic status (Nikolaidis et al. 2022). Comparable studies in adults with disabilities reported similar findings, describing improvements in mental health among some adults mainly due to alleviating social stress, but reduced access to healthcare and worsening symptoms in others, as service barriers and worries surrounding work, finances, safety and security increased (Bundy et al. 2022; Flynn and Hatton 2021; Hatton et al. 2024; Hedley et al. 2021; Oomen, Nijhof, and Wiersema 2021). These trends observed in children and adults with disabilities are similar to the impacts experienced by caregivers such that wellbeing improved during the first and second year of the pandemic (2020–2022), with other stressors remaining the same (Safar et al. 2024; Tarzi et al. 2023).

Although identifying factors associated with poor outcomes is crucial in preventing mental health decline and enhancing targeted supports for vulnerable populations, a singular focus on negative impacts alone may provide an incomplete picture of the range of experiences of people with developmental disabilities during the pandemic. Research aiming at understanding factors that strengthen protective factors and improve resiliency in vulnerable and often marginalised populations is much needed when faced with the current and potential future pandemics or endemics. For instance, it is possible that the reduction of social, sensory and work/school related pressures experienced by some during the pandemic (Bruining et al. 2021; Dvorsky, Breaux, and Becker 2021; Nikolaidis et al. 2021) provide important insights into the maintenance of wellbeing in those that experience challenges in these areas, in the context of massive societal changes.

Recognising the manifold impacts of the pandemic described above, much of the research to date in people with developmental

disabilities has been cross-sectional in nature. While there is a growing body of evidence investigating longitudinal impacts (Bundy et al. 2022; Goldfarb, Gal, and Golan 2021; Scheeren et al. 2022), the overarching focus has been on children, parents and adults without intellectual disabilities. To this end, the impacts of the COVID-19 pandemic on adults with developmental disabilities remains understudied and insufficiently understood. Furthermore, there is a lack of research that has examined these impacts in youth and adults with developmental disabilities in Ontario, Canada. It is important to understand the impacts and experiences of the COVID-19 pandemic in Ontario, given that Ontario had one of the longest lockdown periods in North America, to appropriately support their wellbeing needs, and to help prepare for future public health emergencies.

Given these significant knowledge and research gaps, we conducted a partially longitudinal online survey over 1 year from July 2020 (about 4 months into the pandemic) to September 2021 (the first period of larger-scale opening-up after a lengthy lockdown in Ontario) to assess mental and physical health, daily behaviours, adaptive function, social support and COVID-19 related stress. Drawing on combined quantitative and qualitative analyses, we aimed to contrast the experiences and perspectives of people with developmental disabilities (predominantly adults) and their families in Ontario, who reported positive changes (PCs) as a result of the pandemic, versus those that did not, to illustrate the variety of responses to the pandemic in people with developmental disabilities.

2 | Methods

2.1 | Procedure

Participants included adults with developmental disabilities, as well as caregivers of individuals with developmental disabilities. Caregiver was defined as a person providing care to an individual with developmental disability; we did not require a legal guardian status for inclusion. Caregivers were reporting on presumably different individuals than those providing self-reports; self-reporting adults and caregivers were recruited separately as individual participants, but we have no information to link if a self-reporting individual's caregiver has also participated in the caregiver survey, or vice versa. Collecting data from both self-reporting adults and caregivers provides the necessary depth, breadth and nuance into examining the impacts of the pandemic (Flynn and Hatton 2021). Specifically, collecting caregiver reports improves inclusivity of different ranges of functionality in individuals with developmental disabilities. Developmental disabilities were defined broadly as described by the Ontario government, referring to early emerging and longstanding neurodevelopmental conditions affecting a person's ability to learn (<https://www.ontario.ca/page/adults-developmental-disabilities-ontario>). Recruitment was done through (i) direct email invitations to past research participants of projects at the Centre for Addiction and Mental Health (CAMH), Toronto and (ii) via online social media. Potential participants who were emailed directly (410 emails sent) were clients of services at CAMH for those with confirmed autism or other developmental disabilities diagnoses, and/or were previously involved in developmental disabilities research conducted by our group and consented to

be re-contacted for new studies; the developmental disabilities diagnoses were confirmed based on the inclusion criteria of prior studies, with approaches spanning from using standardised diagnostic measures to clinical diagnoses (Ameis et al, 2020; Desarkar et al. 2022; Lunsby et al. 2018, 2021). Participants recruited via social media (45 participants accessed the survey link) responded to an advertisement that was selectively shared by autism and developmental disability community organisations in Canada on semi-private social media channels (e.g., newsletters) to target the developmental disabilities community and avoid spamming; here, the developmental disabilities diagnoses were ascertained via self-report in the survey. The baseline survey period was 16 July to 10 December 2020. There were five follow-up surveys sent to baseline survey respondents at 2-month intervals on 15 January, 22 March, 17 May, 15 July and 15 September 2021, and each survey remained online for a period of 1 month before closing. For context, an initial State of Emergency was declared in Ontario on 17 March 2020, with some partial reopening starting June 2020, followed by reinstated and tightened measures from September 2020, then a provincewide shutdown in December 2020, which lasted until February 2022 when the provincial government slowly lifted restrictions in a phased manner. Therefore, the baseline and follow-up surveys were carried out mostly during lockdown periods in Ontario. Participants were compensated at a rate of \$10 Canadian dollars in the form of e-gift cards at baseline, with an additional \$6 for each follow-up survey completed. Online consent was obtained at the start of each survey. All procedures were approved by the research ethics board at CAMH (REB# 077/2020).

2.2 | Measures

COVID-19 pandemic impact was assessed using The CoRonavIruS Health Impact Survey, Adapted for Autism and Related Neurodevelopmental Conditions (CRISIS-AFAR) survey (Vibert et al. 2023). CRISIS-AFAR is a standardised and open-access survey instrument, with both baseline and follow-up forms, created by the U.S. National Institute of Mental Health and the Child Mind Institute in New York, in collaboration with the CRISIS-AFAR International Network. A working group of experts in autism and other developmental disabilities led the adaptation of the CRISIS Parent/Caregiver Baseline Form and the CRISIS Adult survey (<http://www.crisissurvey.org/>), to an adapted version to be used with parents/caregivers of children aged 3–21 years (CRISIS-AFAR 3–21) (Vibert et al. 2023). The authors of the current study were tasked to further adapt the CRISIS-AFAR 3–21 to two versions for adults—one reported by parents/caregivers of young adults ages 21 and over (CRISIS-AFAR 21+) and one for self-reporting adults (ages 18 and above) (CRISIS-AFAR Self Report). This adaptation process incorporated feedback from developmental disabilities community stakeholders (i.e., adults and caregivers) via the advisory groups at the Azrieli Adult Neurodevelopmental Centre at CAMH, and involved multiple consultations within the CRISIS-AFAR International Network, in order to harmonise the CRISIS-AFAR survey across all versions.

All three versions were used in this study: the CRISIS-AFAR 3–21, CRISIS-AFAR 21+ and CRISIS-AFAR Self Report. Face validity was established via the shared expertise of the working

group, the iterative measure refinement, and stakeholder consultation. Due to resource and time constraints, beyond what has been reported for CRISIS-AFAR 3–21 (Vibert et al. 2023), no further psychometric information is available. Hence, the findings are considered descriptive, and future refinement may still be needed. Common across the three versions are questions on basic demographic data, exposure to COVID-19, life experiences, daily behaviours, mental and physical health and service-use experiences; these data were therefore used in the present study. In the baseline survey, a subset of items also measures change in these areas, from 3 months prior to the onset of the COVID-19 pandemic, as compared with the last 2 weeks at the time of filling out the baseline survey, in the respondent's geographical area. Finally, the survey also provides text response boxes for participants to provide comments to specific questions or prompts, that offer text-based information for qualitative synthesis.

2.3 | Analyses Framework

This study employed a mixed methods approach to perform both quantitative and qualitative analyses on the baseline and follow-up survey responses. Caregiver versions (CRISIS-AFAR 3–21, CRISIS-AFAR 21+) were combined (owing to feasibility considerations for the quantitative analyses due to sample size limitations, and a lack of thematic differences noted in the qualitative analyses) and analysed separately from the self-report version (CRISIS-AFAR Self Report) in all analyses. At baseline, both the caregiver-report and the self-report samples were stratified a priori into no positive change (NPC) and PC groups according to the responses to the question, 'Has the coronavirus/COVID-19 crisis in your area led to any positive changes in your (your child/family member's) life?'. Participants who selected the response 'None' were in the NPC group, while those that selected the response 'Only a few' or 'Some' were in the PC group. Demographic and descriptive variables were described by NPC and PC groups to concisely represent pertinent information including age, sex, gender identity, race-ethnicity, geographical location, existing health conditions and/or diagnoses, and exposure status to COVID-19 (Appendix A in Data S1) at baseline. For the follow-up surveys, participant membership in the NPC and PC groups was tracked for each time-point, to determine whether membership in these groups remained stable over time.

2.4 | Quantitative Analyses

Several a priori domains (Table 1) corresponding to unidimensional constructs for mental or physical health symptoms, daily behaviours and adaptive function, social supports and relationships and COVID-19-related stress, were defined using relevant items in the CRISIS-AFAR baseline surveys, for both the combined-caregiver and self-report versions. A total domain score was generated by summing the item scores across all questions in the domain. Appendix A in Data S1 displays the items included for each a priori domain, along with the coding framework, for both the combined-caregiver and self-report samples.

A one-way multivariate analysis of variance (MANOVA) was performed for the combined-caregiver and self-report samples,

TABLE 1 | A priori domains, iteratively constructed from the CRISIS-AFAR survey items.

Combined-caregiver report (3–21 and 21+ versions) domains	Self-report domains
<ul style="list-style-type: none"> • Repetitive and Restricted Behaviours and Interests (RRBI) • Problem Behaviours • Adaptive Functioning • Daily Behaviours and Media Use • Stress Due to COVID-19 • Hopefulness 	<ul style="list-style-type: none"> • Pre-Pandemic Health Status • Repetitive and Restricted Behaviours and Interests (RRBI) <ul style="list-style-type: none"> • Emotions and Worries <ul style="list-style-type: none"> • Substance Use • State of Crisis • Daily Behaviours and Media Use <ul style="list-style-type: none"> • Social Support • Relationship Changes • Stress Due to COVID-19 <ul style="list-style-type: none"> • Hopefulness

respectively, at baseline. The independent variable in the analyses was NPC/PC group membership. A priori total domain scores were the continuous dependent variables (Table 1). Univariate ANOVAs were also performed. For the ‘change’ questions included in the domains (i.e., CRISIS-AFAR items that asked about the condition 3 months prior to the pandemic versus that of the last 2 weeks), the last 2 weeks total domain score was used. We then repeated the analyses using the percent change for these domains between the two time points as a supplementary analysis (Appendix B in Data S1). Univariate outliers were assessed using boxplots, and Shapiro–Wilks tests were performed to assess the normality of each dependent variable, by NPC/PC groups. Multicollinearity of dependent variables was assessed using Pearson correlations, and the linearity assumption was also tested for each pair of dependant variables, for each group of the independent variable. Multivariate outliers were tested for using Mahalanobis distances, homogeneity of variance–covariance matrices was assessed using Box’s *M* test of equality of covariance, and the homogeneity of variances between groups of the independent variable was assessed via Levene’s test of equality of variances. Domains that were removed from the MANOVA/ANOVA due to violations of underlying assumptions were investigated separately using Mann–Whitney *U* tests. All quantitative analyses were performed using IBM SPSS Statistics 26 (<https://www.ibm.com/products/spss-statistics>).

For follow-up surveys, heat maps were created to depict changing NPC and PC group membership for the sample over time, for both the combined-caregiver and self-report samples. Due to insufficient follow-up completion, no further quantitative analyses were performed with the follow-up samples.

2.5 | Qualitative Analyses

A thematic analysis of the written, free-text responses was conducted, for baseline as well as follow-up surveys. These responses were prompted by three free-text, open-ended questions present across all versions, at baseline and at follow-up: (1) ‘Please specify positive changes [due to the pandemic]’; (2) ‘Please describe anything else that concerns you about the impact of the COVID-19 pandemic on your friends or family’; and (3) ‘Please provide any comments that you would like to

change about this survey, and/or related topics’. Informed by Braun and Clarke (2006) steps of thematic analysis, two members of the research team read the self-report and caregiver responses to gain a broad-level overview regarding the impact of the pandemic. Next, the responses were read again and independently coded (i.e., assigning a short name to a segment of data) to organise and reduce the data. Following independent coding, the two analysts met to discuss the codes that were generated. All codes were reviewed, discussed and debated, and similar codes were grouped together to form the following categories: opportunity for rest and repose, learning new skills, health benefits, worries, financial stress, social connectedness, social supports and relationships. Once these categories were established, the categories were reviewed with the larger team where the categories, patterns and relationships observed across the data were discussed and refined. Analysis with the larger team was integral to the interpretation of the data to examine the data from multiple directions as the team possessed diverse expertise, and consisted of three child psychiatrists, a psychiatry resident, two clinical psychologists and a post-doctoral fellow.

Following the larger group discussion, analysis continued by comparing the categories (Campos et al. 2019) between the combined-caregiver and self-reports to draw out recurring patterns and interrelationships. Negative cases (i.e., similar to outliers in quantitative analysis) were used to test the rigour of the interpretations, to examine alternative directions, and to explore nuances in the data (Jachyra et al. 2021). Once the cross-analysis was completed, patterns and relationships most commonly observed in the categories were grouped together, and then collapsed into three overarching categories: (i) uncertainty and the impact on behaviours and routines; (ii) changes to supports and impact on daily life; and (iii) impact on mental wellness. The three categories were then discussed at a final team meeting, and descriptively labelled as overarching themes. Analysis was considered complete when primary themes were established and agreed by team members.

Finally, comments made by outliers identified in the quantitative analysis were examined separately, in order to gain a more in-depth understanding of how the themes identified in the qualitative analysis were experienced by participants with more extreme pandemic experiences.

3 | Results

3.1 | Participant Characteristics

A total of 118 participants completed the baseline survey. Out of these, $n=64$ completed the caregiver report (3–21 and 21+; reporting on $n=64$ individuals in their care, including 40 males and 23 females assigned at birth and 1 other sex at birth) and $n=54$ completed the self-report (including 27 males and 27 females assigned at birth). The age range of individuals with developmental disabilities being reported on in the caregiver survey was 6–62 years (mean age 24.4, SD 8.9; $n=24$ reported via CRISIS-AFAR 3–21, mean age 17.1, SD 3.9, range 6–21; $n=40$ reported via CRISIS-AFAR 21+, mean age 28.8, SD 8.3, range 22–62), and 17–55 years (mean age 27.6, SD 8.9) in the self-report survey. Among them, 78.1% ($n=50$) of the combined-caregiver report sample identified their child/family member as having autism spectrum disorder, while 92.6% ($n=50$) of the self-report sample identified themselves as having an autism spectrum disorder, among other conditions (Figure 1). Table 2 describes the sample characteristics.

3.2 | Quantitative Comparisons Between NPC and PC Groups

The main quantitative analyses focused on the baseline survey responses, organised into the domains outlined in Table 1, and on follow-up membership in the PC, or NPC groups, for both the combined-caregiver and self-report samples. In the combined-caregiver sample, there were $n=41$ in the NPC group, and $n=23$ in the PC group. In the self-report sample, there were $n=24$ in the NPC group, and $n=30$ in the PC group.

For the combined-caregiver report, univariate outlier and Shapiro–Wilks test ($p < 0.05$) identified the Hopefulness domain as violating the assumptions underlying MANOVA, and it was subsequently removed from the MANOVA and separately investigated using a Mann–Whitney U test. Distributions of Hopefulness scores for the NPC (mean rank 30.52) and PC (mean rank 36.02) groups were not similar across NPC and PC groups, as assessed by visual inspection, and were not statistically significantly different ($U=552.50$, $z=1.150$, $p=0.250$) (Table 3). In the parsimonious multivariate analysis, differences between the NPC and PC groups were not statistically significant ($F_{(5,58)}=1.746$, $p=0.139$, Wilks $\Lambda=0.869$, partial $\eta^2=0.131$) (Table 4). Univariate ANOVA for domains included in the MANOVA (Table 5) showed a statistically significant difference in the Adaptive Function domain, that the NPC group had higher scores, indicating poorer adaptive functioning, than the PC group ($p=0.023$).

For the self-report, univariate outlier and Shapiro–Wilks tests ($p < 0.05$) identified Substance Use, State of Crisis and Hopefulness domains as violating the assumptions underlying MANOVA, and these domains were subsequently dropped from the MANOVA and investigated separately using Mann–Whitney U tests. Distributions of Substance Use, State of Crisis and Hopefulness domains were all not similar across NPC and PC groups, as assessed by visual inspection. Substance Use scores for the PC group (mean rank 31.45) were statistically significantly higher ($U=478.50$, $z=2.226$, $p=0.026$) than those of the NPC group (mean rank 22.56), indicating more substance use in

the PC group. State of Crisis scores were statistically significantly higher for the NPC group (mean rank 32.54), compared to the PC (mean rank 23.47) group ($U=239.00$, $z=-2.146$, $p=0.032$), indicating a higher state of crisis in the NPC group. Hopefulness scores were not significantly different between NPC (mean rank 29.58) and PC (mean rank 25.83) groups ($U=310.00$, $z=-0.912$, $p=0.362$) (Table 3). In the parsimonious multivariate analysis, differences between NPC and PC groups were not statistically significant ($F_{(7,46)}=1.550$, $p=0.175$, Wilks $\Lambda=0.809$, partial $\eta^2=0.191$) (Table 4). Univariate ANOVA for domains included in the MANOVA (Table 5) showed a statistically significant difference in the Emotions and Worries domain, that the NPC group had higher scores, indicating more negative emotions and worries, than the PC group ($p=0.025$).

Figure 2 depicts heat maps for the combined-caregiver and self-report follow-up time points, for NPC (orange) and PC (blue) groups, respectively. For the combined-caregiver sample, a total of 23 caregivers completed at least 1 follow-up survey (i.e., had at least 2 time-points with data). Out of these, 10 remained exclusively in the NPC group, 3 remained exclusively in the PC group, and 10 changed between the NPC and the PC groups in at least 1 time-point measured. For self-reporting participants, a total of 23 participants out of 54 (43%) completed at least 1 follow-up survey (i.e., had at least 2 time points with data). Out of these, 7 remained exclusively in the NPC group, 8 remained exclusively in the PC group and 8 changed between the NPC and the PC groups in at least 1 time-point measured.

3.3 | Qualitative Synthesis

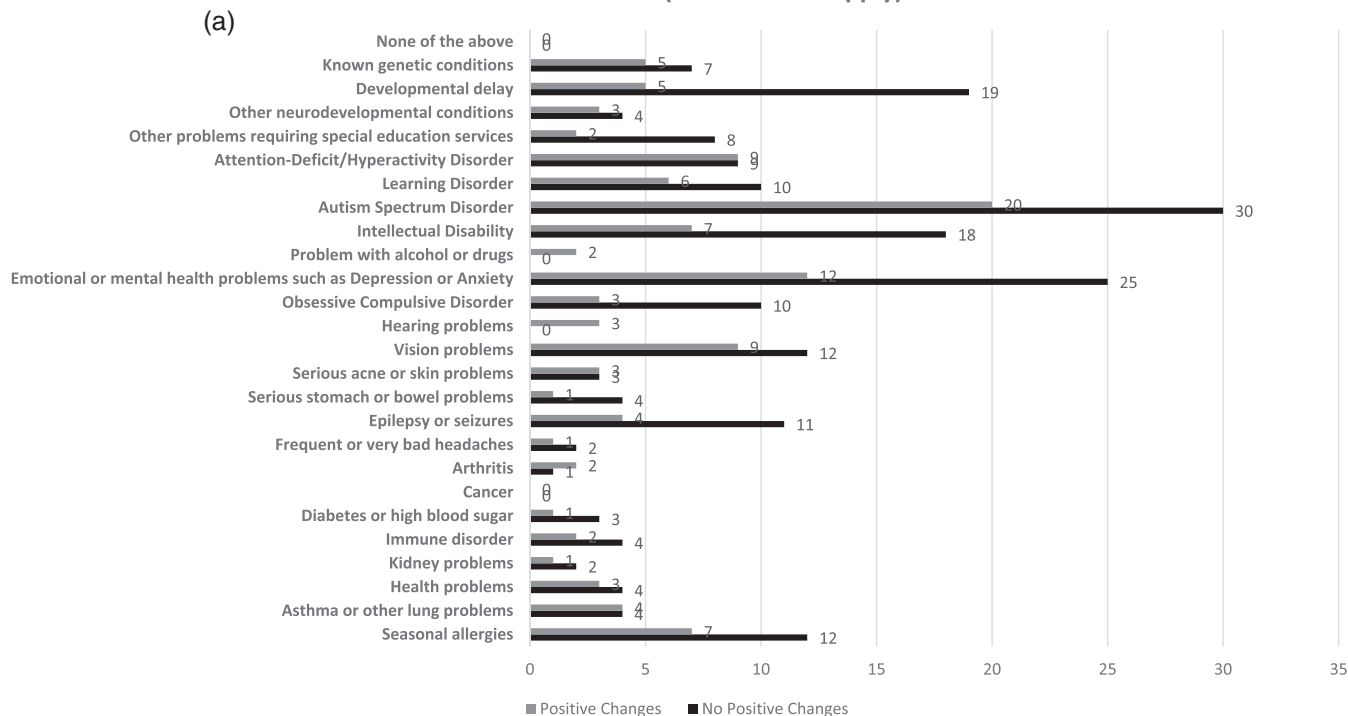
At baseline, 93 participants provided comments for at least one out of the three text-response questions. From these responses, 54 were caregivers' and 39 were self-reported comments. At follow-up, a total of 36 participants provided comments for at least one out of the three text response questions, in at least one follow-up time point. Nineteen of these were caregivers, and seventeen were self-reported comments.

Overall findings illustrated the many ways in which the COVID-19 pandemic impacted the lives of autistic people and other youth and adults with developmental disabilities, and their families both in the short and long term. From changes to daily routines, changes to learning and working structures, through to restricting opportunities to socialise with others, the pandemic significantly altered the lives of some respondents. Other changes noted were the loss of the use of senses such as not being able to physically hold a loved one or support member in terms of crisis. At times, these changes in senses exacerbated crisis situations, as usual coping supports were altered. These changes in turn impacted behaviours, routines and mental wellness during the implementation of pandemic measures at the beginning of the pandemic, and at follow-up. These impacts at follow-up are explicitly outlined in the themes below.

3.3.1 | Uncertainty and the Impact on Behaviours and Routines

Living throughout the COVID-19 pandemic triggered significant uncertainty with regard to the lethality of the virus, the

Has a health or educational professional ever told you that your child had any of the following health conditions (check all that apply):



(b) Has a health or educational professional ever told you that you had any of the following health conditions (check all that apply):

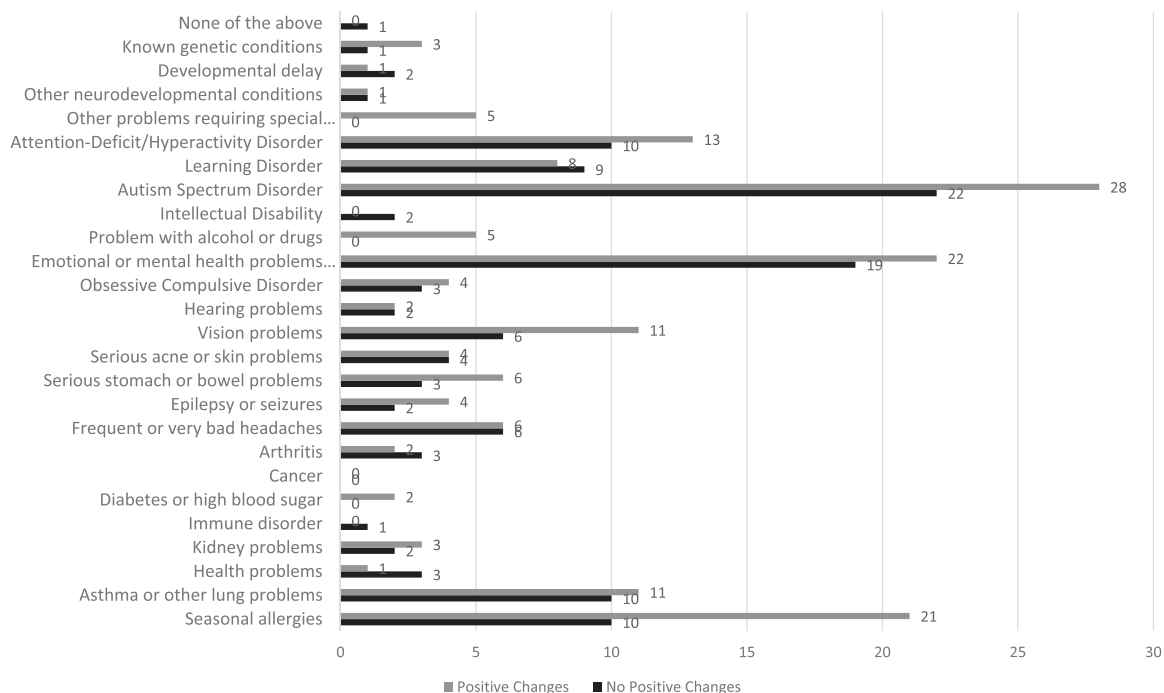


FIGURE 1 | (a) Combined-caregiver sample, health conditions. (b) Self-report sample, health conditions.

duration of lockdowns, and uncertainty with ever changing pandemic guidelines. The uncertainty and changes to daily life negatively impacted participants, where the pandemic abruptly changed routines and regimens. Some participants were frustrated that the progress made with some routines, which for some took years of progress, fell apart in a matter of days. The

lack of consistent and clear communication from federal, provincial and municipal health authorities was noted, and caused significant distress anticipating how to cope with an omni-present threat to physical and mental health. The combination of uncertainty and abrupt changes to daily routines triggered significant behavioural challenges, especially during the early onset of the

TABLE 2 | Baseline demographic and descriptive characteristics of the combined-caregiver and self-report samples.

Combined-caregiver report (n = 64)		
	No positive changes (n = 41)	Positive changes (n = 23)
Age of family member (standard deviation)	25.61 (9.87); range 6–62years	22.16 (6.77); range 9–38years
Sex at birth of family member	Male = 27 Female = 13 Other = 1	Male = 13 Female = 10
Gender of family member (as per caregiver's report)	Boy/Man = 26 Girl/Woman = 11 Trans woman = 1 Non-binary = 2 Did not respond = 1	Boy/Man = 13 Girl/Woman = 9 Non-binary = 1
Geographic region of ancestry	British Isles = 24 New Zealand not of Maori = 1 Northern Europe = 8 Western Europe = 18 Eastern Europe = 8 Southern Europe = 10 Middle East = 1 South Asia = 2 Eastern Asia = 4 Africa = 1 North America, not First Nations = 5 North America First Nations = 3 Don't know = 1 Other = 2	British Isles = 8 Northern Europe = 1 Western Europe = 3 Eastern Europe = 2 Southern Europe = 6 Middle East = 1 North America not First Nations = 6 North America First Nations = 3 Central or South America = 1 Other = 1
Geographic location	Canada, Ontario = 36 Canada, Manitoba = 5	Canada, Ontario = 21 Canada, Manitoba = 1 Canada, Quebec = 1
Exposure to COVID-19	n = 2 with potential exposures ^a	n = 7 with potential exposures ^a
Self-report (n = 54)		
	No positive changes (n = 24)	Positive changes (n = 30)
Age (standard deviation)	28.08 (8.27); range 18–47years	27.27 (9.44), range 17–55 years
Sex at birth	Male = 14 Female = 10	Male = 13 Female = 17
Gender	Boy/Man = 14 Girl/Woman = 8 Non-binary = 2	Boy/Man = 11 Girl/Woman = 14 Trans girl/woman = 1 Non-binary = 4
Geographic region of ancestry	British Isles = 17 Northern Europe = 1 Western Europe = 11 Eastern Europe = 3 Southern Europe = 4 Eastern Asia = 1 South-East Asia = 1 South Asia = 1 North America non-First Nations = 1 North America First Nations = 2 Central or South America = 1 Don't know = 2	British Isles = 16 New Zealand, non-Maori = 1 Northern Europe = 1 Western Europe = 11 Eastern Europe = 7 Southern Europe = 4 Middle East = 2 Eastern Asia = 3 South-East Asia = 1 South Asia = 1 North America, non-First Nations = 5 North America, First Nations = 5 Central or South America = 4 Other = 1

(Continues)

TABLE 2 | (Continued)

Self-report (<i>n</i> = 54)	No positive changes (<i>n</i> = 24)	Positive changes (<i>n</i> = 30)
Geographic location	Canada, Ontario = 24	Canada, Ontario = 30
Exposure to COVID-19	<i>n</i> = 0 with any exposures ^a	<i>n</i> = 1 with potential exposure ^a

^aPotential exposures refer to at least 1 'Yes' response to one of the 3 exposure questions in Appendix A in Data S1.

pandemic. For example, one parent noted that her son's anxiety 'increased about not being able to go to Wonderland, and ride the YRT, the GO, TTC and UP express. This has led to violence, police, handcuffs, and hospital'. Changes to routine also triggered the onset of behaviours such as daily aggression, tantrums and overall uneasiness of 'always being on edge'. These changes were detrimental as parents described not being able to support their daily outbursts and difficult behaviours during the early onset of the pandemic:

The major challenge with my daughter has been with virtual learning. She could not cope without the normal routine so we ended up having to 'drop-out'. She is very worried schools won't resume in Sept & she feels very strongly that she can't learn in the home—she needs to be in a classroom setting. This caused daily outbursts & tantrums so I finally informed the school we were done for this year & stopped attempting to learn virtually. I fear the tantrums I will have to endure (as I work from home) if school does not resume as it is quite stressful & unbearable at times.

At follow-up, parents of both the 3–21 and 21+ years group reported that the uncertainty of the pandemic exacerbated isolation, and limited opportunities for human interaction. Parents were concerned about further deterioration of difficult behaviours, outbursts and the long-term consequences of the pandemic, as the difficulties persisted throughout the follow-up period. The continued and debilitating impact of the pandemic was exemplified by one parent who noted:

My son's anxiety has greatly increased and has had to be escorted from his group home to the hospital by police, because he has been confined for so long. Increased anxiety leads to increased aggressions. Doctors who don't know him want to switch up medications, but that is not the problem. The pandemic is the problem.

Although the pandemic predominantly negatively impacted people as described above, a few individuals highlighted that the pandemic provided more opportunities for employment by working at home. Some participants commented on the positive impact of online classes with the transition being easier and having a smaller class size virtually. This positive impact was highlighted by a self-report participant who noted:

The transition into online classes makes it easier to manage sensory issues brought on in normal class environments. The shutdown of a job I had lined up meant I was able to take extra summer classes and get ahead on my second year of university.

3.3.2 | Changes to Supports and Impact on Daily Life

One of the major impacts of the pandemic was changes to social and professional supports. Across the data, participants described how greatly they were impacted with the lack of social and professional supports that were either cut due to lack of in-person services allowed, or programmes being eliminated. The drastic cuts to programmes negatively impacted both caregivers and individuals with developmental disabilities. One parent reported:

Not sure when the Day Program will begin again. There is not much for him to do. His stimming is increasing, he is gaining weight from lack of exercise unless we do so with him.

Changes to these supports contributed significantly to caregiver burden for some, which had a cascading effect on other parts of their lives. As reported by a parent:

The exhaustion of a parent having to look after my son 24/7 when usually it is done by a team....

With a lack of professional supports available, an increase in aggression, self-injury and symptom severity were also reported by caregivers. These behaviours were not acute in nature, and often lingered even after some supports were available when the first and second wave of the pandemic ended. The multifactorial impacts of the pandemic on supports and behaviour were perhaps best explained by this parent:

Now it is nearly impossible to get him outside the home for any reason. On the first occasion that we tried, he panicked and had a huge meltdown, resulting in self-harm and a major setback. Physical aggression towards me (his mother) was the worst it has ever been. We made no demands on him in an effort to 'keep the peace' within the home. His mental health suffered, as did ours. He very recently moved out of the family home (renting a home with his brother and cousin) and his support staff has returned to work.

TABLE 3 | Mann–Whitney *U* tests for the combined-caregiver (*n* = 64) and self-report (*n* = 54) survey domains (those excluded from the MANOVA).

	Domains	Mean rank	<i>z</i>	<i>U</i>	<i>p</i>
Combined-caregiver survey	<i>Hopefulness</i>				
	NPC (<i>n</i> = 41)	30.52	1.150	552.50	0.250
	PC (<i>n</i> = 23)	36.02			
Self-report survey	<i>Substance use</i>				
	NPC (<i>n</i> = 24)	22.56	2.226	478.50	0.026
	PC (<i>n</i> = 30)	31.45			
	<i>State of crisis</i>				
	NPC (<i>n</i> = 24)	32.54	2.146	239.00	0.032
	PC (<i>n</i> = 30)	23.47			
	<i>Hopefulness</i>				
	NPC (<i>n</i> = 24)	29.58	0.912	310.00	0.362
	PC (<i>n</i> = 30)	25.83			

He is still very anxious and she is having difficulty engaging him.

Although the COVID-19 pandemic put significant strains on supports and impacted day-to-day life, participants also noted a few positive impacts. Some participants spoke about having a better relationship with their loved ones and spending quality time together. Family members took sole charge with providing assistance and support in life, school and day programmes, which in turn seemed to better meet the needs of some individuals with developmental disabilities. In particular, one parent reported:

It has improved her relationship with me since we spend so much time together now more time with family, more support with school work.

Although the pandemic brought upon many positive and negative impacts in supports and daily routines, significant improvements were seen in relationships, friendships and some alternatives were sought when programmes and supports were cut. However, participants spoke about losing social skills and relationships they were able to once nurture due to the loss of day programmes and learning shifting to virtual classes. At follow-up, the previously reported benefits diminished, as the pandemic continued. Qualitative data across participants showed diminishment in the self-report group where structures in work settings were returning to pre-pandemic operations. Yet, these structures did not account for the needs, and negative impacts of the pandemic endured by individuals with developmental disabilities, and their children:

Caring for my (also autistic) child is very difficult as I am trying to homeschool and work full time. I am a single parent and have physical health problems as well. We live in a house with a lot of noise and disruption so its extra hard. I miss a lot of hours at

work and therefore have docked wages so it's getting hard to afford food and medication. I cannot drive so I have to pay \$20+ in delivery fees each week as I can't risk the bus. Getting tested is very hard as well as we have to walk there.

3.3.3 | Impact on Mental Wellness

Across the accounts, participants spoke about numerous impacts of the pandemic. Some respondents highlighted that they often felt isolated, depressed, anxious or bearing the burden of finances causing extensive stress during the pandemic. With the implementation of public health measures, which limited interaction with others, participants highlighted that the pandemic exacerbated feelings of isolation and loneliness.

One parent noted that this loneliness made their 'child feel abandoned'. While participants identified the need for the implementation of public health measures, they also felt like they were abandoned by a system that was meant to protect them. In particular, they felt abandoned in external support domains as therapeutic services and supports were not available. As explained by one parent:

I'm a person with disabilities; injuries and when I was not able to access my therapeutic treatments I became debilitated with pain and was not able to be an active parent to either kids, plus my daughters health greatly declined.

The onset of the pandemic negatively impacted caregivers as it triggered personal hardships such as issues with finances, job losses, strains to other relationships and challenges with daily living as they needed to devote the majority of their time, energy and resources to support their children. These additional responsibilities deteriorated the mental health of caregivers as they were burdened

TABLE 4 | The parsimonious multivariate analyses (MANOVA) for the combined-caregiver ($n=64$) and self-report ($n=54$) CRISIS-AFAR surveys.

	Wilk's lambda	F (df)	F statistic	p	Partial eta squared
Combined-caregiver survey ^a	0.869	5, 58	1.746	0.139	0.131
Self-report survey ^b	0.809	7, 46	1.550	0.175	0.191

^aDomains dropped from the model: Hopefulness.

^bDomains dropped from the model: Substance Use, State of Crisis, Hopefulness.

with such an abrupt addition of required supports. As noted by one participant, these additional burdens contributed to anxiety, panic, fear of the unknown and impacted all aspects of life:

Also my partner lost his job and had to sell his home so now we are moving in Together and we are looking for a home.... causing major anxiety for him as well as this is going to be a huge change for us.

Despite the many hardships of the pandemic, positive impacts were also noted in responses such as allowing individuals to rest; spend more quality time with others; engage in new activities/hobbies; and overall causing less anxiety in return for some. Participants noted increased time for rest or repose, wellness, learning new skills, having new goals and overall learning to be self-sufficient as life slowed down for some participants to a certain degree. These positive impacts are captured by a parent who stated that the pandemic:

Slowed life down significantly, more parent time, less school/homework stress.

Participants not only spoke about how life slowed down, but some also highlighted how some amount of stress was eliminated which enabled them to enjoy life again, contributing to a positive impact to their mental health. Some became more self-sufficient and more independent with one individual in the self-report stating, 'Learned to do things myself due to service closure'. Another participant noted how the pandemic enabled them to 'cooking more, going to the park more, spending more time with family, finding more ways of keeping busy, restarting my photography hobby, reading, appreciating ability to socialize'. Other activities included enjoying daily activities outside of their home whether it was running, picking up a new sport, or being more physically active outdoors. Despite the challenges, the pandemic also provided an opportunity for rest and repose and a more paced lifestyle for their mental wellbeing, which otherwise likely would not have happened. The greatest positive impacts of the pandemic reported qualitatively by participants occurred during the initial onset of the pandemic. However, at follow-up periods, the positive impacts initially reported were not reported further by participants.

While positive impacts were initially reported, mental wellness deteriorated as the pandemic endured. At follow-up, the impacts were wide-ranging from reduced work hours, rising financial debts, difficulty finding work, continued loneliness, difficulty

with engaging with activities of daily living, a sense of hopelessness, decrease in feelings of resilience, to impacts of isolation post-pandemic. Changes in mood were also reported, where participants reported feeling unhappy, increased interpersonal conflicts, and increases in mental health concerns of children, reported by parents. The follow-up responses demonstrated the debilitating long-term impacts of the pandemic, and are exemplified in this self-report response:

It has had a severe impact on my finances, and I lost all my savings. I am now in serious debt and had to take out a line of credit to afford food for my child. We were unable to see our only family members (2) and one of them passed away during this time. My boss threatens to fire me regularly as I am 'distracted' by distance educating my child who is also autistic. I have lost access to important medical appointments as I am unable to get there. I feel like life is in major crisis and I have no supports.

3.4 | Quantitative Outliers' Qualitative Experiences

In the combined-caregiver report, four unique outlier responses were identified in the NPC group, specifically corresponding to the Hopefulness domain. The main theme voiced in this subset of comments was increasing concern about the reduction in services offered to autistic individuals, and the extreme levels of stress this was placing on families, especially those that also experienced work-related disruptions due to the pandemic.

In the self-report, nine unique outliers were identified in the NPC group, corresponding to the Substance Use, Hopefulness and State of Crisis domains. In the outliers of the Substance Use domain, individuals voiced worries both about the uncertainty of the economy and state of the world, and anxiety provoked by the disruptions to their daily routines. Outliers in the Hopefulness domain spoke of the loss of social gatherings, the challenges of not staying connected and voiced fears about losing progress made in social interactions and relationships as a result of the lockdown. Outliers in the State of Crisis domain spoke about the compounded effect of service closures, changes in work environment, family stressors and managing their own mental health as a result of the pandemic.

TABLE 5 | Univariate ANOVA for the combined-caregiver ($n = 64$) and self-report ($n = 54$) survey domains (those included in the MANOVA).

	Domains	Mean	Standard deviation	F (df)	F statistic	p	Partial eta squared
Combined-caregiver survey	<i>Restricted and repetitive behaviours and interests</i>						
	NPC ($n = 41$)	19.29	5.14	1, 62	3.402	0.070	0.052
	PC ($n = 23$)	16.74	5.62				
	<i>Problem behaviours</i>						
	NPC ($n = 41$)	22.39	10.81	1, 62	3.174	0.080	0.049
	PC ($n = 23$)	18.04	5.89				
	<i>Adaptive function</i>						
	NPC ($n = 41$)	9.39	3.38	1, 62	5.447	0.023	0.081
	PC ($n = 23$)	7.52	2.43				
	<i>Daily behaviours and media</i>						
	NPC ($n = 41$)	24.66	6.08	1, 62	1.866	0.177	0.029
	PC ($n = 23$)	22.57	5.48				
	<i>Stress due to COVID-19</i>						
	NPC ($n = 41$)	13.00	4.93	1, 62	0.816	0.370	0.013
PC ($n = 23$)	11.96	3.47					
Self-report survey	<i>Pre-pandemic health</i>						
	NPC ($n = 24$)	6.33	1.81	1, 52	0.055	0.816	0.001
	PC ($n = 30$)	6.43	1.33				
	<i>Restricted and repetitive behaviours and interests</i>						
	NPC ($n = 24$)	17.04	5.74	1, 52	0.135	0.715	0.003
	PC ($n = 30$)	17.57	4.77				
	<i>Emotions and worries</i>						
	NPC ($n = 24$)	34.04	7.09	1, 52	5.292	0.025	0.092
	PC ($n = 30$)	29.63	6.93				
	<i>Daily behaviours and media</i>						
	NPC ($n = 24$)	23.42	3.98	1, 52	1.629	0.207	0.030
	PC ($n = 30$)	21.97	4.28				
	<i>Social support</i>						
	NPC ($n = 24$)	3.13	1.08	1, 52	0.411	0.524	0.008
PC ($n = 30$)	3.33	1.27					
<i>Relationship changes</i>							
NPC ($n = 24$)	10.13	2.05	1, 52	0.150	0.700	0.003	
PC ($n = 30$)	9.90	2.17					
<i>Stress due to COVID-19</i>							
NPC ($n = 24$)	18.46	6.78	1, 52	0.001	0.975	0.000	
PC ($n = 30$)	18.40	6.56					

Note: Bold indicates significance values ($p < 0.05$).

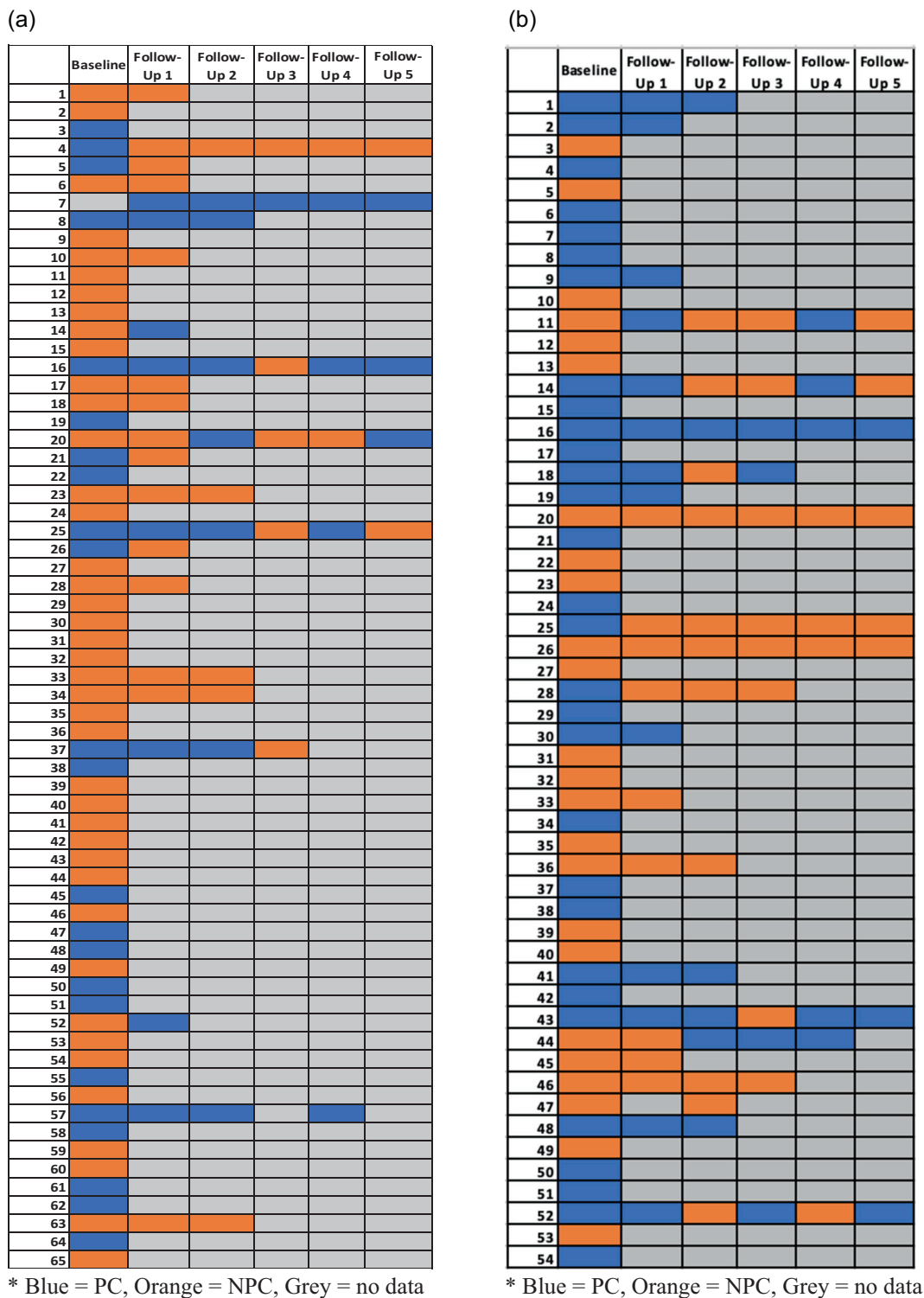


FIGURE 2 | (a) Follow-up heat map reflecting NPC/PC group membership shifts for the combined-caregiver sample. (b) Follow-up heat map reflecting NPC/PC group membership shifts for the self-report sample. The participant in row #7 was included in the follow-up qualitative synthesis, but not in baseline analyses due to incomplete baseline data.

4 | Discussion

Findings from this partially longitudinal online survey from July 2020 (4 months into the pandemic) to September 2021 (the first period of larger-scale opening-up after a lengthy lockdown in Ontario) with individuals with developmental disabilities in

Ontario showed a wide variety of responses to the pandemic, with both positive and negative impacts. Major themes of pandemic impacts included uncertainty and influence on behaviours and routines, changes to supports and influence on daily life, and influence on mental wellness. Those experiencing positive impacts, however, did not stably perceive so over time

during this 1-year period (based on the limited follow-up survey data). This implies that pandemic impacts might vary with time and context, and responsive support should recognise the changing nature of these impacts in different individuals and families.

At baseline, significant group differences in self-report were found for the Emotions and Worries, Substance Use and State of Crisis domains. The greater worries and negative emotions in the NPC than the PC groups might reflect the substantial emotional repercussions that echoed the adults' negative outlook of the pandemic. More substance use in the PC group at baseline might reflect the presence of outliers; however, it could also suggest substance-use coping strategies being used by some adults with developmental disabilities (Weir, Allison, and Baron-Cohen 2021) to handle the disruptions caused by the pandemic. This aligns with findings from general population and adult disability samples in Canadian and US adults, which report increased alcohol and substance use during the pandemic (MacMillan et al. 2022; Okoro et al. 2021) and especially in adults with disabilities (Avena et al. 2021; Czeisler et al. 2021; Lindsay, Ahmed, and Apostolopoulos 2021). For instance, the US Centre for Disease Control and Prevention reported the prevalence of substance use to cope with stress or emotions among US adults with disabilities to be higher than that of adults without disabilities (40% vs. 24.5%, $p < 0.001$) during February to March 2021, which was the second wave of the pandemic (Czeisler et al. 2021). Using negative coping strategies may mask stress for short periods of time, leading to a sense of PCs, but can overall lead to more dysfunctional results in the long term (Avena et al. 2021). This point is evident in our follow-up quantitative and qualitative findings, which suggest that NPC/PC group membership is not stable over time, such that those that experience PCs at baseline may not find PCs at later time points.

Furthermore, elevated scores for the State of Crisis domain in the NPC group of the self-report sample at baseline might reflect the presence of outliers and/or that a proportion of our sample for whom the pandemic has been extremely disruptive. Correspondingly, in the combined-caregiver sample, caregivers of the NPC group reported poorer adaptive functioning of their family members with developmental disabilities than those of the PC group. Several studies have demonstrated heterogeneous trajectories of coping and functioning among people with disabilities during the pandemic (Cost et al. 2022; Fisher et al. 2022; Gignac et al. 2021; Lindsay, Ahmed, and Apostolopoulos 2021; Maljaars et al. 2023; Nikolaidis et al. 2022; Oomen, Nijhof, and Wiersema 2021; Rose et al. 2022; Sonesson et al. 2023), based on social (Fisher et al. 2022) and financial support (Gignac et al. 2021), the extent of the disruption to daily routines (Maljaars et al. 2023), psychosocial factors (Oomen, Nijhof, and Wiersema 2021) and caregiver burden and resilience (Lake et al. 2021; Rose et al. 2022). In our follow-up analyses, it appears that the NPC or PC group designations were not sensitive enough to capture the nuances of the experiences of adults with developmental disabilities and their families over the course of the pandemic, as these groups were not stable over time. However, the qualitative analyses were able to provide more in-depth and nuanced information about the distinct experiences of the sample.

The qualitative findings highlighted that the prolonged nature of the pandemic had wide-ranging impacts. They were described to be both positive and negative, and the negative impacts were very pronounced with significant and abrupt changes in daily routines, employment and level of supports available for individuals with developmental disabilities and caregivers. The negative impacts described in our study are consistent with other research where worsening behavioural and emotional problems (Mutluer, Doenyas, and Aslan Genc 2020), symptom severity (Bhat 2021) and sleep disruptions (Colizzi et al. 2020) have been noted throughout the pandemic, which predominantly has been noted among children and youth with developmental disabilities. This study adds to the knowledge base regarding the impacts of the pandemic on youth and adults with developmental disabilities as data with adults heretofore are underrepresented in the literature. While reasons for these negative impacts are manifold, our qualitative findings demonstrate how the abrupt changes to social and professional supports, elimination of in-person supports, along with ever-changing, confusing and inconsistent government communication about health information are significant contributors. Negative impacts in turn are described to be detrimental to overall wellbeing, in the short-term and persist long-term for some people. While some positive impacts were noted, they were short-term, and diminished over time as the pandemic persisted. Findings from this study suggest a need for improved emergency preparedness planning which considers the long-term impacts of a pandemic on, factors in the needs of, and attempts to mitigate the health disparities experienced by caregivers and individuals with developmental disabilities. For example, ensuring flexible service access (e.g., service provided in-person at home or in different community settings, virtual service delivered synchronously or asynchronously) using the principles of Universal Design (Smith and Lowrey 2017) as a standard and universal way for service delivery during normal times will reduce the risk of service loss during public health crises; ensuring clear, legible, consistent and predictable public health and service communication will reduce the level of uncertainty and associated distress.

Given the impacts of the pandemic described in this study, we advocate for the importance of considering the diverse needs, programmes and services for individuals (especially adults) with developmental disabilities and their caregivers when preparing and instituting public health measures. Potentially different stakeholder perspectives (e.g., there were proportionally more caregivers categorised in the NPC group than for the self-reporting adults) also highlight the importance of a multiperspectival approach. As part of emergency preparedness planning, structural and policy changes which seek to address systemic barriers are needed to achieve long-term health equity. With research by our team and others highlighting that individuals with developmental disabilities are at risk of premature mortality (Lunsky, Lai, et al., 2022) and are more likely to die if they contract COVID-19 (Landes, Turk, and Ervin 2021; Lunsky, Durbin, et al., 2022), the need for health equity in this group is ever more important. To mitigate the negative impacts of the pandemic and future global emergencies (Thompson et al. 2024), we highlight the need to address the social determinants of health for individuals with developmental disabilities and their families (Anderson et al. 2013), which include, but are not limited to, economic resources, education, housing

and health and social service access (Braveman, Egerter, and Williams 2011). Addressing social determinants not only has the potential to reduce the impact of infectious diseases among marginalised groups (Butler-Jones and Wong 2016), but also contribute to reducing mortality and morbidity (Abrams and Szefer 2020) and improving health outcomes (Federico et al. 2020). This is especially important as a pandemic recovery effort to support individuals with developmental disabilities in both the short-term and long-term future.

To maximise wellbeing, we note the importance of maintaining in-person services and programmes where safe and possible to do so. Our findings also highlight the importance of communicating clear, timely and concise health information by the authorities as the frequent and poor communication of public health measures from multiple sources (federal, provincial and municipal health bodies) negatively impacted wellbeing. To this end, we suggest that governments and public health organisations liaise with the developmental disabilities community to communicate health information in a clear and timely manner. The use of blogs such as the Health Care Access Research and Developmental Disabilities COVID-19 Blog [<https://www.hcardcovid.com/info>] in Ontario, Canada is one example of adapting health related information about the COVID-19 pandemic (Lake et al. 2022; Maguire et al. 2022; St. John et al. 2022).

4.1 | Study Limitations and Future Directions

There are important limitations with this study. First, the relatively small sample size, especially by the end of the follow-up period, restricted the scope of analyses (e.g., longitudinal quantitative analyses) and precision of the conclusions we were able to draw. Nevertheless, we were able to draw from the follow-up data for qualitative analyses that offer some longitudinal insights. Second, the low follow-up retention rate might have been affected by pandemic burden, which could further result in selection biases that underrepresented negative impacts. Third, due to the online nature of the survey and the study period (i.e., during the initial 1+ years of the pandemic), it was not possible to verify the developmental disability diagnoses of some participants (whose diagnoses were not verified in previous research participation), to control for the effects of response bias on the findings, or to ask many open-ended questions to gain more precise information from participants. Future studies could combine this data with other samples using the same open-access CRISIS-AFAR survey or similar instruments for validation, comparison or data integration. Despite these limitations, this study provided insights into the impacts of the COVID-19 pandemic among youth and adults with developmental disabilities, which heretofore have been underrepresented in the literature. This work seeks to improve emergency preparedness to maintain and protect the wellbeing and enhance resilience of the developmental disability population and their families (Ameis, Lai, Mulsant, & Szatmari, 2020).

Author Contributions

All authors contributed to the study conception and design. Material preparation, data collection and data analyses were performed by

Caroline Kasse, Patrick Jachyra, Vijitha Mahalingam and Meng-Chuan Lai. Funding support is acquired by Meng-Chuan Lai. The first draft was written by Caroline Kasse and Patrick Jachyra. All authors participated in the revision of the manuscript. All authors read and approved the final manuscript.

Acknowledgements

We thank all the participants for participating in this study. We thank the CRISIS AFAR International Collaborative Study team for assistance in the creation and implementation of the CRISIS-AFAR survey versions used in this study: Bethany Vibert, Patricia Segura, Louise Gallagher, Stelios Georgiades, Panagiota Pervanidou, Audrey Thurm, Lindsay Alexander, Evdokia Anagnostou, Yuta Aoki, Catherine S. N. Birken, Somer L. Bishop, Jessica Boi, Carmela Bravaccio, Helena Brentani, Paola Canevini, Alessandra Carta, Alice Charach, Antonella Costantino, Katherine T. Cost, Elaine Andrade Cravo, Jennifer Crosbie, Chiara Davico, Alessandra Gabellone, Federica Donno, Junya Fujino, Cristiane Tezzari Geyer, Tomoya Hirota, Stephen Kanne, Makiko Kawashima, Elizabeth Kelley, Hosanna Kim, Young Shin Kim, So Hyun (Sophy) Kim, Daphne J. Korczak, Meng-Chuan Lai, Lucia Margari, Gabriele Masi, Lucia Marzulli, Luigi Mazzone, Jane McGrath, Suneeta Monga, Paola Morosini, Shinichiro Nakajima, Antonio Narzisi, Rob Nicolson, Aki Nikolaidis, Yoshihiro Noda, Kerri Nowell, Miriam Polizzi, Joana Portolese, Maria Pia Riccio, Manabu Saito, Anish K. Simhal, Martina Siracusano, Stefano Sotgiu, Jacob Stroud, Fernando Sumiya, Ida Schwartz, Yoshiyuki Tachibana, Nicole Takahashi, Riina Takahashi, Hiroki Tamon, Raffaella Tancredi, Benedetto Vitiello, Alessandro Zuddas, Bennett Leventhal, Kathleen Merikangas, Michael P. Milham, Adriana Di Martino.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

References

- Abrams, E. M., and S. J. Szefer. 2020. "COVID-19 and the Impact of Social Determinants of Health." *Lancet Respiratory Medicine* 8, no. 7: 659–661. [https://doi.org/10.1016/S2213-2600\(20\)30234-4](https://doi.org/10.1016/S2213-2600(20)30234-4).
- Adams, R. E., S. Zheng, J. L. Taylor, and S. L. Bishop. 2021. "Ten Weeks In: COVID-19-Related Distress in Adults With Autism Spectrum Disorder." *Autism: The International Journal of Research and Practice* 25, no. 7: 2140–2145. <https://doi.org/10.1177/13623613211005919>.
- Ameis, S. H., D. M. Blumberger, P. E. Croarkin, et al. 2020a. "Treatment of Executive Function Deficits in Autism Spectrum Disorder With Repetitive Transcranial Magnetic Stimulation: A Double-Blind, Sham-Controlled, Pilot Trial." *Brain Stimulation* 13, no. 3: 539–547. <https://doi.org/10.1016/j.brs.2020.01.007>.
- Ameis, S. H., M.-C. Lai, B. H. Mulsant, and P. Szatmari. 2020b. "Coping, Fostering Resilience, and Driving Care Innovation for Autistic People and Their Families During the COVID-19 Pandemic and Beyond." *Molecular Autism* 11: 1–9. <https://doi.org/10.1186/s13229-020-00365-y>.
- Anderson, L. L., K. Humphries, S. McDermott, B. Marks, J. Sisirak, and S. Larson. 2013. "The State of the Science of Health and Wellness for Adults With Intellectual and Developmental Disabilities." *Intellectual and Developmental Disabilities* 51, no. 5: 385–398. <https://doi.org/10.1352/1934-9556-51.5.385>.
- Avena, N. M., J. Simkus, A. Lewandowski, M. S. Gold, and M. N. Potenza. 2021. "Substance Use Disorders and Behavioral Addictions During the COVID-19 Pandemic and COVID-19-Related Restrictions." *Frontiers in Psychiatry* 12: 653674. <https://doi.org/10.3389/fpsy.2021.653674>.

- Bhat, A. 2021. "Analysis of the SPARK Study COVID-19 Parent Survey: Early Impact of the Pandemic on Access to Services, Child/Parent Mental Health, and Benefits of Online Services." *Autism Research* 14, no. 11: 2454–2470. <https://doi.org/10.1002/aur.2618>.
- Braun, V., and V. Clarke. 2006. "Using Thematic Analysis in Psychology." *Qualitative Research in Psychology* 3, no. 2: 77–101. <https://doi.org/10.1191/1478088706qp063oa>.
- Braveman, P., S. Egerter, and D. R. Williams. 2011. "The Social Determinants of Health: Coming of Age." *Annual Review of Public Health* 32, no. 1: 381–398. <https://doi.org/10.1146/annurev-publhealth-031210-101218>.
- Bruining, H., M. Bartels, T. J. C. Polderman, and A. Popma. 2021. "COVID-19 and Child and Adolescent Psychiatry: An Unexpected Blessing for Part of Our Population?" *European Child & Adolescent Psychiatry* 30, no. 7: 1139–1140. <https://doi.org/10.1007/s00787-020-01578-5>.
- Bundy, R., W. Mandy, L. Crane, et al. 2022. "The Impact of Early Stages of COVID-19 on the Mental Health of Autistic Adults in the United Kingdom: A Longitudinal Mixed-Methods Study." *Autism* 26, no. 7: 1765–1782.
- Butler-Jones, D., and T. Wong. 2016. "Social Determinants of Health: Infectious Disease, Social Determinants and the Need for Intersectoral Action." *Canada Communicable Disease Report* 42, no. S1: S1–S18. <https://doi.org/10.14745/ccdr.v42i1s1a04>.
- Cai, D., M. Zhu, M. Lin, X. C. Zhang, and J. Margraf. 2017. "The Bidirectional Relationship Between Positive Mental Health and Social Rhythm in College Students: A Three-Year Longitudinal Study." *Frontiers in Psychology* 8: 1119. <https://doi.org/10.3389/fpsyg.2017.01119>.
- Campos, C., M. Duck, R. McQuillan, et al. 2019. "Exploring the Role of Physiotherapists in the Care of Children With Autism Spectrum Disorder." *Physical & Occupational Therapy in Pediatrics* 39, no. 6: 614–628. <https://doi.org/10.1080/01942638.2019.1585405>.
- Colizzi, M., E. Sironi, F. Antonini, M. L. Ciceri, C. Bovo, and L. Zocante. 2020. "Psychosocial and Behavioral Impact of COVID-19 in Autism Spectrum Disorder: An Online Parent Survey." *Brain Sciences* 10, no. 6: E341. <https://doi.org/10.3390/brainsci10060341>.
- Cost, K. T., J. Crosbie, E. Anagnostou, et al. 2022. "Mostly Worse, Occasionally Better: Impact of COVID-19 Pandemic on the Mental Health of Canadian Children and Adolescents." *European Child & Adolescent Psychiatry* 31, no. 4: 671–684. <https://doi.org/10.1007/s00787-021-01744-3>.
- Cree, R. A., C. A. Okoro, M. M. Zack, and E. Carbone. 2020. "Frequent Mental Distress Among Adults, by Disability Status, Disability Type, and Selected Characteristics—United States, 2018." *MMWR. Morbidity and Mortality Weekly Report* 69, no. 36: 1238–1243. <https://doi.org/10.15585/mmwr.mm6936a2>.
- Czeisler, M. É., A. Board, J. M. Thierry, et al. 2021. "Mental Health and Substance Use Among Adults With Disabilities During the COVID-19 Pandemic—United States, February–March 2021." *MMWR. Morbidity and Mortality Weekly Report* 70, no. 34: 1142–1149. <https://doi.org/10.15585/mmwr.mm7034a3>.
- Desarkar, P., T. K. Rajji, S. H. Ameis, et al. 2022. "Assessing and Stabilizing Atypical Plasticity in Autism Spectrum Disorder Using rTMS: Results From a Proof-of-Principle Study." *Clinical Neurophysiology* 141: 109–118. <https://doi.org/10.1016/j.clinph.2021.03.046>.
- Dvorsky, M. R., R. Breaux, and S. P. Becker. 2021. "Finding Ordinary Magic in Extraordinary Times: Child and Adolescent Resilience During the COVID-19 Pandemic." *European Child & Adolescent Psychiatry* 30, no. 11: 1829–1831. <https://doi.org/10.1007/s00787-020-01583-8>.
- Emerson, E., R. Stancliffe, C. Hatton, et al. 2021. "The Impact of Disability on Employment and Financial Security Following the Outbreak of the 2020 COVID-19 Pandemic in the UK." *Journal of Public Health (Oxford, England)* 43, no. 3: 472–478. <https://doi.org/10.1093/pubmed/fdaa270>.
- Federico, M. J., A. E. McFarlane II, S. J. Szeffler, and E. M. Abrams. 2020. "The Impact of Social Determinants of Health on Children With Asthma." *Journal of Allergy and Clinical Immunology* 8, no. 6: 1808–1814. <https://doi.org/10.1016/j.jaip.2020.03.028>.
- Fisher, M. H., C. Sung, R. R. Kammes, C. Okyere, and J. Park. 2022. "Social Support as a Mediator of Stress and Life Satisfaction for People With Intellectual or Developmental Disabilities During the COVID-19 Pandemic." *Journal of Applied Research in Intellectual Disabilities* 35, no. 1: 243–251. <https://doi.org/10.1111/jar.12943>.
- Flynn, S., and C. Hatton. 2021. "Health and Social Care Access for Adults With Learning Disabilities Across the UK During the COVID-19 Pandemic in 2020." *Tizard Learning Disability Review* 26, no. 3: 174–179. <https://doi.org/10.1108/TLDR-06-2021-0014>.
- Gignac, M. A. M., F. V. Shahidi, A. Jetha, et al. 2021. "Impacts of the COVID-19 Pandemic on Health, Financial Worries, and Perceived Organizational Support Among People Living With Disabilities in Canada." *Disability and Health Journal* 14, no. 4: 101161. <https://doi.org/10.1016/j.dhjo.2021.101161>.
- Goldfarb, Y., E. Gal, and O. Golan. 2021. "Implications of Employment Changes Caused by COVID-19 on Mental Health and Work-Related Psychological Need Satisfaction of Autistic Employees: A Mixed-Methods Longitudinal Study." *Journal of Autism and Developmental Disorders* 52: 89–102. <https://doi.org/10.1007/s10803-021-04902-3>.
- Government of Ontario. 2021. "Emergency Information: Provincial Status on COVID-19." <https://www.ontario.ca/page/emergency-information>.
- Hatton, C., R. P. Hastings, S. Caton, et al. 2024. "Health and Healthcare of People With Learning Disabilities in the United Kingdom Through the COVID-19 Pandemic." *British Journal of Learning Disabilities* 52, no. 2: 260–271. <https://doi.org/10.1111/bld.12578>.
- Hedley, D., S. M. Hayward, K. Denney, et al. 2021. "The Association Between COVID-19, Personal Wellbeing, Depression, and Suicide Risk Factors in Australian Autistic Adults." *Autism Research* 14, no. 12: 2663–2676. <https://doi.org/10.1002/aur.2614>.
- Jachyra, P., R. Renwick, B. Gladstone, E. Anagnostou, and B. E. Gibson. 2021. "Physical Activity Participation Among Adolescents With Autism Spectrum Disorder." *Autism* 25, no. 3: 613–626. <https://doi.org/10.1177/136236132094934>.
- Lake, J. K., P. Jachyra, T. Volpe, et al. 2021. "The Wellbeing and Mental Health Care Experiences of Adults With Intellectual and Developmental Disabilities During COVID-19." *Journal of Mental Health Research in Intellectual Disabilities* 14, no. 3: 285–300. <https://doi.org/10.1080/19315864.2021.1892890>.
- Lake, J. K., T. Volpe, L. St. John, et al. 2022. "Mental Health and COVID-19: The Impact of a Virtual Course for Family Caregivers of Adults With Intellectual and Developmental Disabilities." *Journal of Intellectual Disability Research* 66, no. 8–9: 677–689. <https://doi.org/10.1111/jir.12965>.
- Landes, S. D., M. A. Turk, and D. A. Ervin. 2021. "COVID-19 Case-Fatality Disparities Among People With Intellectual and Developmental Disabilities: Evidence From 12 US Jurisdictions." *Disability and Health Journal* 14, no. 4: 101116. <https://doi.org/10.1016/j.dhjo.2021.101116>.
- Levante, A., S. Petrocchi, F. Bianco, et al. 2021. "Psychological Impact of COVID-19 Outbreak on Families of Children With Autism Spectrum Disorder and Typically Developing Peers: An Online Survey." *Brain Sciences* 11, no. 6: 808. <https://doi.org/10.3390/brainsci11060808>.
- Lillie, E., B. E. Alvarado, and H. Stuart. 2013. "Unemployment Among Canadians With Physical and a Co-Morbid Mental Disability: An Examination of the 2006 Participation and Activity Limitation Survey (PALS)." *Disability and Health Journal* 6, no. 4: 352–360. <https://doi.org/10.1016/j.dhjo.2013.03.001>.
- Lindsay, S., H. Ahmed, and D. Apostolopoulos. 2021. "Facilitators for Coping With the COVID-19 Pandemic: Online Qualitative Interviews

- Comparing Youth With and Without Disabilities.” *Disability and Health Journal* 14, no. 4: 101113. <https://doi.org/10.1016/j.dhjo.2021.101113>.
- Lunsky, Y., C. Albaum, A. Baskin, et al. 2021. “Group Virtual Mindfulness-Based Intervention for Parents of Autistic Adolescents and Adults.” *Journal of Autism and Developmental Disorders* 51, no. 11: 3959–3969. <https://doi.org/10.1007/s10803-020-04835-3>.
- Lunsky, Y., A. Durbin, R. Balogh, E. Lin, L. Palma, and L. Plumtre. 2022a. “COVID-19 Positivity Rates, Hospitalizations and Mortality of Adults With and Without Intellectual and Developmental Disabilities in Ontario, Canada.” *Disability and Health Journal* 15, no. 1: 101174. <https://doi.org/10.1016/j.dhjo.2021.101174>.
- Lunsky, Y., M.-C. Lai, R. Balogh, et al. 2022b. “Premature Mortality in a Population-Based Cohort of Autistic Adults in Canada.” *Autism Research* 15, no. 8: 1550–1559. <https://doi.org/10.1002/aur.2741>.
- Lunsky, Y., A. Tint, J. A. Weiss, A. Palucka, and E. Bradley. 2018. “A Review of Emergency Department Visits Made by Youth and Adults With Autism Spectrum Disorder From the Parent Perspective.” *Advances in Autism* 4, no. 1: 10–18. <https://doi.org/10.1108/AIA-08-2017-0019>.
- MacMillan, T., M. J. Corrigan, K. Coffey, C. D. Tronnier, D. Wang, and K. Krase. 2022. “Exploring Factors Associated With Alcohol and/or Substance Use During the COVID-19 Pandemic.” *International Journal of Mental Health and Addiction* 20, no. 3: 1814–1823. <https://doi.org/10.1007/s11469-020-00482-y>.
- Maguire, R., C. Pert, S. Baines, et al. 2022. “Adapted Guided Self-Help Booklets for Supporting the Well-Being of People With Intellectual Disabilities During the COVID-19 Pandemic: An Evaluation of Impact.” *Tizard Learning Disability Review* 27, no. 1: 17–25. <https://doi.org/10.1108/TLDR-08-2021-0024>.
- Maljaars, J., E. Gijbels, K. Evers, et al. 2023. “Impact of the COVID-19 Pandemic on Daily Life: Diverse Experiences for Autistic Adults.” *Journal of Autism and Developmental Disorders* 53, no. 1: 319–331. <https://doi.org/10.1007/s10803-022-05437-x>.
- Margraf, J., K. Lavallee, X. Zhang, and S. Schneider. 2016. “Social Rhythm and Mental Health: A Cross-Cultural Comparison.” *PLoS One* 11, no. 3: e0150312. <https://doi.org/10.1371/journal.pone.0150312>.
- Mutluer, T., C. Doenyas, and H. Aslan Genc. 2020. “Behavioral Implications of the Covid-19 Process for Autism Spectrum Disorder, and Individuals’ Comprehension of and Reactions to the Pandemic Conditions.” *Frontiers in Psychiatry* 11: 561882. <https://doi.org/10.3389/fpsy.2020.561882>.
- Nikolaïdis, A., J. DeRosa, M. Kass, et al. 2022. “Heterogeneity in COVID-19 Pandemic-Induced Lifestyle Stressors Predicts Future Mental Health in Adults and Children in the US and UK.” *Journal of Psychiatric Research* 147: 291–300. <https://doi.org/10.1016/j.jpsy.2021.12.058>.
- Nikolaïdis, A., D. Paksarian, L. Alexander, et al. 2021. “The Coronavirus Health and Impact Survey (CRISIS) Reveals Reproducible Correlates of Pandemic-Related Mood States Across the Atlantic.” *Scientific Reports* 11, no. 1: 8139. <https://doi.org/10.1038/s41598-021-87270-3>.
- Okoro, C. A., T. W. Strine, L. McKnight-Eily, J. Verlenden, and N. D. Hollis. 2021. “Indicators of Poor Mental Health and Stressors During the COVID-19 Pandemic, by Disability Status: A Cross-Sectional Analysis.” *Disability and Health Journal* 14, no. 4: 101110. <https://doi.org/10.1016/j.dhjo.2021.101110>.
- Oomen, D., A. D. Nijhof, and J. R. Wiersma. 2021. “The Psychological Impact of the COVID-19 Pandemic on Adults With Autism: A Survey Study Across Three Countries.” *Molecular Autism* 12, no. 1: 21. <https://doi.org/10.1186/s13229-021-00424-y>.
- Pettinicchio, D., M. Maroto, L. Chai, and M. Lukk. 2021. “Findings From an Online Survey on the Mental Health Effects of COVID-19 on Canadians With Disabilities and Chronic Health Conditions.” *Disability and Health Journal* 14, no. 3: 101085. <https://doi.org/10.1016/j.dhjo.2021.101085>.
- Repke, M. A., and C. Ipsen. 2020. “Differences in Social Connectedness and Perceived Isolation Among Rural and Urban Adults With Disabilities.” *Disability and Health Journal* 13, no. 1: 100829. <https://doi.org/10.1016/j.dhjo.2019.100829>.
- Rose, J., P. Willner, V. Cooper, P. E. Langdon, G. H. Murphy, and B. Stenfert Kroese. 2022. “The Effect on and Experience of Families With a Member Who has Intellectual and Developmental Disabilities of the COVID-19 Pandemic in the UK: Developing an Investigation.” *International Journal of Developmental Disabilities* 68, no. 2: 234–236. <https://doi.org/10.1080/20473869.2020.1764257>.
- Safar, Y., F. Formuli, T. Volpe, L. St John, and Y. Lunsky. 2024. ““Everything has Changed Since COVID”: Ongoing Challenges Faced by Canadian Adults With Intellectual Disabilities During Waves 2 and 3 of the COVID-19 Pandemic.” *Journal of Intellectual Disabilities*: 17446295241229364. Epub ahead of print. <https://doi.org/10.1177/17446295241229364>.
- Scheeren, A. M., P. Howlin, L. Pellicano, I. Magiati, and S. Begeer. 2022. “Continuity and Change in Loneliness and Stress During the COVID-19 Pandemic: A Longitudinal Study of Autistic and Non-autistic Adults.” *Autism Research* 15, no. 9: 1621–1635. <https://doi.org/10.1002/aur.2787>.
- Smith, S. J., and K. A. Lowrey. 2017. “Applying the Universal Design for Learning Framework for Individuals With Intellectual Disability: The Future Must Be Now.” *Intellectual and Developmental Disabilities* 55, no. 1: 48–51. <https://doi.org/10.1352/1934-9556-55.1.48>.
- Soneson, E., S. Puntis, N. Chapman, K. L. Mansfield, P. B. Jones, and M. Fazel. 2023. “Happier During Lockdown: A Descriptive Analysis of Self-Reported Wellbeing in 17,000 UK School Students During Covid-19 Lockdown.” *European Child & Adolescent Psychiatry* 32, no. 6: 1131–1146. <https://doi.org/10.1007/s00787-021-01934-z>.
- St. John, L., T. Volpe, M. I. Jiwa, et al. 2022. ““More Together Than Apart”: The Evaluation of a Virtual Course to Improve Mental Health and Well-Being of Adults With Intellectual Disabilities During the COVID-19 Pandemic.” *Journal of Applied Research in Intellectual Disabilities* 35, no. 6: 1360–1369. <https://doi.org/10.1111/jar.13024>.
- Tarzi, G., O. Mendoza, Y. Lunsky, and L. S. John. 2023. “The Experiences and Attitudes of Family Caregivers of Adults With Intellectual and Developmental Disabilities Throughout the COVID-19 Pandemic.” *Disability and Health Journal* 16, no. 3: 101472. <https://doi.org/10.1016/j.dhjo.2023.101472>.
- Thompson, N., K. Kyaw, L. Singh, J. Cikomola, N. Singh, and B. Roberts. 2024. “The Effect of COVID-19 on the Non-COVID Health Outcomes of Crisis-Affected Peoples: A Systematic Review.” *Conflict and Health* 18, no. 1: 37. <https://doi.org/10.1186/s13031-024-00592-7>.
- Vibert, B., P. Segura, L. Gallagher, et al. 2023. “CRISIS AFAR: An International Collaborative Study of the Impact of the COVID-19 Pandemic on Mental Health and Service Access in Youth With Autism and Neurodevelopmental Conditions.” *Molecular Autism* 14, no. 1: 7. <https://doi.org/10.1186/s13229-022-00536-z>.
- Weir, E., C. Allison, and S. Baron-Cohen. 2021. “Understanding the Substance Use of Autistic Adolescents and Adults: A Mixed-Methods Approach.” *Lancet Psychiatry* 8, no. 8: 673–685. [https://doi.org/10.1016/S2215-0366\(21\)00160-7](https://doi.org/10.1016/S2215-0366(21)00160-7).
- Wolicki, S. B., R. H. Bitsko, R. A. Cree, et al. 2021. “Mental Health of Parents and Primary Caregivers by Sex and Associated Child Health Indicators.” *Adversity and Resilience Science* 2, no. 2: 125–139. <https://doi.org/10.1007/s42844-021-00037-7>.

Supporting Information

Additional supporting information can be found online in the Supporting Information section.