

COVID19 and the “New Normal”

Introduction

COVID19 has forced the world to change the way we live, particularly balancing working remotely and home life. These changes to our lives have impacted us all in different ways. It is important to consider how the pandemic has impacted the neurodiverse community and what we can learn from this. Below are a number of surveys, articles and personal anecdotes from the Neurodiverse community discussing how COVID19 has changed daily life. This curation of resources discusses three themes related to Neurodiversity and COVID19: Mental Health, Workplace and Education.

COVID19, Autism and Mental Health

Key Insights from Autistica / DARE (United Kingdom)

Autistica / DARE are currently developing a report from recent studies regarding mental health and how it has been impacted by COVID19. The key findings from the study describe the difference in mental health and wellbeing pre-COVID19 and during COVID19.

Early key findings:

- There have been significant reductions in the quality of life pre-COVID19 vs during COVID19 in terms of workplace productivity and leisure.
- Out of the 73 autistic participants in the study, the average score highlighted was “severe” stress during COVID19. Depression and Anxiety levels were on the threshold of the “severe” category.
- 36% of autistic participants experienced severe to extreme depression
- 49% of participants experienced severe to extreme anxiety
- The study reports that participants felt there has been poor guidance from the workplace on COVID19, which could be a cause of stress.
- Issues of ableism in the workplace, causing stress

Autistica and currently working on the final report.

Survey by Ghent University

A survey conducted by Ghent University investigated how the pandemic impacted the mental health and daily lives of autistic adults. The survey found that across the two groups (neurotypical and neurodivergent), there was a reported three-quarters of participants that experienced an increase in depression and anxiety symptoms in response to the pandemic.

The survey found that Autistic adults reported to worry more about particular topics (e.g. pets, access to medication, groceries, following medical health guidelines in response to COVID19).

Main findings found through the survey:

- Stress around grocery shopping
- Loss of daily routine
- Impact of lack of social contact
- Higher levels of anxiety and stress

Find more information about the survey here:

<https://www.ugent.be/en/news-events/impactofcovidonautisticadults.htm>

SPARK Survey

SPARK is a national online autism research network that provides support and research for those with autism and their families. Dr. Wendy Chung, the principle investigator of the Spark study, conducted and distributed a survey on how Coronavirus had affected families with autistic members.

The results show the strategies families have developed to navigate education, therapies and daily routine and those who are struggling to handle the uncertainty of the pandemic.

Findings from the survey:

- Cases of children being happier with online learning
- Online school allowing for slower pace learning
- Structure is essential in avoiding meltdowns

- Families finding engagement outside virtual learning like mindfulness, meditation, yoga, interacting with friends and family via video call, etc.
- 75% families finding COVID-19 moderately to severely disrupted ASD services or therapies.
- Moderate increase in impact from urban vs rural families.
- 70% of families feel moderately to severely stressed/overwhelmed by the pandemic's disruption to their child's services.

More can be found at the link below:

<https://www.prnewswire.com/news-releases/spark-the-largest-study-of-autism-families-in-the-us-announces-findings-on-effects-of-covid-19-301035224.html>

Another important piece of evidence to consider is the influx of new patient requests that therapists and other services are experiencing throughout the pandemic. This indicates how COVID19 has magnified feelings of anxiety and stress in the Neurodiverse community.

Anxiety and Stress and other Mental Health Issues in an Isolated World – Autism Awareness Centre

This blog post by the Autism Awareness Centre highlights the elevated feelings of anxiety, depression and lack of human touch during the pandemic and how that is further isolating the autism community.

The post also discusses the importance of sleep and how the pandemic has caused people, especially the autism community, to spend excessive amounts of times on their devices.

This, on top of stress, anxiety and fear of the unknown around this pandemic, is only exacerbated for autistic people as well as the neurotypical. Find out more in the article link below about COVID19's impact on the mental health of autistic individuals.

<https://autismawarenesscentre.com/increased-anxiety-stress-and-other-mental-health-issues-in-an-isolated-world/>

American Association on Health and Disability Survey

[The American Association on Health and Disability](#) (AAHD) conducted an online survey to assess the pandemic's impact on the autism community and various intellectual disabilities and their access to health care. The survey was available online from 17 April 2020 to 1 May 2020.

A total of 2,469 participants responded to the survey, with 930 (38%) of them identifying that they had an intellectual disability such as autism and epilepsy. 80% of respondents were aged between 18-44, 17% aged between 45-64 and 3% being 65 and older.

In terms of access to regular health care treatment, 56% reported their access to their regular health care had been disrupted and 44% stated that access had not been affected. The survey also addressed how the respondents received their information about the pandemic, with 32% identifying relatives as the most important source, followed by 29% indicating TV and 15% saying the internet.

In terms of anxiety and depression, 64% of respondents stated they were experiencing anxiety and depression during this pandemic. Within this group, 80% of respondents claim to have access to emotional support or services.

This survey has revealed some challenges that the pandemic poses to the autism community. This requires further monitoring and the need to establish frameworks to make sure these people are supported during this time. Find more in-depth details about survey results below:

https://www.aahd.us/wp-content/uploads/2020/06/COVID-19_DCRM_Intellectual-Disability_Autism_Epilepsy_or_Brain_InjuryBMSF_508.pdf

Mental Health of Autistic Youth during the Pandemic

Young Minds Organisation, which aims to empower young adult's minds and support mental health and wellbeing, have highlighted the personal experience of autistic teenager Madeleine during the pandemic. She discusses how the virus has impacted her anxiety surrounding rules and guidelines, as well as feeling withdrawn from friends. Additionally, the change to learning at home has allowed her flexibility in her schedule, as she has discovered when she works best and how to manage her own time. She also offers her

methods of coping with stress and anxiety during these uncertain times such as limiting her exposure to the news, prioritising self-care over productivity or playing with sensory items.

Find more about Madeleine's experience here:

<https://youngminds.org.uk/blog/coronavirus-autism-and-my-mental-health/#change-in-routine>

COVID19, NEURODIVERSITY AND THE WORKPLACE

We have all had to adjust to the demands of COVID19, whether that be studying or working from home or learning how to peacefully co-exist with members of our families 24 hours a day. This has proven difficult for all, particularly those that are neurodivergent and find security in routine and structure. The following sources discuss themes of changes in flexibility and accessibility in work and education during the pandemic and how it can hopefully bring us closer to a cultural shift towards Neurodiversity acceptance.

What learning, teaching and working from home can teach us about Neurodiversity – Beth Radulski

The link below is an article by Beth Radulski, La Trobe University PhD Candidate & Project Officer: Neurodiversity, which outlines the parallels of adapting to new social communications such as Zoom calling to the common struggles of minority neurotypes. It also discusses how accessible work environments should be considered essential and not a matter of preference.

<https://www.latrobe.edu.au/mylatrobe/what-learning-teaching-and-working-from-home-can-teach-us-about-neurodiversity/>

Neurodiversity is an Iso Superpower – Macquarie Bank

The following link is an article written by Greg Moore, the Product Director of Deposits and Payments at Macquarie Bank, and reflects on his experience of the “new normal” and his experience with ASD. He discusses his initial struggles and how he believes neurodiversity is a superpower in this time of isolation.

<https://www.macquarie.com/au/en/perspectives/neurodiversity-is-an-iso-superpower.html>

COVID-19 creating a more inclusive workplace?

This article discusses how working from home could be an unexpected benefit from this pandemic in terms of workplace inclusivity. It discusses the disposal of traditional workplace norms and the introduction of new communication preferences to improve productivity. The workplace for all employees could become more inclusive and considerate environment due to the removal of physical cues and the workplace culture and politics. Overall this article highlights how organisations should adapt to improve workplace support and rewrite the norms of recruitment and work routines.

<https://www.weforum.org/agenda/2020/05/uncovering-neurodiverse-culture-an-opportunity-for-change/>

COVID19 AND ITS IMPACT ON EDUCATION

Survey from West Chester University

Cherie Fishbaugh, Director of Autism Services at the University of West Chester, PA, conducted a survey amongst 43 autistic students, seeking to understand the impact of COVID19 has had on their education experience and wellbeing.

To support these students, the following modifications had been made:

- 1-hour support groups until the end of Spring Break
- 1-hour group meetings for discussion and teaching format (zoom etiquette, grading policies, living at home, expectations for online learning)
- Virtual hangouts (socialising) twice a week
- Skill specialist meetings (working on goals) weekly for an hour to work on goals
- Check in with the director weekly or every other week
- Addition of a check in-out system for students who were struggling with motivation.

The survey found that 54% of students maintained the same level of motivation throughout online learning and 35% had less motivation. A smaller group (11%) of students found more motivation. It is also important to note that the survey indicated that 100% of participants found the weekly check-ins with the director valuable and 18% of them wanted to increase the frequency of meetings. This indicates the importance of supporting autistic students during these uncertain times.

Additional Findings from the West Chester University Survey:

<u>Benefits of Online Learning</u>	<u>Difficulties with Online Learning</u>
Highlights from the survey indicated that 37% of students found being at home and not having to go anywhere as well as working at their own pace was a benefit from online learning. Additionally, 22% of students found faculty availability was another highlight from their online learning experience.	It was found that 26% struggled with attention, 22% with communication, 18% with motivation and 15% struggled with the lack of socialisation.

Based on this survey, the West Chester University will implement the following modifications to the Fall 2020 Semester to support their autistic students. Remote learning shall resume at the university. Hybrid options are available for students not residing on campus. In-person meetings can be made, but by appointment only.

This will consist of:

- Virtual sessions
 - o Career development and counselling for students four times a week for an hour
 - o Social hang-outs four times a week for an hour
- Virtual/Hybrid/In-person
 - o Weekly one-hour skill specialist meetings
 - o Study hours for accountability purposes (min. 2 hours/week)
 - o Check-in with director or assistant director weekly or fortnightly.

(These survey results have been used with permission of West Chester University.)

Navigating Remote Learning

This article by the Canberra Times highlights the challenges for young autistic students and remote learning. It presents the surprising benefits and not so surprising drawbacks from learning online. For example, some autistic high school students are thriving with remote learning as they are able to tweak their learning to a mode that works best for them. The

removal of social pressures and sensory distractions of school, it has allowed them to focus better. On the other side of this, younger autistic students find doing classes on zoom a socially taxing task to do and the overall loss of routine has been challenging. On the whole, the article finds that there is an overall increased level of anxiety surrounding the pandemic and the idea of returning to face-to-face amongst autistic students

It also discusses the future of education, welcoming the idea of specialised remote learning post-coronavirus in the ACT.

<https://www.canberratimes.com.au/story/6750099/how-the-covid-19-pandemic-has-impacted-children-with-autism/>

Unforeseen Advantages of Virtual Learning

Whilst the shift of learning at school to the home has been challenging, there has been benefits for those in the neurodiverse community. As seen at the Chapel Haven Schleifer Centre in New Haven, CT, virtual learning has shown higher levels of attendance as well as learning improvement through personal environment adjustments. The typical social barriers that prevented those on the autism spectrum from attending school have been removed and therefore allowing greater flexibility in learning. This article also discusses how online learning also has opened opportunity for teachers and students to learn from each other and better understand student's learning needs, which may not have been identified without the pandemic.

<https://autismspectrumnews.org/unforeseen-advantages-of-virtual-learning-improved-attendance-participation-and-more/>

Important Considerations to take from the “New Normal”

The challenges outlined above have shown how the world has been forced to quickly adapt to an unprecedented pandemic. The shift from the workplace to home has shown employees, students and other communities that disability access can be provided. This is what the Neurodiverse community have been demanding for years in their access to education, work and more. The pandemic has highlighted how changes to work and learning expectations have been adopted when neurotypicals are in need.

Fears surrounding restrictions lifting and life post-coronavirus has also been a standout perspective from the autism community, with some individuals getting used to existing without having to do face-to-face social interaction and thriving when working from home.

“I worry that everything and everyone else will go back to normal, but I cannot or will not.”

It appears where stress and anxiety are removed in one aspect of life, it reappears in another. Whilst some part of our society is eager for the return of normalcy, there is also ever-growing anxiety surrounding life post-pandemic and how the autism community will be affected. The article below also discusses how disappointing it is for the autism community that services such as working from home, telecommuting and telehealth have been standardised due to the pandemic.

“It’s about time organisations adapted.”

Online learning and working from home have traditionally been the exception rather than the rule. With Coronavirus changing the world as we know it, it is important to carry on the continued support for those with disabilities, whether it be neurodiversity or physical impairments and ensure they are not forgotten post-pandemic.

<https://www.sbs.com.au/news/for-some-australians-with-autism-going-back-to-normal-life-after-coronavirus-isn-t-so-welcomed>

NOTE: These resources have been curated by Hayley Chan, Melbourne, Australia (Untapped intern - July 2020)