

**Understanding the Impact of the COVID-19 Pandemic on Autistic People**

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D.Clin.Psy. Thesis (Volume 1), 2021

University College London

## **UCL Doctorate in Clinical Psychology Thesis Declaration Form**

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

A solid black rectangular box redacting the signature.

Name: Rebecca Bundy

Date: 16<sup>th</sup> June 2021

## Overview

This thesis investigated the impact of the COVID-19 pandemic on autistic people. Focusing specifically on the mental health impact of the pandemic, access to service support and experiences of telehealth delivery.

*Part One: Scoping Review.* The literature review examined the research conducted during the COVID-19 pandemic relating to telehealth delivery of health and social care to autistic people. Following a rigorous systematic search of databases, 28 sources of published and grey literature were included. Sources were synthesised into two themes pertaining to the nature of the shift to telehealth and its effects of autistic people and services evaluated during the pandemic. Results revealed that large disruptions had been felt across services and experiences of telehealth support were variable. Some areas of progression in the evidence-based are identified, alongside key areas warranting future research.

*Part Two: Empirical Study.* The empirical study sought to gain a deeper understanding of any changes in the mental health of autistic adults over the COVID-19 pandemic and the nature of support services available. Using an online survey, qualitative and quantitative data were gathered from 133 autistic adults in the United Kingdom about their experiences of the pandemic in relation to their mental health. Results revealed the mental health impact had been variable. While a sizeable minority experienced mental health improvements, most participants described an overall decline in their mental health. Based on findings, recommendations are outlined for how autistic people can be supported as the pandemic persists and once normality returns.

*Part three: Critical Appraisal.* The critical appraisal provides professional and personal reflections on completing the thesis. Considerations are given to the impact of the pandemic, undertaking the analysis and wider limitations.

## Impact Statement

Alongside contributing to the academic evidence-base for autism, in order for findings to be most impactful dissemination to individuals at various levels is required. These include, policy makers, clinicians and researchers, and autistic people. Given the timely nature of the research, the process of disseminating findings is already underway and a clear plan for how findings can reach wider audiences' has been carefully considered.

*Policy Makers:* Chapter one, a scoping review of the literature conducted during the COVID-19 pandemic relating to autistic people and telehealth practices, contributes to a larger project commissioned by NHS England. Therefore it has direct influence on policy-makers. The review will form part of an NHS England briefing paper, which aims to improve health and social care for autistic people. There is also plans to submit the review for publication in a peer-reviewed journal following this.

*Clinicians, Researchers and Autistic People:* Chapter two, the empirical study was completed prior to chapter one. Due to the timely nature of the research and limited information during early stages of the pandemic about the impact on autistic adults' mental health, the study was written for publication in the peer-reviewed journal, *Autism* and submitted in February 2021. It is currently at the 'revise and resubmit' stage of this process. To optimise the studies visibility and dissemination of findings, alongside the journal submission it was also published as a preprint (Bundy et al., 2021). The journal *Autism* was chosen due to its open access agreement with UCL, allowing for broader dissemination of results to researchers, clinicians and wider society. The empirical study is due to be presented at Autisticas' 'Research Festival' on 12<sup>th</sup> July 2021, which is the UK's leading autism research conference. This conference brings together autism researchers, professionals who work and support autistic people, as well as autistic people and families.

*Future Plans:* Considerations have been given to future plans to further widen the pathway of impact. In particular, the potential to use social media, including, Twitter or blog posts to allow findings to reach larger audiences’.

## Table of Contents

UCL Doctorate in Clinical Psychology Thesis Declaration Form.....	1
Overview.....	2
Impact Statement .....	3
Table of Contents.....	5
Contents of Tables and Figures.....	7
Acknowledgements.....	8
<b>Part One: Literature Review .....</b>	<b>9</b>
Abstract.....	10
Introduction.....	11
Method.....	16
Search Strategy .....	17
Search terms and selection criteria.....	17
Inclusion and Exclusion Criteria.....	18
Inter-Coder Agreement .....	19
Data Extraction and Assessment.....	19
Results.....	22
Nature of the Shift to Telehealth and its Effects on Autistic People.....	22
Types of Services Evaluated During the Pandemic .....	26
Discussion.....	40
Development of Pre-Existing Gaps in the Literature.....	41
Parallels with Telehealth Literature Prior to the Pandemic.....	42
Methodological Quality of Studies .....	44
New Areas of Development.....	45
Limitations .....	47
Conclusion .....	48
References.....	49
<b>Part Two: Empirical Paper .....</b>	<b>64</b>
Abstract.....	65
Introduction.....	66
Method.....	69
Design .....	69
Community Involvement .....	69

Context.....	70
Participants.....	70
Materials .....	73
Data Analysis .....	74
Researchers Positionality .....	75
Results.....	76
Quantitative Results .....	76
Qualitative Results .....	80
Discussion .....	90
Limitations .....	95
Conclusion .....	96
References.....	97
<b>Part Three: Critical Appraisal.....</b>	<b>109</b>
Introduction.....	110
Professional Context and Choice of Research Topic .....	110
COVID-19 Disruptions .....	112
Working with Pre-Established Research Teams .....	114
Experience of Undertaking the Analysis .....	114
Navigating the Scientist-Practitioner Role.....	116
Wider Limitations and Areas for Improvement .....	117
Conclusion .....	119
References.....	121
Appendices.....	124
Appendix A: Scoping Review Search Terms .....	124
Appendix B: Example Search Run in OVID MEDLINE .....	125
Appendix C: Recruitment Poster for the Original Longitudinal Survey.....	132
Appendix D: Ethical Amendment Application.....	133
Appendix E: Participant Information Sheet .....	138
Appendix F: Participant Consent Form .....	141
Appendix G: COVID-19 Questions.....	143
Appendix H: Stages of Coding and Theme Development.....	147

## Contents of Tables and Figures

<b>Part One: Literature Review</b> .....	9
Table 1.....	34
Table 2.....	36
Table 3.....	38
Figure 1.....	21
<b>Part Two: Empirical Paper</b> .....	64
Table 1.....	71
Table 2.....	79
Figure 1.....	76
Figure 2.....	77
Figure 3.....	80



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**Part One: Literature Review**

**Autistic People and Telehealth Practice During Covid-19: A Scoping Review of Current Literature**

## **Abstract**

Restrictions imposed during the COVID-19 pandemic have meant health and social care services have needed to dramatically adjust their models of service delivery. In line with significant reductions in face-to-face appointments, there has been increasing reliance on telehealth methods to meet growing healthcare needs. Prior to the pandemic, there was increasing interest in telehealth use with autistic people, however, little is known about its use during the COVID-19 pandemic. This scoping review was the first to investigate the literature carried out during the pandemic relating to telehealth use with autistic people. Following a rigorous systematic search of ten databases, 28 sources of published and grey literature were included in the scoping review. To synthesise the literature, sources were categorised into two themes: (1) Nature of the shift to telehealth services during the COVID-19 pandemic and its impact on autistic people and, (2) Types of services evaluated during the pandemic. Nine sources shed light on theme one and twenty sources on theme two (one source overlapped). Results indicated that large disruptions had been felt across healthcare settings, and experiences of telehealth services were variable. Studies evaluated over the pandemic were dominated by behavioural interventions. However some areas were developed, including, telehealth interventions completed directly with autistic children and adults, as well as autistic people with intellectual disability and language impairments. Indicating some progression in the evidence-base. Key priorities for future research are outlined and consideration given for changes to be made at individual and systemic levels.

## Introduction

The COVID-19 pandemic has caused widespread disruptions to healthcare services around the world (WHO, 2021). Due to the immense pressures placed on services to treat the virus, alongside restrictions imposed to mitigate transmission, such as physical distancing measures, service-delivery models have required considerable modification (Parmasad et al., 2020). This has included significant reductions in face-to-face appointments (NHS England, 2020). The indirect effects of the pandemic and control measures are likely to affect physical and mental health (Mansfield et al., 2021), further enforcing pressures placed on healthcare systems to explore new ways to deliver care. This has led to the introduction or expansion of telehealth technologies (Pereira-Sanchez et al., 2020). Although no universal definition for telehealth exists, it broadly refers to the delivery of care services where providers and patients are separated by distance (WHO, 2016). Telehealth covers a range of activities, largely involving telecommunications, such as, telephone or videoconferencing tools, and is considered an important factor to achieve universal health coverage, by improving access to high quality, cost-effective, healthcare (Monaghesh & Hajizadeh, 2020).

In the decade prior to the COVID-19 pandemic, there was increasing interest in the use of telehealth for individuals with Neurodevelopmental Disorders (NDD), with majority of this literature focusing on those with Autism Spectrum Disorder (Valentine et al., 2021). Despite autistic people<sup>1</sup> reporting higher rates of mental health and physical health problems prior to the pandemic (Cashin et al., 2018; Lai et al., 2019; Kinnear et al., 2020), they are

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<sup>1</sup> This thesis will use identity-first language. From a disability rights, equality and diversity framework, autism is considered a central, identity-defining feature, which is argued cannot be separated from the individual (Gernsbacher., 2017; Vivanti., 2020). Furthermore, the use of person-first language has been considered to perpetuate stigmatizing views (Vivanti., 2020).

Moreover, the empirical study in part two of the thesis, found that the majority of the sample preferred identity-first language (68.4%) to person-first language (10.5%).

understood to face barriers to accessing appropriate care, across healthcare services (Calleja et al., 2020; Mason et al., 2021; Nicolaidis et al., 2015; Pellicano & Stears, 2020). Barriers have been identified at patient-level (verbal communication skills, sensory sensitivities, atypical communication), provider-level (providers lack of knowledge about autism, incorrect assumptions and use of inaccessible language) and system-level (availability of supporters, complexity of the healthcare system and stigma often associated with autism) (Nicolaidis et al., 2015). These healthcare disparities often result in long delays to assessments or intervention (Calleja et al., 2020), or missed opportunities entirely (Simacek et al., 2021). In the face of such challenges, telehealth technologies have been considered a plausible means to increase accessibility of healthcare provisions for autistic people (Alfuraydan et al., 2020).

Although the majority of studies on telehealth services for autistic people have focused on the delivery of interventions, some research has investigated assessments, including, language assessments (Sutherland et al., 2019), and autism screening and diagnostic tools (Valentine et al., 2021; Dahiya et al., 2020). A recent systematic review prompted by the COVID-19 pandemic identified 16 studies published between 2008 – 2018, which investigated telehealth diagnostic and screening assessments with children (Dahiya et al., 2020). This review of the pre-Covid literature supported the use of live-video evaluations, video observations and online or phone technology (Dahiya et al., 2020). Several studies modified established autism assessment and screening tools making them applicable for use over telehealth (Chambers et al., 2017; Gabrielsen et al., 2015; Juárez et al., 2018; Reece et al., 2015; Reese et al., 2013; Smith et al., 2017; Sturner et al., 2016). These included, the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000), the Autism Diagnostic Interview-Revised (ADI-R) (Rutter et al., 2003), and the Screening Tool for Autism in Two-Year-Olds (STAT) (Stone et al., 2008). Generally, results from these studies were promising, and indicated good diagnostic accuracy and sensitivity, as well as positive user-satisfaction

(Dahiya et al., 2020). However, despite the perceived effectiveness of telehealth diagnostic assessments, studies have been criticised for their small sample sizes (Valentine et al., 2021), and more research is required, particularly in determining the feasibility of telehealth methods in the context of the COVID-19 restrictions (Dahiya et al., 2020).

Reviews reveal that the majority of telehealth intervention studies have investigated the use of telehealth to provide training to parents or carers of autistic children (Antezana et al., 2017; Parsons et al., 2017; Sivaraman & Fahmie, 2020; Unholz-Bowden et al., 2020), or professionals working with autistic people (Tomlinson et al., 2018; Ferguson et al., 2019; Kizir, 2019). Far less attention has been given to telehealth use with autistic adults, or, to the delivery of direct interventions to autistic people (Sutherland et al., 2019). Research has largely drawn on the use of telehealth to provide varying forms of behaviour analytic provisions and train caregivers to implement behavioural procedures, including, aspects of Applied Behaviour Analysis (ABA) such as Functional Communication Training (FCT), Functional Analysis (FA) and Discrete-Trial Training (DTT), as well as the Early Start Denver Model (ESDM). (Ferguson et al., 2019; Hall et al., 2016; Tomlinson et al., 2018;; Unholz-Bowden et al., 2020). To a lesser degree, a few studies have delivered anxiety interventions and social communication interventions over telehealth (Hepburn et al., 2015; Parsons et al., 2017; Simacek et al., 2021), however, in general more research is required to investigate how different models of support, other than behavioural interventions, can be delivered via telehealth.

Systematic reviews outline that the majority of telehealth interventions in autism services have demonstrated promise for being clinically effective in improving caregiver competence and knowledge, and have been associated with improvements in child participation, communication responses and reductions in problem behaviour (Ferguson et al., 2019; Hall et al., 2016; Tomlinson et al., 2018; Unholz-Bowden et al., 2020; Valentine et

al., 2021). Studies providing training to parents, carers or professionals have demonstrated high fidelity to the treatment model (Neely et al., 2017; Parsons et al., 2017), indicating promise that such interventions can be effectively taught over telehealth. However, little is known about the long-term effectiveness of telehealth interventions for autistic people, specifically, how skills are generalised or maintained following the intervention, and this area warrants further investigation (Simacek et al., 2021). It has been considered that in order to consolidate skills, additional follow-up sessions may be required when interventions are delivered over telehealth (Neely et al., 2017). Positive user satisfaction for telehealth interventions and improved accessibility to treatment, particularly for service-users in rural settings, have been reported (Kizir, 2019; Sutherland et al., 2019). Additionally, some studies have indicated positive economic outcomes of telehealth and presented it to be a cost-effective option for service delivery (Kizir et al., 2019; Simacek et al., 2021). However, more research is required to substantiate this evidence (Valentine et al., 2021). Despite clear benefits of telehealth interventions, a number of barriers have been identified. Due to this, prior to the pandemic, telehealth interventions for autistic people were generally recommended to be used to augment, rather than replace, face-to-face contact (Simacek et al., 2021; Valentine et al., 2021).

Barriers to telehealth delivery for autistic people have been identified at individual and systemic levels. Individual factors, for example, difficulties accessing or using telehealth technology, language, cultural or financial barriers, as well as preferences for support provided in a particular way, may impact on an autistic person's engagement or ability to access telehealth support (Tomlinson et al., 2018; Simacek et al., 2021; Sivaraman & Fahmie et al., 2020). Educational history may also play a role in how accessible telehealth is for service-users. For example, one study found that parents with lower-level education were more likely to drop out of telehealth treatment, and, as a result, argued that self-directed

interventions were more suited to parents with higher levels of education (Dai et al., 2018). While mechanisms behind this are unclear, one could speculate that limited skills and experience of using technology, as well as socioeconomic factors which may impact on access to technology or internet, could form additional barriers for these individuals accessing telehealth support.

Concerns have also been raised about how accessible telehealth services are for those with additional needs including, an Intellectual Disability (ID), or minimally verbal individuals, who may require more direct modelling or intensive support (Tomlinson et al., 2018), as well as how the therapeutic relationship may be impacted over telehealth (Tomlinson et al., 2018). Further practical barriers include, the cost, logistics, and technical difficulties associated with the equipment. With these findings in mind, some studies have proposed that telehealth should be considered on an individual basis (Tomlinson et al., 2018). Once telehealth appointments commence, individualised treatment and feedback are considered key components to the success of ongoing work (Neely et al., 2017; Valentine et al., 2021).

Professional and systemic level barriers to telehealth delivery have also been identified by studies. One of these includes the lack of confidence and expertise felt by clinicians to effectively deliver telehealth interventions. For example, a systematic review identified that professionals found reading body language and facial expressions difficult over telehealth (Valentine et al., 2021). This not only has potential to impact on the effectiveness of the intervention, but coding of non-verbal communication is often an essential aspect of autism assessments. Characteristics of service settings have been identified as having potential to cause further complications, including administrative support and limited learning opportunities for adapting evidence-based practice (Antezena et al., 2017). Furthermore, ethical concerns have been raised in relation to managing confidentiality or



obtaining informed consent via telehealth, particularly in situations which require video footage to be transferred to professionals for observational purposes (Barkaia et al., 2017; Fischer et al., 2017;).

Despite some benefits of telehealth delivery for autistic people, the barriers identified prior to the pandemic indicated that caution is required when implementing telehealth into clinical practice (Dahiya et al., 2020; Simacek et al., 2021; Valentine et al., 2021;). However, the pace at which COVID-19 swept through society gave services little time to prepare for the transition to remote service delivery via telehealth. This review aimed to examine how telehealth methods had been implemented with autistic people during the COVID-19 pandemic. Given the novel nature of the pandemic, a scoping review was conducted to broadly examine the nature, extent, and range of research available. Scoping reviews follow a systematic approach to map and synthesize evidence on a particular topic, and identify the main concepts, theories, sources and gaps in knowledge that may require additional investigation (Tricco et al., 2018). With this in mind, scoping reviews can also be used to determine whether a systematic review on a particular topic is warranted. Contrary to a systematic review, scoping reviews allow for a rapid investigation of the literature which is less restricted by methodological quality of the evidence (Munn et al., 2018). Specifically, this review hoped to answer the following research question: (1) What is the state of the literature carried out during the pandemic, relating to autistic people and telehealth? and (2) What gaps have been identified?

## **Method**

The PRISMA extension for scoping reviews (PRISMA-ScR) checklist was followed to ascertain the key aspects to report (Tricco et al., 2018) (see figure 1). This review was pre-registered on Prospero prior to being conducted (Prospero registration number: CRD42021244901).

## **Search Strategy**

The following electronic bibliographic databases were searched for published papers: MEDLINE, Embase, PsychINFO, EMcare, Web of Science, Scopus and the Cochrane Library. Given the novelty of this area, a targeted search of ‘grey literature’ was also completed. Grey literature refers to literature which remains unpublished. This included databases and websites providing information on theses, dissertations, conference articles, pre-prints and other research studies or government advice in progress. Alongside, Web of Science, Embase and PsychINFO, which contain conference articles and dissertations, the following sources were searched for grey literature: MedNar, ProQuest, the COVID-19 Portfolio, as well as autism organisations including, the National Autistic Society (NAS), Autistica, Ambitious About Autism, Autistic Women and Nonbinary Network (AWN) and autism charities and networks. References were managed using EndNote, through which duplicates were removed.

## **Search terms and selection criteria**

The search was comprised of systematic steps using search terms listed in Appendix A in the aforementioned bibliographic databases. Search terms for autism and telehealth were based on previous systematic reviews published in this area where comprehensive data pertaining to searches were available (Aref-Adib et al., 2019; Lai et al., 2019). Search terms for COVID-19 were based on NICE Guidelines (NICE, 2020). Appendix B contains an example search run in OVID MEDLINE.

The search took a two-pronged approach. The first search ran on the bibliographic databases included all search terms relating to autism, telehealth and COVID-19. The search was then run again to include search terms for autism and telehealth, which was refined by date between 2020 – 21. This allowed us to search papers which may not have mentioned

COVID-19 in their title or abstracts, and therefore allowed for a more detailed search to be conducted. All searches took place between 26<sup>th</sup>– 28<sup>th</sup> March 2021.

The lead researcher (RB) ran the search on the bibliographic databases for the published papers, while a second researcher (DA)<sup>2</sup> ran a search for the grey literature sources. Searches were then combined, and duplicated data were eliminated. Each reviewer independently screened titles and abstracts of all potentially eligible papers based on some of inclusion and exclusion criteria. The full criteria were implemented at the full-text review stage.

## **Inclusion and Exclusion Criteria**

### *Inclusion Criteria:*

- Full-text peer-reviewed publications reporting primary data, explicitly relating to telehealth methods and autistic individuals, in the title, abstract or full-text. Included grey literature sources: pre-prints, official clinical evaluation reviews/reports.
- Studies must include one or more individual of any age, who are either autistic, or are supporting an autistic person. For studies that included a mixture of participants who were autistic and non-autistic, autistic people were required to make up at least two thirds of the sample or results were required to be clearly disaggregate between autistic and non-autistic people.
- Telehealth methods from any services where health and social care had been delivered remotely via digital communication technology, including video-conferencing, telephone, e-mails, apps, and web-based training.

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<sup>2</sup> This review contributed to a large scale study commissioned by NHS England, investigating telehealth use with autistic people. While the review was led by RB and written solely by RB, another researcher (DA) supported the grey literature searching. In line with international standards and recommendations a double screening approach was followed (Edwards et al., 2002), whereby RB and DA independently screened full-text articles. This ensured study criteria was consistently applied and the likelihood of systematic errors was reduced (Waffenschmidt et al., 2019).

- Articles must be written in English.
- Studies published between 2020-2021.

*Exclusion Criteria:*

- Studies that had been published between the desired timeframe, but conducted prior to the COVID-19 pandemic.
- Studies that did not mention COVID-19.
- Studies focusing solely on educational service provisions, or studies in which professionals were the sole focus.

Following initial screening, full-text articles of published and grey literature were assessed for inclusion by RB and DA independently. Accepted studies were then combined, and reviewed in collaboration with a third reviewer (WM).

**Inter-Coder Agreement**

At this stage, there was 88% agreement between the two reviewers for the inclusion of published papers (112/127 of identified studies) and 86% agreement for the inclusion of grey literature (18/21 of identified studies). Following a meeting at which differences between raters were discussed and resolved, 22 published papers and 6 grey literature sources were agreed.

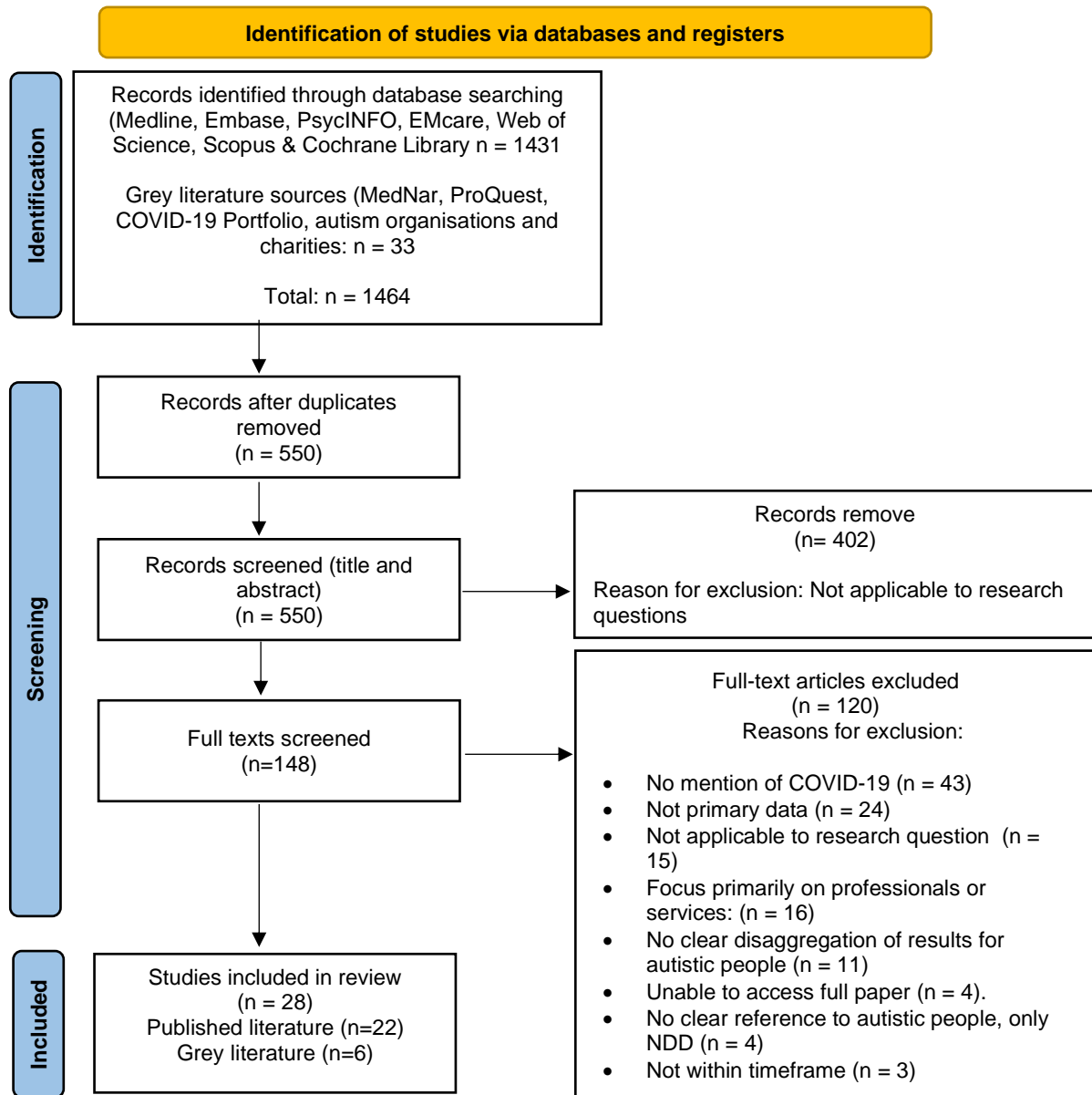
**Data Extraction and Assessment**

Two reviewers (RB, DA) extracted and cross-checked data independently for all included full-text articles. The following information was extracted from papers: Author name, date and title, methodology used, literature type, participant characteristics and demographics, participants country, technology used, service provided (e.g. assessment / intervention) and summary of outcomes.

The Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018), was used to evaluate the published and grey literature sources. The MMAT is a critical appraisal tool designed for the systematic appraisal of methodologically diverse studies. It permits appraisal of the methodological quality of five broad types of research: (1) qualitative research, (2) randomised controlled trials, (3) non-randomized studies, (4) quantitative descriptive studies and (5) mixed method studies (Hong et al., 2018). All studies were independently rated by RB and DA and checked by WM to resolve any disagreements. As it is discouraged to calculate an overall score from the ratings of each criteria using the MMAT, presentations of the ratings in relation to each criteria are discussed in the results section, to inform on the quality of the studies included (Hong et al., 2018). A copy of the codes assigned to studies using the MMAT can be found in Table 3.

**Figure 1.**

*PRISMA Flow Diagram of Reviewed Studies*



## **Results**

To synthesise the literature and answer the two research questions, sources are categorised into two main themes: (1) Nature of the shift to telehealth services during the COVID-19 pandemic and its impact on autistic people (2) Types of services evaluated during the pandemic. Details of each study included in the review can be found in tables 1 and 2. Only one study overlapped both themes and was therefore included in both categories.

### **Nature of the Shift to Telehealth and its Effects on Autistic People**

The search yielded nine articles investigating the nature of the shift to telehealth during the pandemic and its effects on autistic people (see table 1). Of these, six were published papers and three were grey literature sources. The published literature consisted of five surveys, including two longitudinal surveys and one experimental study. Grey literature sources comprised surveys and in-depth interviews. Across published and grey literature, samples consisted of, autistic adults (3 studies), parents or carers of autistic children or dependent adults (4 studies), professionals working with autistic people (1 study), and a combination of autistic adults, young people and families (1 study). Studies were conducted in various countries around the world, including, the UK (3 studies), the USA (3 studies), Australia (1 study), Canada (1 study) and Iran (1 study). While one study clearly referenced the use of telephone or videoconferencing methods (Adamou et al., 2021), there was a lack of clarity in the remaining literature regarding what telehealth methods had been used, although some references were made to videoconferencing, mobile applications, and phone calls.

Studies revealed there had been a large disruption to services, which had considerably impacted physical and mental health of autistic people. While some services had transitioned to offer full or partial telehealth services, others had shut down entirely. In a UK study comprising professionals working with autistic individuals, 65% reported major disruptions to autistic people's services, 27% felt the disruption had been mild and 8% reported complete

loss of services (Spain et al., 2021). Disruptions were felt across settings and therapies, including speech and language therapy, physical and occupational therapies, ABA services, and respite care (Jacques et al., 2021; White et al., 2021a). A longitudinal survey conducted in the US two months apart with autistic adults, during initial stages of the pandemic (March – June 2020), reported a greater disruption in services at Time 2 (T2) than Time 1 (T1), indicating a cumulative effect in service disruption as the pandemic progressed. In this study, online services did not significantly contribute as a predictor to distress. However, T1 perceived benefit of remote services was a significant predictor of T2 distress, with those who perceived less benefit from remote services at T1 reporting significantly more distress at T2. (Bal et al., 2021).

There was considerable variability among studies in how many participants had accessed telehealth services, which ranged from the majority of parents or carers reporting their autistic child not to have received any (White et al., 2021a) to 66% of autistic adults in another study reporting to have (at T1) received some form of online support (Bal et al., 2021). Of those receiving online services, one study reported that only mental health and medical services were felt by a majority of caregivers to be significantly or moderately beneficial (55% and 63% respectively) (White et al., 2021a). Across studies there was general preference for in-person contact, however, where telehealth was an option, some individuals were grateful for the continuation of services and perceived telehealth as useful under the circumstances. Other perceived benefits reported by autistic people themselves, and by clinicians supporting autistic people, included reductions in time loss and stress for some individuals (Pellicano et al., 2021; Spain et al., 2021).

Across the literature, different informant types indicated some potential age-related differences in telehealth use. This related to satisfaction with telehealth methods, as well as perceptions of autistic people's experiences and benefit from telehealth services. While



professionals working with autistic adults and children in one study viewed telehealth methods as being more appropriate to younger people, due to familiarity with the methods (Spain et al., 2021), studies conducted directly with autistic individuals found results on the contrary. One study with autistic adults reported 100% of adults aged between 41-50 years old felt able to communicate effectively over telehealth, while responses to this varied in younger aged adults (21-30yrs), with 85.7% in this age group reporting feeling unable to communicate well over telephone and video-call (Adamaou et al., 2021). This study also reported differences across age groups in whether telehealth should be offered in future consultations, with more younger-aged adults disagreeing that this should be the case (Adamou et al., 2021). Age-related differences were also reported in studies containing a combination of adults and children. In an online survey by White et al (2021a), parents reported a greater proportion of dependent adults (68%) significantly or moderately benefited from online services than school aged children (54%) or preschool aged children (22%). However, this longitudinal survey found a significant difference between those that completed the survey at the two times points (Times 1 and 2). One difference being those that completed both time points had higher household incomes and were more likely to come from large metropolitan areas. Therefore, the representativeness of the sample may be questionable. A separate study by Samadi et al., (2021), found differences between younger and older-aged carers of autistic children in satisfaction scores relating to a parenting intervention. This study found that prior to the intervention, younger aged parents were more positive than older parents about telehealth services, however, following completion of the intervention, the percentage of positive ratings reduced in younger parents (by 68%) and increased in older parents (by 51%). Taken together, these studies indicate that older autistic people and older carers of autistic people could benefit more from telehealth methods than

younger-aged adults, or autistic children. However, given the limited number of studies, it is not possible to sustain a clear message at the present time.

Vulnerability factors were identified across studies in relation to the use of telehealth with autistic adults and children. The ability to effectively communicate over telehealth methods was variable across studies. As noted above, some autistic adults reported feeling able to effectively communicate (Adamou et al., 2021), however, other studies including autistic adults, as well as parents or carers of autistic children highlighted increased social communication difficulties over telehealth (White et al., 2021b; Bundy et al., 2021). Some reasons proposed for these challenges included increased pressure placed on non-verbal communication over telehealth, including, eye contact and conversational cues, as well as challenges interpreting body language over telehealth. Enhanced sensory aspects were also associated with potential barriers to telehealth delivery due to background noises often associated with calls making processing of conversations more challenging (Bundy et al., 2021; Pellicano et al., 2021). Some professionals felt that telehealth methods were potentially confusing or daunting for some children or adults with intellectual disabilities and recalled a general preference for audio calls without video during telehealth sessions with these clients (Spain et al., 2021).

A study involving professionals working with autistic people outlined concerns that telehealth methods could exacerbate inequalities for the autistic community. Limited access to provisions required to engage with telehealth were proposed as potential barriers at both an individual and provider levels. Authors identified areas including diagnostic services, and acute care for autistic people as being potentially vulnerable to limited service provisions (Spain et al., 2021). Coinciding with this, autistic adults in a qualitative study completed during early stages of the pandemic reported perceived exacerbations in waiting times for autism diagnostic clinics (Bundy et al., 2021). Anticipation of these barriers, combined with

the aforementioned communication difficulties, meant that some autistic people chose not to engage with telehealth methods, and in extension services, at all.

Results from the MMAT indicated that four of the nine studies included in this theme, displayed strong methodological quality, covering all aspects outlined on the measure (Bundy et al., 202; Pellicano et al., 2021; Spain et al., 2021 White et al., 2021b). Of the remaining five studies, concerns involved, the representative of the sample (Adamou et al., 2021; Bal et al., 2021), limited information on the quality of the analysis used (Samadi et al., 2020) and inadequate integration of qualitative and quantitative components of the study (Jacques et al., 2021). One study also indicated a high risk of response bias when evaluated using the MMAT (White et al., 2021a). **Types of Services Evaluated During the Pandemic**

In total, twenty papers explored the types of service that had been evaluated for autistic people over the course of the pandemic (see table 2). Of these, seventeen were published papers and three grey literature sources. Studies included, a combination of parents or carers with autistic children or adults (11 studies) parents or carers alone (3 studies), autistic children or adults alone (5) and a healthcare team and school (1 study). Studies contained participants from the USA (13 studies), Iran (1 study), China (1 study), Turkey (1 study), and across Belgium, India, Mexico and Costa Rica (1 study). In three papers it was unclear where the participants were from, or where the study had been conducted (Rothman et al., 2021; Singh et al., 2021; Wanger et al., 2020). In relation to telehealth methods used, the majority utilised various forms of videoconferencing software (17 studies) or mobile phone applications (3 studies).

### ***Assessment***

Only one study focused solely on an assessment delivered via telehealth over the course of the pandemic with autistic children and parents or carers (Wagner et al., 2020). This study evaluated a novel tool for tele-diagnostic assessments, the TELE-ASD-PEDS, which is

a caregiver-mediated instrument for children under three years old. In this study, 204 telemedicine assessments were completed with children with developmental concerns. Results revealed that 71% of children went on to receive an autism diagnosis. Providers reported feeling comfortable in guiding carers to use the tool and make diagnoses of autism based on the findings. However, this study excluded children with severe impairments, impacting on the representativeness of the sample.

### ***Assessment and Intervention***

Three studies investigated the delivery of assessments and interventions via telehealth. Two of these were case studies, one involving a parent and a non-verbal autistic child (O'Brian et al., 2021) and the other, a caregiver and autistic adult (Shawler et al., 2021); both participants had an intellectual disability. The third study included seven autistic children and their parents (Gerow et al., 2021b). All three studies aimed to reduce 'problem behaviour' in children through functional analysis (FA) and functional communication training (FCT). Results in all three studies indicated reductions in challenging behaviour and high levels of fidelity to the treatment. Treatment fidelity was reported between 87-98% for assessment and 81-94% for treatment in two studies (Gerow et al., 2021b; O'Brian et al., 2021). Furthermore, a follow-up appointment completed 6-months post intervention in one case study demonstrated sustained improvements (O'Brian et al., 2021). However, all three studies contained small samples (between 1-7 participants), and there was limited information across studies on how confounders had been controlled for. Furthermore, in the absence of control groups it is not possible to ascertain whether the improvements in challenging behaviour noted were due to the interventions alone.

### ***Intervention***

Nineteen studies investigated telehealth interventions. Of these, the majority consisted of varying forms of behavioural interventions. Eight of these studies used ABA procedures,

involving, autistic children (Ferguson et al., Nohelty et al., 2020) a combination of autistic children or dependent adults with parents or carers (Gerow et al., 2021b; Kunze et al., 2021; OBrian et al., 2020; Shawler et al., 2020; Turan et al., 2020) and archival data (Pollard et al., 2021). Five studies implemented more broad behavioural techniques, with parents and autistic children (Gerow et al., 2021a; Lapin et al., 2020; Sivaraman et al., 2021), professionals working with autistic children (Singh et al., 2021) and autistic children directly (Ura et al., 2021). Two studies investigated a combination of Acceptance and Commitment Therapy (ACT) and behavioural training with parents (Andrews et al., 2020; Yi & Dixon, 2021). Other interventions included one social skills intervention with autistic children (Cihon et al., 2021), two parent training programmes (Samadi et al., 2020; McDevitt et al., 2021) and one dance psychotherapy intervention with an autistic adult (Rothman, 2021).

### ***Applied Behavioural Analysis and Other Behavioural Interventions***

Of the eight studies investigating the delivery of ABA procedures via telehealth, three as detailed above, consisted of FA and FCT. A further three studies involved more comprehensive ABA interventions (Kunze et al., 2021; Pollard et al., 2021; Turan et al., 2020). Utilising archival data, Pollard et al., (2021) reported on 17 autistic children and adult cases that had transitioned from in-person to telehealth ABA during the pandemic. Results demonstrated that despite the transition, participants continued to access a similar dosage of treatment, and either maintained or improved correct independent responding on all targets. Positive results were also reported by two other studies involving autistic children and their parents or carers, with a strong basic effect found between the intervention and parental strategy use in one (Kunze et al., 2021) and improvements in flexible behaviours and reductions in inflexible behaviour in children in both (Kunze et al., 2021; Turan et al., 2020). Two further studies investigated Discrete Trial Training (DTT) delivered directly with children via telehealth (Ferguson et al., 2020; Nohelty et al., 2020). No caregivers were

present in one study and only two of eight children had caregivers present in the other.

Across both studies, all participants acquired mastery for target responses by the end of the intervention.

A further five studies investigated interventions delivering other forms of behaviourist learning principles over telehealth. Of these, one was delivered with caregivers alone (Ura et al., 2021), three with parents and children (Gerow et al., 2021a; Lapin et al., 2020; Sivaraman et al., 2021) and one delivered remote consultations with professionals (Singh et al., 2021). The studies involving caregiver-mediated delivery yielded positive results in improving adaptive behavioural skills (Gerow et al., 2021a) social communication targets (Ura et al., 2021) and target behaviours, including, mask-wearing duration (Sivaraman et al., 2021) and toilet training (Lapin et al., 2020). Furthermore, three of the four studies reported high levels of fidelity to the treatment model (Gerow et al., 2021a; Lapin et al., 2020; Sivaraman et al., 2021). A single-case experimental design conducted by Sing et al., (2021), investigated telehealth consultations with professionals, using a behavioural support plan and a mindfulness-based intervention, named the 'Soles of Feet Programme' (SOF). The purpose of the intervention was to reduce self-injurious behaviour (SIB) in autistic adolescents. Results demonstrated reductions in the frequency of SIB for all adolescents following both the behavioural support plan and SoF intervention, however, only the SoF programme demonstrated a significant reduction in SIB. However, it is worth noting that these were all uncontrolled studies, meaning it is not possible to ascertain whether the change noted was due to the intervention or other confounding factors.

Results from the MMAT indicated methodological flaws across ABA and behavioural studies. Sample sizes were small, varying from 1-41 participants and samples tended to lack diversity, in terms of Intelligence Quotient (IQ), language ability and participant demographics. No studies involved control group samples, and there was limited

information on how confounding variables had been controlled for. In the absence of this information is not possible to ascertain whether changes observed in participants are due to the interventions themselves, or other factors. Furthermore, only one case study included a follow-up appointment.

Two further studies utilised a combination of ACT and behavioural parent training via telehealth (Andrews et al., 2020; Yi & Dixon et al., 2021), with the purpose of improving parental adherence to behavioural interventions. Both studies reported positive additions of ACT on adherence, with a reduction in experiential avoidance and stress also reported in one (Andrews et al., 2020). Both studies set-out to include control groups, however, experienced significant drop-out rates in their control group samples during early stages of their interventions. This resulted in an altered study design in one (Andrews et al., 2020) and incomplete dataset in the other (Yi & Dixon et al., 2021). Participants in the RCT completed early stages of the intervention prior to the COVID-19 pandemic, which had initially involved some in-person consultations alongside the telehealth intervention. However, when stay-at-home restrictions were imposed half-way through, 100% of participants in the control group chose to postpone the intervention, compared to 28% of participants in the ACT group.

### ***Other Interventions***

Additional interventions reported over this period included a social skills intervention with autistic children (Cihon et al., 2021), a dance psychotherapy intervention with an autistic adult with Downs Syndrome (Rothman, 2021) and two parenting support interventions (McDevitt et al., 2021; Samadi et al., 2020).

Positive results were reported in the social skills intervention (Cihon et al., 2021) with all children reaching mastery criteria by the end, and two of the three children demonstrating the ability to generalise skills to another adult outside of the intervention. However, while this

study reports that results from a social validity measure indicate the intervention to have been an acceptable and effective replacement for in-person support, with 3/3 of the children's clinicians returning the questionnaire, only 1/3 parents returned the measure. Furthermore, authors report interrater agreement to be high, however, this measure was only collected on the primary dependent variable on 37.5% of all sessions. The MMAT indicated issues relating to outcome measurement blinding and lack of control over confounders. Furthermore, in the absence of a control group it is not possible to determine whether the observed changes were due to the intervention alone, therefore further limiting the methodological quality of the studies.

In Rothman (2021)'s case study involving a dance psychotherapy intervention with an autistic adult with Downs Syndrome, the practitioner took a number of steps to help facilitate the intervention. These included a gradual transition to videocalls, starting with phone calls which helped to build the client's confidence. Prior to starting videocalls, the practitioner sent a detailed, easy-read guide to the client detailing what to expect and outlining practical suggestions about where the client could complete the sessions (private, well-lit space). Barriers identified included, technical issues impacting on communication fluidity, and the clinician reporting to feel a loss of control in protecting the client's privacy over telehealth. Overall, the telehealth intervention was felt to be beneficial in allowing the client to continue engaging in therapeutic support during the pandemic. The clinician also observed an increase in confidence in the client over the course of the intervention, in taking a lead and sharing movements more explicitly, which was felt to have been encouraged by the medium of telehealth.

The parenting interventions included one qualitative study (McDevitt et al., 2021) and one mixed-methods study (Samadi et al., 2020). Results indicated that parents had felt supported by both interventions, particularly in cultivating parent support networks. Although



parental satisfaction was generally high across both studies, one found that when children had more than one diagnosis, parents were less positive about the course (52%) than parents of children with a single diagnosis (68%) (Samadi et al., 2020), indicating that the complexity of a child's difficulties may impact on parental engagement. Potential barriers to telehealth delivery were identified in both studies involving parents or carers including, technical problems and the financial burden associated with telehealth services, as well as concerns about how confidentiality is managed over telehealth. Some parents also argued that telehealth services lacked personalisation. Additionally, McDevitt et al., (2021) identified some transcultural barriers to delivering telehealth interventions with parents across countries. In this study, the way in which trainers living in the US (who had immigrated from China) conceptualised autism, differed substantially to how parents receiving the intervention in China did. The authors noted differences in the social and cultural contexts between the two countries, namely, the lack of disability awareness and stigma associated with autism in China. This differed to the US conceptualisation where autism is widely considered part of neurodiversity and personal identity. The authors state that social pressures and structural barriers in the parents' cultural context often impacted the intervention. Results from the MMAT indicated that across both studies information on how the qualitative data had been analysed was either limited or entirely absent. While McDevitt et al., (2021) referenced the use of a thematic analysis, no additional information was provided, including the theoretical orientation taken. There were no references to the approach taken to analyse the qualitative data in Samadi et al., (2020)'s study. Without this information, it is not possible to ascertain the rigour of the qualitative analysis and thus, the findings.

### ***Risk Management***

Across the literature, risk was mentioned primarily in studies targeting 'problem behaviour', where participants were often excluded based on the severity of their challenging

or self-injurious behaviour. Generally, there was limited information regarding the way in which decisions were made to exclude participants, based on risk. However, two studies outlined additional steps taken to assess risk prior to the interventions. One involved a ‘safety interview’ conducted with parents or carers of autistic children (Gerow et al., 2021b), and the other conducted a risk analysis based on a tiered system, to determine behavioural plans and the level of support required by families (e.g. frequency of phone calls). In their telehealth model (based on parental accounts,), when children were assigned to tier 4 (severe maladaptive behaviours that pose immediate risk) in-home services or crisis management was offered (Yi & Dixon et al., 2021).

**Table 1.***Papers Describing the Shift to Telehealth and its Effects on Autistic People*

Author (year) Country	Literature Type	Methodology	Participant Characteristics	Technology Used	Service Provided
Adamou et al., (2021). UK	Peer reviewed, published	Survey	117 service users of autism and ADHD diagnostic pathways	Telephone, video-conferencing and combination of the two	Service users who had been assessed by autism and ADHD assessment services
Bal et al., (2021) US	Peer reviewed, published	Online Survey	adults with autism (18-74yrs)	Not specified – ‘online service’	Not specified. However, the majority reported accessing MH services prior to the pandemic, suggesting MH support are likely to be the services mostly utilised
Samadi et al., (2020). Iran	Peer reviewed, published	Non randomised experimental	336 parents of autistic children. Mean age 8yrs. Dual diagnoses incl. ADHD, CP and ID (45%)	Mobile application	30 day-care centres in Iran
Spain et al., (2021). UK	Peer reviewed, published	Online Survey	Professionals working in clinical educational and academic settings with autistic people – include views of clients and some direct quotes. Professionals: psychologists, SLT, OT, Nurses, psychological therapists, medical doctor, unqualified staff	Not specified, although Zoom mentioned	Not specified
White et al., (2021a). US	Peer reviewed, published	Online Survey	3502 parents and carers of autistic people. Mean age 12yrs, 21% ID, 13% non-verbal	Not specified	Not specified

White et al., (2021b) US	Peer reviewed, published	Online Survey	70 caregivers of autistic children and adults. 48.6% minimally verbal, 12.9% nonverbal	Not specified	Not specified
Bundy et al., (2021). UK	Grey Literature source Preprint	Online Survey	133 autistic adults (20-73yrs).	Not specified, but some mention of telephone, videoconferencing and texts	Not specified
Jacques et al., (2021). Canada	Grey Literature source Preprint	Online Survey	109 parents of autistic children (2.6–18 years) and 56 autistic children (5.75–18 years)	Not specified	Not specified
Pellicano et al., (2021). Australia	Grey Literature source Preprint	In-depth interviews	131 autistic people and families (35 autistic adults, 80 parents of autistic children and 16 young autistic people aged between 12 and 18 years). 4% ID,	Not specified	Not specified

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**Table 2.***Papers Describing the Type of Services Evaluated During the Pandemic*

Author (year) Country	Literature Type	Methodology	Participant Characteristics	Technology Used	Service Provided
Cihon et al., (2021). US	Published , peer reviewed	Experimental	3 children with autism	Videoconferenci ng (zoom)	Telehealth delivery of the Cool Versus Not Cool social skills intervention
Ferguson et al., (2020). US	Published , peer reviewed	Experimental	6 autistic children	Videoconferenci ng (zoom)	Discrete Trial Teaching ( an implemented ABA procedure)(teaching ‘tact relations’)
Gerow et al., (2021a) US	Published , peer reviewed	Experimental	Four autistic children (5- 9yrs) and parents	Videoconferenci ng	Total-task chaining procedure (ABA)
Gerow et al., (2021b) US	Published , peer reviewed	Experimental	7 autistic children (3- 11yrs)and parents	Videoconferenci ng	Parent implemented Functional Analysis and Functional Communication Training.
Kunze et al., (2021), US	Published , peer reviewed	Experimental	6 mother- child dyads (on ASD diagnostic waitlists)	Videoconferenci ng	Behavioural Interventions for Young Children on the Waitlist for an Autism Diagnosis
McDevitt et al., (2021) China	Published , peer reviewed	Semi- structured interviews and focus group interviews	4 trainers, 294 parents of autistic children	Mobile application	12 week online Parent education and training programme (PET)
O’Brian et al., (2021). US	Published , peer reviewed	Case study (Mixed Methods)	3-year-old autistic non- verbal female, with autism and moderate intellectual disability and parents	Videoconferenci ng	Functional Analysis and Functional Communication Training
Pollard et al., (2021), US	Published , peer reviewed	Archival data	17 children and adults with autism (3-29yrs)	Videoconferenci ng	ABA directly to individuals of varying needs.
Rothman, (2021), unclear	Published , peer reviewed	Case study	1 adult with autism and Downs Syndrome	Videoconferenci ng (zoom and Microsoft teams)	Dance psychotherapy intervention

Samadi et al., (2020), Iran	Published , peer reviewed	Experimental	female, early 20s) 336 caregivers of autistic children	Mobile application	Online support and training for parents
Shawler et al., (2021), US	Published , peer reviewed	Case study	Caregiver and adult with autism, Downs Syndrome, Intellectual Disability (Severe to profound) and Mixed Expressive-Receptive Disorder	Videoconferencing (zoom)	Functional Analysis and Functional Communication Training
Singh et al., (2021). Unclear	Published , peer reviewed	Experimental	Community-based mental health team and school	Videoconferencing (Zoom)	Behaviour support plan and informed mindfulness-based Soles of Feet programme SOF)
Sivaraman et al., (2021), Belgium, India, Mexico and Costa Rica	Published , peer reviewed	Experimental	6 children with autism and their families and / or therapists	Video conferencing,	Behavioural intervention to teach face mask wearing to children
Turan et al., (2020), Turkey	Published , peer reviewed	Case study	1 autistic child (11yrs male) and family	Mobile application – Special Children Support System (SPCC)	Behavioural analysis: Mobile application providing behavioural support – Special children support system
Ura et al., (2021). US	Published , peer reviewed	Experimental	41 parents of children (2-18yrs) with autism	Videoconferencing	Naturalistic instruction and behavioural strategies to increase social communication skills
Wagner et al., (2020), unclear	Published , peer reviewed	Experimental	204 Carers and children (under 3 yrs) with developmental concerns	Videoconferencing (Zoom)	TELE-ASD-PEDS evaluation of too for caregiver-medicated evaluation of ASD)-remote observations of ASD in young children
Yi & Dixon et al., (2021), US	Published , peer reviewed	RCT	14 families (7 in ACT group and 6 in control group)	Videoconferencing (Zoom or GoToMeeting)	ACT intervention to improve adherence to telehealth ABA parent training)
Andrews et al., (2020), US	Grey Literature	Experimental	4 parent-child dyads	Videoconferencing	ACT plus behaviour training

	Dissertation					
Lapin et al., (2020), US	Grey literature, Dissertation	Experimental	3 parent-child dyads (child diagnosed with autism)	Videoconferencing (GoToMeeting)	Toilet training intervention	
Nohelty et al., (2020), US	Grey literature, pre-print	Experimental	7 autistic children (4-16yrs)	Videoconferencing	DTT and Natural Environment Teaching	

**Table 3.**

*The Mixed Methods Appraisal Tool (MMAT)*

Qualitative Studies								
First author	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	1.1. Is the qualitative approach appropriate to answer the research question?	1.2. Are the qualitative data collection methods adequate to address the research question?	1.3. Are the findings adequately derived from the data?	1.4. Is the interpretation of results sufficiently substantiated by data?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
McDevitt	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Rothman	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Turan	2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Pellicano	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Randomised Controlled Trials (RCT)								
First author	Year	S1. Are there clear research questions?	2.1. Is randomization appropriately performed?	2.1. Is randomization appropriately performed?	2.1. Is randomization appropriately performed?	2.1. Is randomization appropriately performed?	2.1. Is randomization appropriately performed?	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?
Yi & Dixon	2020	Yes	Yes	Can't tell	Yes			Can't tell
Non Randomised Studies								
First author	Year	S1. Are there clear research questions?	2.1. Is randomization appropriate?	3.1. Are the participants representative of the	3.2. Are measurements appropriate	3.3. Are there complete	3.4. Are the confounders accounted for	3.5. During the study period, is

			ately performed?	target population?	regarding both the outcome and intervention (or exposure)?	outcome data?	in the design and analysis?	the intervention administered (or exposure occurred) as intended?
Cihon	2021	Yes	Yes	No	No	No	No	Yes
Ferguson	2020	Yes	Yes	No	Yes	Yes	No	Yes
Gerow	2021a	Yes	Yes	No	Yes	Yes	No	Yes
Gerow	2021b	Yes	Yes	No	Yes	Can't tell	No	Yes
Kunze	2020	Yes	Yes	No	Yes	Yes	No	Yes
Shawler	2021	Yes	Yes	No	Yes	Yes	No	Yes
Singh	2021	Yes	Yes	No	Yes	Yes	No	Yes
Sivaraman	2021	Yes	Yes	No	Yes	Yes	No	Yes
Ura	2021	Yes	Yes	Yes	Yes	No	No	Yes
Andrews	2021	Yes	Yes	No	Yes	No	No	No
Lapin	2020	Yes	Yes	No	Yes	Yes	No	Yes
Nohelty	2020	Yes	Yes	No	Yes	Yes	No	Can't tell

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Quantitative Descriptive Studies

First author	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	4.1. Is the sampling strategy relevant to address the research question?	4.2. Is the sample representative of the target population?	4.3. Are the measurements appropriate?	4.4. Is the risk of nonresponse bias low?	4.5. Is the statistical analysis appropriate to answer the research question?
Adamou	2021	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes
Bal	2021	Yes	Yes	Yes	No	Yes	Can't tell	Yes
Pollard	2021	Yes	Yes	Yes	No	Yes	Yes	Yes
White	2021a	Yes	Yes	Yes	Yes	Yes	No	Yes

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Mixed Methods Studies

First author	Year	S1. Are there clear research questions?	S2. Do the collected data allow to address the research questions?	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?	5.2. Are the different components of the study effectively integrated to answer the research question?	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?	5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?
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Spain	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
O'Brian	2021	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Samadi	2020	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No
Wagner	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell
White	2021b	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Bundy	2021	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jacques	2021	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Can't tell

## Discussion

The purpose of this scoping review was to examine the available evidence for telehealth support offered to autistic people over the course of the COVID-19 pandemic.

Studies revealed that large disruptions had been felt across healthcare services by both autistic people and professionals. Across studies there was variability in what proportion of autistic participants had accessed telehealth services. This, is likely to be a reflection of multiple factors, including, the number of services that had shifted to offering telehealth support, at what point during the pandemic studies were conducted, as well as sampling strategies and biases among studies. It is also likely to reflect variability among autistic people themselves, in whether they chose to engage with telehealth support if offered. In general, across studies, there was a preference for some degree of in-person contact. Of those that engaged with telehealth, for some, it provided a level of consistency, allowing them to continue with pre-existing support services amidst the turbulence of the pandemic. Continuity of care has been identified as an important aspect to improve in-person healthcare access for autistic people (Mason et al., 2021). Across studies, some autistic people and caregivers reported overall positive experiences of telehealth, even beyond that of in-person support and felt telehealth support should be incorporated into future practice.

## **Development of Pre-Existing Gaps in the Literature**

Prior to the pandemic, there was less focus on telehealth interventions delivered directly to autistic children or young adults (Sutherland et al., 2019). This review found that while the majority of studies involved parents or carers to a degree, three studies delivered interventions directly with autistic children and one with an autistic adults, with little or no caregiver involvement. Studies involved the delivery of practical skills to children, including, social skills and DTT, with positive results reported across social, language and adaptive domains following the telehealth intervention. Results indicate promise that in certain cases, telehealth interventions with children may not require substantial caregiver involvement. However, more research is required to substantiate this. While these studies report to have been effective, no control groups were used, meaning it is not possible to ascertain if the intervention itself caused the improvements noted. Additionally, only one collected data on social validity and despite outlining the intervention to have been acceptable and effective, received poor response rates (Cihon et al., 2021).

A further gap in the literature prior to the pandemic related to telehealth delivery to autistic people with additional needs, including those with intellectual disabilities or language impairments (Tomlinson et al., 2018), as well as autistic people with mental health presentations or acute psychiatric conditions. Unfortunately this review highlighted that no studies had been conducted over the pandemic which pertain to mental health or physical health interventions, indicating two significant gaps in the literature. While selection bias against intellectual disability was seen in surveys investigating autistic peoples experiences of the pandemic, which aligns with research throughout autism literature (Russel et al., 2019), two surveys involving caregivers, did include carers of autistic children with intellectual disabilities and language impairments. Similarly, while intervention studies were heavily dominated with individuals without intellectual disability, three case studies involved autistic

people with comorbidities, including, Down Syndrome, intellectual disability and language impairments. Of these, one case study outlined steps to help facilitate telehealth interventions with these clients. For example, in order to prepare the client for telehealth appointments, written and verbal guidance was initially sent to them, and during sessions different forms of telehealth (phone calls followed by video calls) were introduced gradually. While such steps are undoubtedly vital when supporting an autistic person with an intellectual disability over telehealth, given some of the barriers identified by this review, we feel that these steps should be routinely taken when delivering care to any autistic person via telehealth.

### **Parallels with Telehealth Literature Prior to the Pandemic**

In line with the trend observed in the literature prior to the pandemic (Antsezena et al., 2017; Ferguson et al., 2019; Kizir, 2019; Parsons et al., 2017; Sivaraman & Fahmie, 2020; Tomlinson et al., 2018; Unholz-Bowden et al., 2020) results revealed that the majority of telehealth services evaluated over the course of the pandemic delivered interventions, as opposed to assessments, to autistic people. Aligning with the pre-pandemic literature, as well as autism research in general, there was a bias towards child studies (Pellicano et al., 2014). Only one study evaluated the delivery of a diagnostic tool with parents of autistic children. In line with previous systematic reviews on telehealth diagnostic tools (Dahiya et al., 2020; Valentine et al., 2021), results were favourable in relation to future diagnoses given and practitioner satisfaction. However, aligning with previous research into tele-diagnostic assessments, the sample used in this study was questionable (Dahiya et al., 2020; Valentine et al., 2021). This calls for future research to evaluate tele-diagnostic tools with more diverse samples, including children with severe impairments and intellectual disability as well as older autistic children and adults. Across studies, videoconferencing software was the most commonly used telehealth method, and to a lesser degree, mobile phone applications.

Interventions were heavily dominated by varying forms of behavioural studies including ABA. This not only aligns with the telehealth research with autistic people prior to the pandemic (Hall et al., 2016; Tomlinson et al., 2018; Ferguson et al., 2019; Unholz-Bowden et al., 2020), but also reflects the most commonly delivered care for autistic people in general (Denne et al., 2018). Studies delivering forms of ABA were all conducted in America. This is somewhat unsurprising given ABA originated in America (Lovaas et al., 1973) and is considered ‘treatment as usual’ in the majority of states (Keenan et al., 2015). Principles from ACT were implemented in combination with behavioural telehealth interventions in two studies, which coinciding with previous research for in-person parent training, reported improvements in intervention adherence (Gould et al., 2017). This indicates a potential method to increase telehealth uptake and engagement with autistic people.

In relation to evaluation of studies, most behavioural studies (including those investigating ABA) evaluated the effectiveness or efficacy of interventions, largely concluding that interventions were successful in improving target behaviours under the study conditions (Gartlehner et al., 2006). This coincides with systematic reviews conducted prior to the pandemic (Tomlinson et al., 2018; Unholz-Bowden et al., 2020). A few studies included in the review also evaluated the fidelity of interventions and where scores were provided, these tended to be high, indicating the intervention had been completed as planned (Moncher & Prinz., 1991). It is increasingly recognised that ‘acceptability’ should be taken into account when evaluating and implementing healthcare services, to achieve the best clinical outcome in the context of available resources (Sekhon et al., 2017). One indicator of acceptability is dropout rates in interventions, which across studies included in this review, were generally low. However, there was limited other ways in which acceptability was assessed. A few studies implemented social validity measures. Social validity is often used to determine how acceptable and effective interventions are for individuals (Winnett et al., 1991)

and has been considered an important component of behaviour-analytic methodology for decades (Carr et al., 1999). Over the past decade, there have been controversies in the ABA literature relating to the high prevalence of conflict of interests in published studies (Bottema-Beutel & Crowley, 2021; Devita-Raeburn, 2016; Wilkenfeld & McCarthy, 2020), as well as reports from autistic people about harmful experiences of ABA (Kupferstein., 2018; McGill & Robinson, 2020). Given the high prevalence of ABA telehealth studies identified in this review, it is imperative that a greater understanding of how autistic people experience these interventions is determined. We recommend that any future research on telehealth with autistic people, should include ways of evaluating autistic peoples' experiences. This in turn will help services to better determine telehealth engagement and uptake with autistic people.

### **Methodological Quality of Studies**

Results from the MMAT indicated that coinciding with a review completed prior to the pandemic (Ferguson et al., 2019) the methodological quality of studies included in the present review was generally low. Across studies evaluating telehealth services, sample sizes were small and tended to lack diversity. Other than one RCT, which experienced a loss of their control group during the intervention due to the COVID-19 pandemic (Yi & Dixon et al., 2021), no other studies included control groups. In the absence of this, it is not possible to ascertain whether changes observed in participants are due to the intervention, or other factors. Across studies there was also limited information on how confounders had been controlled for. Prior to the pandemic, research had indicated that additional, follow-up appointments maybe required when completing telehealth interventions (Neely et al., 2017) however, only a small number of studies included in this review involved a follow-up session. It is therefore still not possible to ascertain whether skills taught via telehealth are generalised to other settings or consolidated after the telehealth intervention is complete.

## **New Areas of Development**

### ***Individual Factors***

Some age-related differences were noted across studies in relation to parental perceptions regarding the effectiveness of telehealth for their children, and from autistic adults themselves. In both cases, older autistic peoples' experiences of telehealth were presented in more favourable light than younger-aged adults, or children. However, given the limited number of studies, it is not possible draw a clear conclusion on this yet and more research is warranted. Age-related differences have been recognised in research investigating telehealth-use with the general population. One study examining remote mental health support during the pandemic found that significantly more children dropped out of telehealth psychotherapy support than adults. However, this was not the case for psychiatric appointments completed over telehealth (Hoffnung et al., 2021). This study also found that practitioners felt less hopeful about delivering psychotherapy over telehealth with children than adults (Hoffnung et al., 2021). Based on these findings, authors suggest that pragmatic support for children may be more applicable to telehealth delivery (Hoffnung et al., 2021). In the absence of any studies delivering mental health support to autistic children over the pandemic, it is not possible to draw the same conclusions from this review. However, this would be an important area for further exploration. Arguably, the dominance of behavioural interventions within the literature coincides with the view that pragmatic support delivered via telehealth may be more appropriate.

Some potential autism-specific barriers to accessing telehealth were suggested by this scoping review. While the ability to communicate effectively over telehealth was felt to be variable across studies, two studies involving qualitative interviews with autistic people highlighted perceived increases in social communication difficulties via telehealth (Bundy et al., 2021; Pellicano et al., 2021). Heightened pressures placed on non-verbal

communications, enhanced sensory aspects associated with videocalls and cognitive factors including, processing of conversations were identified to have been more challenging over telehealth. While we acknowledge that these two papers are yet to be published following peer review, they do provide useful insights and reflect many of the barriers that have previously been identified in literature investigating in-person healthcare accessibility for autistic people (Nicolaidis et al., 2015; Mason et al., 2019; Mason et al., 2021). Furthermore, professionals in a subsequent study shared concerns that limited access to appropriate provisions required to engage with telehealth could exacerbate healthcare disparities for autistic people and services. On an individual level, lack of provisions could result in further marginalisation of autistic people (O’Conner et al., 2020) and on a wider level, services could see an exacerbation in pre-existing challenges, including, lengthy delays for autism diagnostic services (Jones et al., 2014). Indeed, these were noted by autistic adults in one of the qualitative studies included in this review (Bundy et al., 2021). Combined, these results indicate that telehealth could have the potential to exacerbate inequalities and disparities for autistic people in relation to healthcare access. Given the current reliance on telehealth due to the pandemic, it is essential that more research is conducted in a timely manner to further investigate this.

### ***Risk Management***

Across studies there was limited information about how risk had been managed over telehealth, other than in two studies. One outlined a detailed guide on how to implement the telehealth curriculum, which included a thorough risk assessment and risk management pathway (Yi & Dixon et al., 2021). Although risk management via telehealth has been given some consideration in the literature with the general population (Edmunds et al., 2017; Kramer et al., 2016), there remains no universal framework to follow. To our understanding, prior to the pandemic, nothing had been published relating specifically to managing risk via

telehealth with autistic people. With this in mind, we feel that the guide published by Yi & Dixon et al., (2021) could be helpfully disseminated to services working with autistic people over telehealth.

### **Limitations**

Limitations of this review should be taken into account when interpreting the findings. The first limitation refers to the inclusion of grey literature sources. While the decision to include grey literature was based on the limited studies likely to have been published during the COVID-19 pandemic, we recognise that these papers have not been subjected to peer review. However, given the nature of a scoping review is to broadly examine the available evidence-base, it was felt that grey literature could provide beneficial insights.

Results from the MMAT indicated variability in relation to the quality of the studies included in the review. As scoping reviews are less restricted by methodological quality of studies, this may not impact wholly on these findings. However, it would be beneficial for a systematic review to follow this paper, to better determine the quality of the available evidence.

The vast majority of studies included in the review came from America (16 studies) and to a much lesser degree, the UK (3 studies). While other countries including, Iran, Turkey, China and Canada, were also included, we recognise that that the review is largely dominated by research originating from high-income countries. This is expected to impact on the generalisability of the results, as there are likely to be between-country variations in relation to accessibility and barriers to accessing telehealth support for autistic people. Indeed, cultural differences in how autism is conceptualised between-countries was identified in one study included in this review (McDevitt et al., 2021).



## **Conclusion**

This scoping review was the first to provide evidence on telehealth services for autistic people during the COVID-19 pandemic. Pre-determined gaps in the literature were developed, indicating some progression in the evidence-base. These included, studies involving the direct delivery of interventions with autistic children and adults, including those with additional needs, such as intellectual disability and language impairments.

This review was the first to synthesis information on risk management via telehealth with autistic people. Based on the limited studies available, a risk management framework is recommended for autism services to consider when delivering telehealth support. Some individual-level factors were identified which warrant further investigation, including, potential age-related differences in telehealth engagement and benefits, as well as potential autism-specific barriers to accessing telehealth. Autisms-specific barriers identified at both individual and systemic levels have the potential to further exacerbate pre-existing healthcare disparities for autistic people and services, unless carefully considered. Behavioural studies dominated the intervention literature, calling for an increase in diversity in both assessment and interventions over telehealth, in particular, mental health and physical health support.

During the COVID-19 pandemic there has been large disruptions to services and variability in telehealth use with autistic people. The available evidence suggests that the delivery of pragmatic support, largely involving behavioural interventions appear to be effective over telehealth. However, little is known about how autistic people experience these interventions. Due to some concerning autism-specific barriers identified, we argue that a present, telehealth support for autistic people should be considered on an individual basis, regularly reviewed and include some degree of in-person contact.

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## **Part Two: Empirical Paper**

### **The Impact of COVID-19 on the Mental Health of Autistic Adults in the UK**

## **Abstract**

The COVID-19 pandemic has been associated with mental health declines in the general population. Those with pre-existing vulnerabilities are known to be at particular risk. This may include autistic people, who have high levels of mental and physical health problems. Yet little is currently known about the impact of the pandemic on autistic people. Using an online survey, this study gathered data from 133 autistic adults in the United Kingdom (UK), about their experiences of the pandemic in relation to their mental health. Results indicated that the mental health impact of the pandemic on autistic adults was variable. A sizeable minority reported improvements in their mental health associated with COVID-19 restrictions. By contrast, most participants described an overall negative impact their levels of depression, anxiety and stress. Analysis of qualitative data using thematic analysis highlighted four themes that contributed to mental health changes in autistic adults: (i) adjusting to changes to the social world, (ii) living with uncertainty, (iii) disruptions to self-regulation, and (iv) barriers to fulfilling basic needs. Based on these findings, we discuss recommendations about how to support autistic people; both as the pandemic persists and once normality returns.

## Introduction

Discovered in late 2019, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes COVID-19, has spread rapidly through the world burdening healthcare systems globally. Early measures to reduce the spread of the virus included physical distancing rules, restrictions on social contact and quarantine regulations. The World Health Organisation (WHO) declared the COVID-19 outbreak a ‘pandemic’ in March 2020, and national ‘lockdowns’ were imposed across the world. In the UK, lockdown measures included school and workplace closures, which had widespread implications on social, educational, and economic activity (Han et al., 2020).

Emerging research has examined the impact of COVID-19 on mental health. This includes an ongoing study with over 70,000 UK respondents in the general population, plus two systematic reviews and one meta-analysis examining the effects in various countries (Fancourt et al., 2021; Salari et al., 2020; Vindegaard & Benros, 2020; Xiong et al., 2020). Higher rates of stress, anxiety and depression were reported in all studies, with one also identifying an exacerbation in pre-existing psychiatric conditions, including eating disorders (Vindegaard & Benros, 2020). Risk factors associated with mental health decline included being female, being a young adult, having pre-existing physical or psychiatric conditions, being unemployed or a student, living alone or having a child, having lower household incomes, living in urban areas and frequent exposure to social media or news relating to COVID-19 (Fancourt et al., 2021; Salari et al., 2020; Vindegaard & Benros, 2020; Xiong et al., 2020). Certain groups in society also seem particularly vulnerable to the ill-effects of the pandemic. One such group is those on the autistic spectrum.

Autistic people’s experiences during the pandemic are likely to be distinct from others with pre-existing vulnerabilities. Autistic people report higher rates of mental health problems (Lai et al., 2019), alongside increased risk of physical disabilities (Kinnear et al.,

2020) and chronic diseases (Bishop-Fitzpatrick & Rubenstein., 2019; Kinnear et al., 2020; Cashin et al., 2016).

Lifestyle changes caused by ever-changing, externally imposed regulations might be a struggle for autistic people, who often have a strong preference for sameness, predictability and adherence to routines (American Psychiatric Association, 2013). Autistic people also experience high rates of unemployment and reduced educational opportunities (Keen et al., 2016; Taylor et al., 2015), which may leave them vulnerable to the economic effects of COVID-19. Longitudinal research conducted during the pandemic, has indicated employment to be a protective factor for autistic adults' mental health (Goldfarb et al., 2021). With deteriorations in mental health reported by participants who lost their jobs during COVID-19, as well, a to a lesser degree those that transitioned to remote-working (Goldfarb et al., 2021). Taken together, the pandemic could affect autistic people's mental health in a distinct way. Conversely, autistic people report less social participation (Shattuck et al., 2011) and fewer close friendships (Baron-Cohen & Wheelwright, 2003; Liptak et al., 2011), thus, they could be less affected by the social changes caused by the pandemic. Indeed, given the social communication and interaction difficulties for autistic people (American Psychiatric Association, 2013), for some, reductions in social pressures could lead to mental health improvements.

Although prior to the pandemic autistic people were likely to have more contact with healthcare services (Vohra et al., 2016; Foley et al., 2018), pre-existing healthcare disparities were apparent (Calleja et al., 2020; Nicolaidis et al., 2015). One factor contributing to these disparities, is healthcare access for autistic people, where barriers were identified across three domains: patient-level, provider-level and system-level barriers (Nicolaidis et al., 2015; Mason et al., 2021; Vogán et al., 2017). Given the pressures places on healthcare services

during the pandemic, these barriers have the potential to be further exacerbated unless they are adequately addressed.

Over the course of the pandemic, healthcare services have been attempting to reduce the burden of COVID-19 by offering remote therapy (Zhou et al., 2020), which is showing some short-term success in the general population (Jiménez-Molina et al., 2019; Liu, et al., 2020). Prior to the pandemic, there was increasing interest in the use of telehealth technologies, for autistic people (Valentine et al., 2021; Unholz-Bowden et al., 2020; Dahiya et al., 2020; Alfuraydan et al., 2020). In the face of longstanding challenges, telehealth was considered as a plausible means to increase accessibility of healthcare provisions for autistic people. Although results show some promise, barriers identified, including, how telehealth services can be used to support autistic individuals with more complex needs (Tomlinson et al., 2018), meant that the majority of reviews outline that further research is required.

Initial research has begun to examine the psychological impact of the COVID-19 on the autistic community. While most focused on the experiences of children and families (Colizzi et al., 2020; Ersoy et al., 2020; Manning et al., 2020), a few studies have examined the effects of the pandemic on autistic adults, including participants from Belgium, the Netherlands and UK, the US and Australia (Oomen et al., 2021; Pellicano et al., 2021; Bal et al., 2021). Reductions in external pressures, but overall increases in anxiety and depression were found in two studies (Oomen et al., 2021; Pellicano et al 2021). Furthermore, risk factors for mental health decline in autistic adults were identified by one, as being female, younger, having a pre-existing mental health condition, personal COVID-19 experience, and less hope for the future (Bal et al., 2021). Access to service support varied between studies, with some autistic adults reporting to have lost some, if not all support, to others experiencing increased accessibility to healthcare (Oomen et al., 2021; Pellicano et al., 2021). This was also true of the move to online services (Bal et al., 2021). While these differences are likely

in part to reflect international differences in health systems, as well as variability in the way countries have been affected by and responded to the pandemic, it also suggests that there is considerable diversity in autistic adults' experience, and that more exploration is warranted.

The goal of this research was to gain a better understanding of how the COVID-19 pandemic impacted the mental health of autistic adults in the UK. We conducted an online survey with autistic adults during the first UK lockdown, combining multiple choice and open-ended questions about the impact of COVID-19 on their mental health and available support. We sought to gain a deeper understanding of (1) any changes in mental health over this period and how participants related this to the pandemic, and (2) the nature of support services available during the pandemic and how they were perceived.

## **Method**

### **Design**

Data were collected as part of a larger scale, longitudinal online study on “autistic adults' social behaviours, relationships and wellbeing” (which began before the COVID-19 pandemic) (see Appendix C for initial recruitment poster). Ethical approval for the study (collecting data at multiple time points) was obtained from University College London's (UCL) Research Ethics Committee (note: an ethical amendment was submitted to collect data for the current study during the pandemic) (see Appendix D). Individuals who expressed an interest in participating in the current, COVID-related study accessed an information sheet and provided their written consent online (see Appendix E & F) before completing an online survey (all via Opinio). As an incentive to participate, there was a lottery to win an i-Pad.

### **Community Involvement**

The researcher was supported by a team of researchers from University College London (UCL) and King's College London (KCL). Together, the research team comprised of

one autistic and seven non-autistic researchers. All members of the research team had academic and/or clinical experience with autistic people.

## **Context**

On 23rd March 2020, the UK entered a national lockdown. Many businesses and schools physically closed and moved online, and people were only permitted to leave the house for limited purposes, including, food shopping, one form of daily exercise, urgent medical needs and work where necessary. Participants were contacted for this study between 29<sup>th</sup> May and 1<sup>st</sup> July 2020, meaning results are based on experiences of 10-15 weeks in lockdown.

## **Participants**

Participants were initially recruited for a large-scale, longitudinal study between February-April 2020, via social media, autism support groups and the Cambridge Autism Research Database (CARD). To be eligible to take part, participants needed to be over the age of 18, without a diagnosed intellectual disability and either formally or self-diagnosed as autistic<sup>3</sup>. Including self-diagnosed autistic people is common practice (Benevides et al., 2020; Lewis, 2017) and allowed access to a more diverse population, given barriers to accessing diagnoses in adulthood (Huang et al., 2020). Of the 258 UK participants that opted into the original (pre-Covid) longitudinal study, 133 chose to take part in the current study on COVID-19<sup>4</sup>. Participants reported their nationalities as British, English or Scottish; no participants reported being from Northern Ireland or Wales. English was the first language for all participants. Of the sample, 93.2% had received a formal diagnosis of autism, and 6.8%

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<sup>3</sup> There were no statistically significant differences in mean autism trait scores (AQ-10) between those that self-identified as autistic (M=7.56) and those with a formal diagnosis (M=8.2),  $t(131) = -1.165$ ,  $p = .246$ , 95% CI [-1.74, 0.45].

<sup>4</sup> Comparisons between individuals that participated in only the first study prior to the pandemic (N=125) and those that participated in both waves (first study and follow-up) (N=133), showed no difference in their likelihood of being female (OR = 1.06, 95% CI: 0.62, 1.80) or whether they were university educated (OR:0.87, 95% CI: 0.53, 1.43). There were no statistically significant differences in mean autism trait scores (AQ-10) between the first study (M=7.90) and the follow-up (M=8.16),  $t(256) = -1.186$ ,  $p = .491$ , 95% CI [-0.68, 0.17].

self-identified as autistic. Over half of the sample (69.2%) reported their birth sex as female and gender identity as female (63.2%). Participants ranged from 20 to 72 years old. More detailed participant characteristics can be found in table 1.

**Table 1.**

*Participant Characteristics (N=133)*

Characteristics		n (%)
Birth sex:	Female	92 (69.2%)
	Male	39 (29.3%)
	Other (intersex and no sex)	2 (1.5%)
Gender identity <sup>a</sup> :	Female	84 (63.2%)
	Male	38 (28.6%)
	Non-binary / Bigender	8 (6%)
	Cisgender	6 (4.5%)
	Other	5 (3.8%)
	Gender Neutral	4 (3%)
	Transgender	1 (0.8%)
Age (years):	Mean	42.93
	SD:	12.76
	Range:	20-72
Description of diagnosis:	Autism	91 (68.4%)
	Atypical autism	28 (21.1%)
	Autism spectrum disorder	14 (10.5%)
Diagnostic status	Formally diagnosed	124 (93.2%)
	Self-diagnosed	9 (6.8%)
Autism Spectrum Quotient-10 (AQ-10):	Mean	8.16
	Median	9
	Mode	9
	SD	1.61



Living arrangements:	At home with partner and / or children	64 (48.1%)
	At home alone	35 (26.3%)
	At home with parents and / or grandparents and / or siblings	19 (14.3%)
	At home with flatmates / friends	8 (6%)
	Other	6 (4.5%)
	In supported accommodation	1 (0.8%)
Highest level of education / qualification	Postgraduate university degree	47 (35.3%)
	Undergraduate university degree	34 (25.6%)
	Secondary / high school or equivalent	25 (18.8%)
	Technical school / trade school / apprenticeship	15 (11.3%)
	Other qualifications	12 (9%)
Current education & employment <sup>a,b</sup>	Full-time paid work	46 (34.6%)
	No employment, not looking for work	34 (25.6%)
	Part-time paid work	26 (19.5%)
	Other	19 (14.3%)
	Working voluntarily	9 (6.8%)
	No employment, looking for work	6 (4.5%)
	Not in education	110 (82.7%)
	Part-time education	15 (11.3%)

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<sup>a</sup> *Category not mutually exclusive*

<sup>b</sup> *Employment status prior to the pandemic*

## **Materials**

The online questionnaire comprised of, demographic questions, the Autism Spectrum Quotient-10 (AQ-10) and questions relating to the mental health effects of the pandemic. The COVID-19 questions were adapted from questions used in a large scale longitudinal study (UCL Social Study) with over 70,000 adults from the UK general population (Fancourt et al., 2021). While this study contained questions relating to a number of areas, only questions specifically relating to the mental health impact of COVID were included and adapted in the present questionnaire. Adaptions involved, including additional demographic questions relating to gender identity and health comorbidities. These took into account the high rates of comorbidities and gender-dysphoric traits reported by the autism community (George & Stokes, 2017; Mannion & Leader, 2013), Further adaptions involved, increasing Likert scale response options and dividing questions relating to the mental health impact into two areas (in response to the virus and in response to lockdown measures). Lastly, in line with one of our research questions, a question was included in relation to access to service support during the pandemic.

Eighteen COVID-19 questions were analysed, which focused specifically on the two research questions relating to mental health changes and access to service support during the pandemic (see Appendix G). Questions were divided into four broad sections: access to service support, mental health change, hardships that had impacted mental health and factors supporting mental health.

Of the eighteen questions that were the focus of this paper, eight were open-ended questions. Participants were asked to describe the following: How easy or difficult it had been to understand and access government information relating to COVID-19, how easy it had been to access or receive financial support during COVID-19, to what degree their needs had been met by services, how COVID-19 had impacted their mental health, how hardships had impacted them, factors which had helped their mental health during the pandemic, and whether their life had improved in any way as a result of the pandemic. The remaining ten questions involved, multiple choice, or rating scales, relating specifically to perceived mental health changes and access to support services.

### **Data Analysis**

Quantitative data are presented descriptively, providing total numbers, percentages, and frequencies, which provided insight into participants perceived mental health changes and access to service support. This was then understood in more depth through analysis of the qualitative data, using reflexive Thematic Analysis (Braun & Clarke, 2006, 2013, 2019). Thematic analysis is a method for identifying, analysing and reporting patterns across a dataset (Braun & Clarke., 2006). Qualitative analysis was conducted from a critical-realist framework, meaning participants accounts were taken as being true to them, as well as impacted by factors from wider social contexts (Braun & Clarke, 2013; Willig, 2013). An inductive, or 'bottom-up' approach was used to generate themes, which were identified at a semantic level, meaning that themes were strongly linked to the data, rather than being driven by preconceived analytic assumptions of the researcher (Braun & Clarke, 2020). This paper adopted a reflexive thematic analysis which allowed the researcher to engage in a reflective and thoughtful manner with the data and with the analytic processes itself (Braun & Clarke., 2019). The analysis was led by R.B, but followed a collaborative approach with regular input

at all stages from a second researcher J.C<sup>5</sup> and the wider team. Working with more than one researcher in the analytic process, allowed for a coding approach which was collaborative and reflexive, and allowed the development of richer, more nuanced reading of the data (Braun & Clarke, 2019). This was felt to be appropriate, given the complexity of the COVID-19 pandemic. Analysis involved recursively moving through the data by reading and re-reading responses, while simultaneously making notes of emerging patterns. Extracts of data were then assigned ‘codes’, which were revisited and revised by R.B. Codes were then organised into broader analytical themes. Appendix H outlines stages of coding and theme development throughout the qualitative analysis. Finally, a negative case analysis was undertaken to highlight any data that contradicted the identified themes and strengthen the rigor of the analyses (Tenzek, 2017).

### **Researchers Positionality**

In thematic analysis, researchers are viewed as active participants in the production and development of themes (Braun & Clarke, 2006). With this in mind, consideration is given to the researchers background, beliefs and positionality, which will impact on the analysis.

The researcher is a white, well educated, non-autistic, able-bodied female, with no lived experience of accessing mental health services. The researcher has personal relationships with autistic people, and experience working as an aspiring psychologist with autistic people in a variety of mental health settings. These experiences have developed an awareness of the large gaps in knowledge and limited service provisions that exist in relation to autism, and a desire to advocate for change to improve lives for autistic people. With regards to positionality, the researcher views autism within a social model of disability, that

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<sup>5</sup> JC is a PhD student part of the wider research team.

reflects the principles of developmental psychopathology. This approach seeks to improve the lives of autistic people by improving the fit between the individual and their environment (Mandy & Lai, 2016). Crucially, this approach places emphasis on the need to modify the environments in which autistic people exist, rather than placing sole emphasis on the need for autistic people to adapt to fit current structures in society (e.g., Mandy et al., 2016). This is likely to affect the way in which the data are interpreted.

## Results

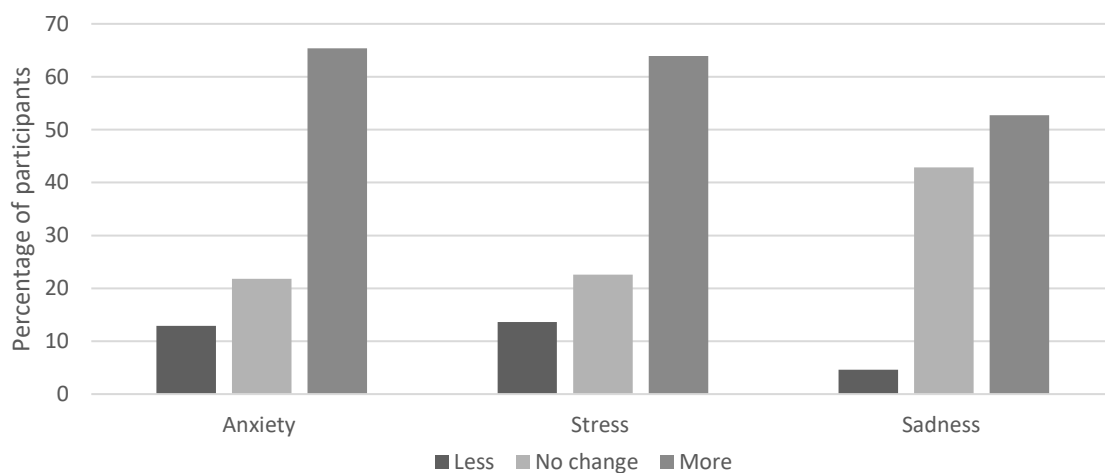
### Quantitative Results

#### *Mental Health Response to the COVID-19 Virus*

Over half of participants reported experiencing more anxiety (65.4%), stress (63.9%) and sadness (52.7%) due to the COVID-19 virus. Fewer reported no changes in anxiety (21.8%), stress (22.6%) or sadness (42.9%), and even fewer reported experiencing less anxiety (12.9%), stress (13.6%) and sadness (4.6%) (see Figure 1).

**Figure 1.**

*Participants Perceptions of Changes in Anxiety, Stress and Sadness as a Result of the Covid-19 Virus*

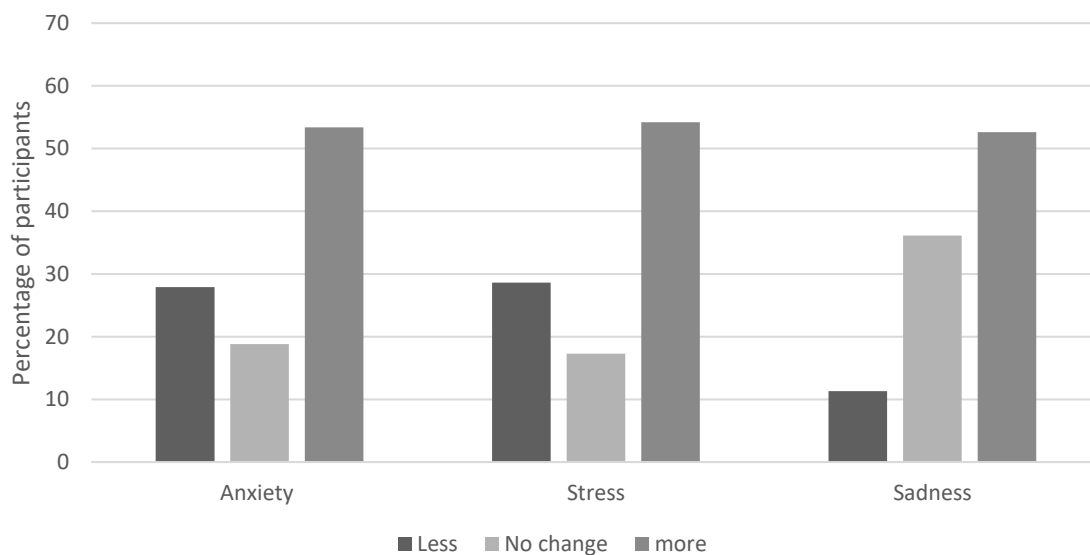


#### *Mental Health Response to the Lockdown Measures*

Over half of participants reported more anxiety (53.4%), stress (54.2%) and sadness (52.6%) due to lockdown measures, and fewer noticed no changes to anxiety (18.8%), stress (17.3%) and sadness (36.1%). In relation to mental health improvements due to lockdown measures, 27.9% of participants noted improvements in anxiety, 28.6% in stress and 11.3% in sadness.

**Figure 2.**

*Participants Perceptions of Changes in Anxiety, Stress and Sadness as a Result of the Lockdown Measures*



### ***Service Support***

Regarding how well participants had been supported by usual support services during the pandemic, 55.6% reported this question to not apply to them, due to having not previously accessed support services. Of the remaining participants, 24% reported their needs to have been met, 14.3% reported their needs to have not been met and 6% reported no changes to their support services during the pandemic.

### ***Factors Negatively Impacting Mental Health***

From the categories that might negatively impact participants mental health and wellbeing, the three most common factors were: changes to normal routines (71.4%), fear about someone close to them becoming ill with COVID-19 (60.9%) and uncertainty about lockdown measures (58.6%).

### ***Hardships***

The most common hardships reported as a consequence of COVID-19 and related measures were: being unable to access usual support services (30.8%), increased caring responsibilities (27.1%) and being unable to access enough or suitable foods (24.1%).

### ***Factors Supporting Mental Health***

The most common factors reported to have supported participants mental health were: engaging in leisure activities alone (68.4%), socialising with others via phone calls, virtual meetings, text messages or emails (49.6%) and exercising (48.1%) (see Table 2).

**Table 2.**

*Factors Effecting Mental Health, Experiences of Hardships and Factors Supporting Mental Health for Participants over the COVID-19 Pandemic*

	n (%)
Factors negatively impacting mental health and wellbeing:	
Changes to normal routines	95 (71.4%)
Fear about someone close to me becoming ill with Covid-19	81 (60.9%)
Uncertainty about lockdown measures	78 (58.6%)
Changes in the home (increased time at home with other members of the household)	69 (51.9%)
Feeling isolated or lonely	62 (46.6%)
Fear about becoming ill with Covid-19	58 (43.6%)
Changes to social support	46 (34.6%)
Uncertainty about employment and financial circumstances	45 (33.8%)
Poor physical health	43 (32.3%)
Current financial pressure	31 (23.3%)
Increases in caring responsibilities	28 (21.1%)
Someone close getting ill with Covid-19	16 (12%)
Being ill with Covid-19	12 (9%)
Experience of hardships:	
Unable to access usual support services	41 (30.8%)
Increased caring responsibilities	36 (27.1%)
Unable to access enough / suitable food	32 (24.1%)
Unable to access medication	20 (15%)
Major reduction in income	16 (12%)
Self or someone close becoming unwell with Covid-19	13 (9.8%)
Unable to pay bills / rent / mortgage	6 (4.5%)
Loss of job or regular income	4 (3%)
Evicted / loss of accommodation	1 (0.8%)



Factors supporting mental health:	Spending time engaging in leisure activities alone	91 (68.4%)
	Spending time socialising with others via phone calls, virtual meetings, text messages, emails etc.	66 (49.6%)
	Spending time exercising	64 (48.1%)
	Creating daily and / or weekly routines or sticking to an existing daily or weekly routine	61 (45.9%)
	Spending time on self-care for mental health	44 (33.1%)
	Spending time engaging in leisure activities with members of the household	40 (30.1%)

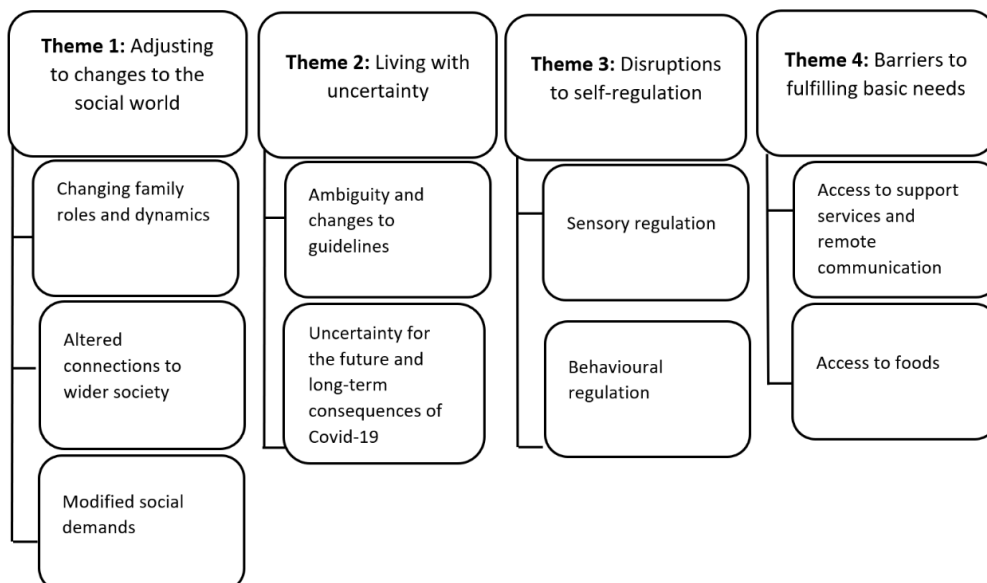
*Note.* Categories not mutually exclusive

### Qualitative Results

Using thematic analysis, four overarching themes were identified: (1) adjusting to changes to the social world, (2) living with uncertainty, (3) disruptions to self-regulation and (4) barriers to fulfilling basic needs, each with several subthemes (see Figure 3). Participant ID numbers are given after quotes.

### Figure 3.

*Themes and Subthemes of how the Covid-19 pandemic Impacted the Mental Health of Autistic Adults'*



## **Theme 1: Adjusting to Changes to the Social World**

This theme refers to COVID-19-related social changes experienced inside and outside the household.

*Sub-theme 1: Changing family roles and dynamics.* Participants described various ways that household dynamics had changed during lockdown. Family played a central role in the lives of many, and for some, the additional time spent together engaging in shared activities strengthened their bonds:

“Time spent with my family doing things together can be lovely - there are no other people I relate to so well and enjoy being with so much, although I still get exhausted through the contact. I love the feeling of being a network rather than an individual with them” (52).

Due to the importance of loved ones, many of the participants expressed concerns about loved ones becoming unwell with COVID-19, and how the pandemic had impacted on their lives:

“The children have been distressed, anxious and have found it too hard to cope with not knowing what is going to happen and we have had to cope with very distressed behaviours and increased instances of self-harm” (45).

At the same time, increased time spent together resulted in family disputes and household disconnect more frequently occurring, which negatively impacted participants’ mental health: “Increased time spent around family has caused me extra stress and anxiety as well as feelings of guilt, worthlessness and anger” (123). Furthermore, some participants also recognised challenges associated with changes to household dynamics, including increased responsibility. The ‘caring-role’ and need to portray external strength to protect others often impacted on participants’ own mental wellbeing: “I am the carer, the one who puts people

back together so I have to seem strong and not dissolve - but inside I do. I also have constant housework to do which is not valued - it's unrelenting. I feel invisible. I feel exhausted” (52).

For others, the pandemic brought the need to adopt entirely new caring-roles for vulnerable people in their household. For some participants this was amplified in the absence of others who may ordinarily share such responsibilities. Adjusting to new roles was challenging and at times contributed to heightened anxiety:

“The main concern was taking care of my parents. I am not a natural caregiver so it was a steep learning curve for me to adjust to having to cook and clean for them at first. My older sister isn't autistic but she works as a senior nurse so wasn't allowed to visit us and help out like she normally would have” (114).

Challenges for many were often exacerbated in the absence of adequate “alone-time”, which was a vital form of coping through self-regulation:

“Having zero time at home alone. My wife is at home all day so [...]I have no down time to process the day. Just before lockdown the OT [Occupational Therapist] in the autism service encouraged me to have time alone each day, especially when I get in from work. Lockdown is making that impossible. Always anticipating an interruption to my thoughts or whatever (meaningful or meaningless) task I am doing” (59).

***Sub-theme 2: Altered connections to wider society.*** The pandemic had altered most participants' sense of connectedness, but in various ways. For the majority, reduced in-person contact resulted in loss of connection to communities and social groups that participants had worked hard to build, and the desire to reconnect to these communities was associated with distress, loneliness, and isolation: “This has caused loneliness and a sense of meaninglessness in my life as despite my social anxiety I strongly want to feel connected to people, something which the current isolation has denied me” (123).

Prior to lockdown, many relied heavily on social support to manage their daily lives, the absence of which left participants fearful of how they would cope with the ongoing challenges of the pandemic:

“Practically all my coping strategies prior to COVID-19 involved other people, or travelling to places. All of that has been prevented by lockdown measures and I don't know how to cope anymore. [...] Trouble is, I can't get someone to hold my hand so I feel safe until I learn how things have changed and develop new ways to cope. I feel trapped, imprisoned alone” (10).

For a few participants, the need for social connection was felt so extremely that it resulted in self-harm and suicidal ideation, requiring them to break lockdown rules:

“I've had a couple of in-person visits from one of my partners since lockdown started - this contravenes lockdown rules but was necessary due to the severity of my mental health, which was causing me to self-harm due to despair at the lack of contact, and was pushing me close to suicide” (10).

Other participants however, felt the shared challenges of pandemic contributed to heightened feelings of connection to others. These participants were comforted by others' efforts to reconnect with them, which they felt had been encouraged by the pandemic. The experiences of shared struggles elicited feelings of validation for some participants, partly due to prior experiences of marginalisation: “Often I struggle on my own and feel bad I can't just 'do normal' like other people. It's validating to be struggling alongside others for a change” (90). Entirely in contrast with this were a small number of participants that felt no desire to connect to wider society. These participants noticed a sharp improvement in their mental health in light of altered connections: “It has taught me that the further I am from neurotypical people, the stronger my mental health is!” (63).

*Sub-theme 3: Modified social demands.* While some participants felt a strong desire to connect with others during these times, many recognised that some of the social demands that had existed outside the home (e.g., workplace, school) prior to lockdown had negatively affected them and appreciated the relief:

“The pressure of having social engagements I'd rather avoid has gone! [...]I can stay at home without guilt - in fact I've been told to stay here!” (52).

Fewer in-person social demands meant participants did not have to conform, mask, or “care about how to act, or what other people think” (56) as much. For some participants this led to increased awareness of masking: “I have been much more aware of my masking when I have had to go into a work situation and realised just how much I do this and have been able to relax it during lockdown” (39). However, some recognised that the forced social avoidance of lockdown also exacerbated fear of socialising and raised concerns about having to reintegrate back into society when lockdown eased:

“I have become anxious about leaving the house (something I have always found slightly difficult especially if I haven't left the house at least every other day). Being in lockdown has meant being at home much more and this has made my anxiety about going out much worse. I have not felt able to go out on my own” (118).

Alternatively, due to increased reliance on remote technology during lockdown, a subset of participants commented on feeling heightened pressures to socialise relative to pre-lockdown. Little time to recharge between interactions was associated with feelings of fatigue for these participants, who recognised the importance of managing the frequency and length of remote interactions: “I don't mind being in contact with other people but they tend to be on the phone for too long, and that can take its toll; I prefer short and often, they prefer long and not every often” (6).

## **Theme 2: Living with Uncertainty**

This theme encapsulates the level of uncertainty felt throughout the pandemic, focusing specifically on rules and guidelines, as well as long-term consequences of the pandemic.

*Sub-theme 1: Ambiguity and changes to guidelines.* Although some participants described feeling distressed by the perceived lack of time to prepare for lockdown, many found information presented at the start of lockdown clear and relatively easy to understand. However, as lockdown began to ease, participants found rules and guidelines increasingly difficult to understand due to the lack of clarity and “mismatch” (10) of information across sources. Many described a duty to “obey to the letter” (8), but the ambiguity of messages often left them unable to do so, which resulted in extreme distress, and fear of breaking rules. As a result, some participants further isolated themselves:

“There were written articles online, but every single one contradicted each other and the rules were never consistent. It made me extremely anxious, angry and worried that I weren't following the correct procedures and rules, and that I might get in trouble by the police if I went outside for any reason. So I completely isolated myself in my house because I was too scared to get in trouble. This was very hard on my mental health” (110).

Changes to government rules and recommendations were also felt to be cognitively demanding due to participants having to remain vigilant to changes:

“It takes a lot out of my mental energy and adds to my cognitive load because I am always on edge and alert trying to figure out what the next thing to do is, or what the right thing to do” (9).

Some described increased demands placed on their executive functions, for example,

when making plans to leave the house: “Having to think extra things when I have had to go out (executive functioning) about protective measures like hand washing, not touching my face, taking hand sanitiser with me, keeping two metres apart from others can be tiring” (39).

Not only was there concern about participant’s personal understanding of guidelines, but how well others understood them and followed them. This was often associated with emotional distress:

“I am very distressed by people getting more lax about social distancing outdoors, even though I don't feel I'm at high risk from COVID-19. I'm more upset that people aren't doing what they should be which makes me anxious and upset.” (90).

***Sub-theme 2: Uncertainty for the future and long-term consequences of COVID-19.***

Uncertainty about job security, healthcare, education and more broadly “how life will differ” (42) in the long-term, contributed to stress for many. Some questioned their ability to adapt back to ‘normality’ in the future due to the extent to which things had changed. “I am fearful of how I will cope when I need to return to work due to the amount that will have changed. It will be difficult to manage and I don’t cope with change well”. (135)

For participants that were studying during lockdown, disruption to the way in which courses were taught alongside uncertainty about employment trajectory, left them fearful of the long-term consequences of the pandemic: “I don't know if people will see my degree as lesser due to finishing online or if I will be able to find any good employment afterwards [...] I wonder if it's even worthwhile trying anymore”. (56)

**Theme 3: Disruptions to Self-Regulation**

This theme encompasses changes that occurred to self-regulation, including sensory regulation and behavioural regulation.

***Sub-theme 1: Sensory regulation.*** Due to closures and restrictions during lockdown, participants described their sensory worlds changing. Some noticed a reduction in sensory input and greater control over their sensory environment, which positively impacted their ability to cope: “I have not had any meltdowns since lockdown. I believe this is because I am working from home, no commute, no bus, no open plan office, no shopping centres. No sensory overload” (126).

At the same time, participants recognised challenges of managing their sensory environment at home. Due to more people staying at home, some experienced increased noise pollution in neighbourhoods and households during lockdown. This was further compounded by limited space to escape from the noise to self-regulate:

“Noise from the neighbours being constantly home and in their garden, having parties, screaming kids etc. means having an open window increases the noise, but closing it means I am too hot. The noise and heat both overload my senses and I feel like screaming” (31).

***Sub-theme 2: Behavioural regulation.*** The ability to establish structured routines was helpful for many in managing the multifaceted stressors of the pandemic. When achieved, some felt more in control of routines due to less disruptions from external factors. At the same time, many participants described challenges maintaining routines in the face of frequent and often unexpected changes. For many deviation from normality led to anxiety, and having to frequently learn to adjust to such changes negatively affected their mental health:

“My routine has changed dramatically and it has really thrown me. It has taken me many weeks to try and establish a new routine with when to go to bed, when to get up, how to work from home, how to work at school safely looking after the key worker



children. And now it has all changed all over again. every time it changes, it brings new anxiety” (9).

For those that could access their routines, there was more time to engage in hobbies and special interests of both solitary nature and with households. Increased appreciation for nature was found by many participants over this period, alongside ‘self-care’ activities, including mindfulness, journaling or exercising: “I have enjoyed spending time in my garden and found a new enjoyment in nature” (41). For some participants increased reliance on remote communication provided greater structure, consistency and control over chosen social outlets and offered opportunities, such as workshops, webinars and online exercise classes, that were “free from travel hassles” (132), and supported their wellbeing:

“My employer has put on be-well webinars for us to learn about homeworking, mental wellbeing, nutrition exercise etc, which inspired me to get into good habits with taking exercise, having a routine, switching off, going for walks, vitamins” (126).

However, for other participants engaging in special interests was challenging due to restrictions, which left them feeling a loss in their “purpose in life” (88), leading to worsened mental health: “Some of my special interests have just stopped for the foreseeable future. This made it the most hard for me to adjust.” (12).

#### **Theme 4: Barriers to Fulfilling Basic Needs**

This theme refers to participants’ ability to fulfil basic needs of accessing healthcare and food during the pandemic.

*Sub-theme 1: Access to support services and remote communication.* Experiences of accessing healthcare were variable. Longstanding feelings of services not meeting the needs of the autistic community were felt to have been exacerbated in the current climate. Many

struggled with waiting times for healthcare services and/or felt concerned about continuity of their healthcare in the future: “Add the existing problems with waiting lists to the huge backlog that will result from the lockdown and nobody is going to get adequate care for a long time” (13). Participants with co-occurring health conditions experienced challenges accessing routine medications, which, compounded by inadequate support, contributed to a heightened sense of vulnerability: “It feels like too much to deal with, made worse by no guidance or support services at all. We are trapped and frightened and feel entirely alone” (45).

There was general recognition that lockdown had increased reliance on remote interactions to access service support and sustain social connections during the pandemic, including, texts, phone calls, emails and video calls. Several participants were offered remote support services. While a minority felt well supported by this, for the majority, remote support appeared to come with a new set of difficulties. Many described challenges associated with sensory aspects, such as, background noise which made conversations more challenging to process: “I also found video calls very tiring because there is so much noise and so much going on, trying to follow the conversations are really hard, especially with computer lag etc” (9). Video calls were associated with heightened pressure on non-verbal communication, including eye contact and conversational cues, and challenges interpreting body language. Additionally, some participants noticed feeling self-conscious when using video calls, due to having to view themselves on screen, and reported feeling a lack of control over who was watching them on the other end:

“Video calling and phone calls aren't helpful for me due to the level of eye contact, appropriate conversation spacing and other skills required to maintain a decent level of social interaction. I find these just make me more stressed and anxious afterwards than when I began” (104).

Due to these challenges, some participants declined offers of remote therapy with concerns about it being inappropriate or inaccessible, and opted to wait for in-person contact to resume. Of participants that engaged, some found videocalls a poor replacement to in-person contact due to being “too unpleasant and cold” (123) or feeling unsafe, which ultimately led to disengagement from service support entirely: “I have also been unable to continue with psychotherapy for depression and complex trauma as I couldn't tolerate video therapy (I felt the human connection and sense of safety were lacking, both of which are incredibly important for me)” (123).

***Sub-theme 2: Access to foods.*** Some participants also struggled with changes to their food routine. This included shopping at different places and needing to purchase new brands or foods due to limitations. Owing to this, as well as general emotional upset, some described a reduction in their food intake, which resulted in an exacerbation of eating disordered behaviour for a few: “I have an eating disorder, which is common in able autistic women, and being unable to get foods I rely on or brands I need is difficult, as is the limit of 3 of any one item” (90).

## **Discussion**

We aimed to investigate the mental health impact of the COVID-19 pandemic on autistic adults across the UK. We combined quantitative and qualitative data, to achieve a rich understanding of how the pandemic had influenced the lives of autistic adults. Overall, our results indicated that the impact of the pandemic on autistic peoples' mental health has been variable. Some participants experienced both positive and negative mental health changes. For others, experiences were either entirely positive or negative. Although a sizeable minority experienced mental health improvements, negative mental health effects were evident to a greater degree. Unfortunately, at the time of writing the COVID-19 pandemic is far from over, thus these results and associated recommendations can inform

support for autistic adults' as the pandemic persists as well as for the time after and during any future pandemics.

### **Beneficial Effects of the Pandemic**

The quantitative data demonstrated that a sizeable minority of participants reported improvements in anxiety and stress in response to the lockdown measures taken to combat COVID-19. Specific mechanisms underpinning these mental health improvements were suggested by the qualitative analysis. Relief from social pressures due to less in-person social demands led to an improvement in anxiety for many, and alleviated feelings of guilt which were previously associated with avoidance of social occasions. In relation to this, some felt that a reduction in the need to “mask” or ‘camouflage’ also contributed to general mental health improvements. Camouflaging has been associated with mental health challenges including anxiety, depression, and higher rates of suicidality (Cassidy et al., 2018; Hull et al., 2017; Mandy, 2019). It is worth highlighting that the participants had originally been recruited for a study about ‘social behaviours’, which could increase the likelihood that participants who took part engage in camouflaging behaviours.

### **Declines in Mental Health**

Quantitative results indicated that over half of the sample noted worsening in feelings of anxiety, stress and sadness in relation to the COVID-19 virus and lockdown measures. Although it is worth noting that more participants noted worsening in anxiety and stress in response to the virus than lockdown measures. This finding is concerning given autistic people’s heightened risk of depression and anxiety pre-pandemic (Kirsch et al., 2020). Our qualitative findings suggest that factors including lack of connection to others, loss of social support, changes to household roles and dynamics and family disputes all contributed to mental health declines. Having reduced time and space to self-regulate during lockdown, and disruptions to routines and sensory environments, were further factors that left participants

feeling overwhelmed and suffering subsequent mental health declines. Given the unrest caused by COVID-19 and the association between autism and difficulties with emotional regulation (Mazefsky et al., 2013) and emotional processing (Dijkhuis et al., 2017) this finding is somewhat unsurprising. However, with lockdown measures placing restrictions on many people's ways of coping, the need for additional service support for the autistic community appears even more essential.

Prior to the pandemic, accessibility was a huge problem for autistic people (Pellicano & Stears, 2020), and this appears to have been amplified over this period. Our results indicate that autistic people struggled to get some of their basic needs met during the lockdown (e.g., access to specific foods). Similar to research with the general population (Vindegaard & Benros, 2020), this left some experiencing more eating disordered behaviour. Given the elevated prevalence of eating disorders in autistic people (Brede et al., 2020; Westwood et al., 2017; Westwood et al., 2018), this is concerning. Additional measures for the autistic community, such as, including them in priority access times for supermarkets and delivery slots could be a useful way to support this.

Autistic people are more likely to experience barriers to effectively accessing healthcare (Mason et al., 2019). This was true of our findings, with 30% of the sample experiencing challenges to accessing appropriate care during the early stages of the pandemic. Challenges such as waiting times for appointments and diagnostic assessments were perceived to have been exacerbated above the pre-existing lengthy delays (Jones et al., 2014). With our results, alongside others (Oomen et al., 2021; Pellicano et al., 2021; Bal., 2021) indicating a possible increase in mental health need in autistic adults over the pandemic, it is essential that additional mental health provisions are place during this period. Due to the immense pressures on all areas of healthcare during the pandemic, disruptions were likely unavoidable (Maringe et al, 2020; Søreide et al, 2020; Wastnedge et al, 2020).

However, with disparities for autistic people accessing healthcare prior to the pandemic, this gap is only likely to further widen unless autism-specific provisions are urgently put in place.

Our results indicated some variability in participants' experiences of telehealth. While a small proportion found it beneficial, barriers to accessibility were experienced by the majority. Our results identified individual level autism-specific barriers that compounded the accessibility of telehealth, including challenges associated with sensory sensitivities, body awareness, processing speed and non-verbal communication; findings in line with previous research into general healthcare accessibility for autistic adults (Nicolaidis et al., 2015). Alongside awareness of individual level-barriers, our findings align with previous recommendations: to increase accessibility of healthcare for autistic people, changes are required at provider- and system-levels (Nicolaidis et al., 2015). Some potential alterations that could be made to support autistic people using telehealth platforms, include, providing information and resources on how to navigate telehealth in advance of appointments, allowing individuals time to prepare. Increasing provider understanding of potential autism-related barriers when using telehealth, which, in the context of increased communication and processing speed challenging, could involve, allowing for additional sessions, or covering less material during sessions.

Similar to previous studies (Pellicano et al., 2021; Oomen et al., 2021), our results highlighted that the lack of clarity in government guidelines regarding COVID-19. This left participants feeling distressed and led to some participants further isolating themselves indoors. Guidelines were felt to be cognitively demanding, with particular pressure placed on executive functions, which have been associated with barriers to healthcare in autistic adults (Mason et al., 2019). The frequency with which guidance changed, and the lack of time to prepare for changes, was distressing for many participants. Given the association between predictability and general health and wellbeing for autistic people (Rodger & Umailbalan,

2011), it is somewhat unsurprising. Our recommendations align with principles outlined by behavioural and social scientists to improve adherence to government messages during the pandemic (Bonell et al., 2020). This includes ensuring guidance is clear, specific, and reviewed regularly, which can support people to anticipate possible barriers in advance of any changes. While these recommendations are made for the general population, based on our results, we argue that this is particularly important for the autistic community.

While a relatively small number of participants had experienced occupational loss at the time our data was collected (early stages of the pandemic), in line with other research conducted during the pandemic (Goldfarb et al., 2021), our results indicated that financial and employment uncertainty contributed to distress for many. In the context of pre-determined low rates of employment and earnings (Roux et al., 2019) for autistic adults, as well as poorer employment opportunities, educational outcomes (Shattuck et al., 2012) and employment longevity (Taylor et al., 2015), the economic crisis caused by COVID-19 is likely to further exacerbate these disparities. Although research has begun to investigate this area (Goldfarb et al., 2021), to better understand the economic impact on the autistic community, careful monitoring and additional, longitudinal research is required.

### **Ways to Mitigate Against the Effects of the Pandemic**

The various factors that helped participants to manage the daily struggles of the pandemic enforces the importance of accounting for the heterogeneity of autistic people, particularly when considering how they can best be supported (Nicolaidis et al., 2015). Factors that supported participants included, maintaining consistent daily routines and sensory environments, as well as increased time with loved ones and engagement in various activities helped with self-regulation. Within these activities, many participants took active steps to engage in varying forms of grounding techniques, mindfulness and journaling, and found enjoyment in nature or exercise. Such ‘self-care’ activities, are likely to help

participants connect to their present moment, and in the face of instability, allow for a greater sense of control. Mindfulness teaches attention regulation skills, self-awareness and emotional regulation (Tang et al., 2015), which may be particularly helpful for some autistic people during the pandemic. Furthermore, the shared experience of the pandemic left some participants overcoming feelings of social marginalisation, which is unfortunately a common experience for many autistic people (O'Connor et al., 2020).

Previous research has identified that many autistic young people struggle to know what 'normal' feels like, and in turn, what support would be useful for them (Crane et al., 2019). With this in mind, our findings could be beneficial in supporting autistic people to better establish what works for them, and in turn, learn to self-regulate. These pieces of information should be translated into routine practice, both during the pandemic and after.

### **Limitations**

In relation to sampling characteristics, participants were not eligible for the present study if they had an intellectual disability, meaning the sample is not fully representative of the autism population. However, it does study a group (autistic individuals without an intellectual disability) that commonly get overlooked in research relating to support needs (Crane et al., 2019). Participants were also recruited from support groups and online communities and are therefore less likely to be totally isolated pre-pandemic. There was also female-dominance in our sample, which is contrary to standard conceptions of the autistic population (Geelhand et al., 2019), however, often seen in online research with autistic adults (Pellicano et al., 2021; Oomen et al., 2021).

The use of single questions to measure mental health aspects (anxiety, stress and sadness), in the absence of formal, standardised measures is a further limitation of the present study. We acknowledge that by asking participants to rate their perceived mental health



change may not be wholly reliable. However, the quantitative data presented was included as an adjunct to the qualitative analysis, intending to support the qualitative analysis, rather than provide standalone information.

Furthermore, the absence of a comparison group means it cannot be concluded that autistic people were more or less vulnerable to the effects of pandemic. We also acknowledge that results are based on very early stages of the pandemic, and in the absence of longitudinal data, it is difficult to ascertain which aspects of mental health declines relate specifically to the COVID-19 pandemic. To answer these questions, longitudinal research is required.

### **Conclusion**

This research increases our understanding of how UK-based autistic adults' mental health has been impacted by the COVID-19 pandemic, adding to the limited evidence-base that exists in this area. Our results provide a richer understanding of this complex area, and ways in which the autistic community can be better supported as the pandemic persists and when 'normality' ensues.

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### **Part Three: Critical Appraisal**

## **Introduction**

This chapter will present a critical reflection on the process of completing the thesis, making reference to both chapter one (scoping review) and chapter two (empirical study). It will initially reflect on my professional context prior to the DClInPsy and how this influenced my decision to conduct research with autistic people. Early on in this chapter, ways in which the COVID-19 pandemic disrupted initial plans are discussed and reflections shared on the process of having to adjust to the required changes. Considerations are given to joining pre-established research teams, conducting the analysis, and conflicting emotions relating to navigating the scientist-practitioner role. The chapter will consider some broader limitations of the thesis, before concluding with final reflections.

### **Professional Context and Choice of Research Topic**

I started the DClInPsy in 2018 with four years' experience working in a variety of clinical settings with autistic people. This ranged from working with non-verbal autistic children with intellectual disability and rare genetic conditions, to working in a private diagnostic service for autistic adults and older adults. Through this experience I was confronted by the large gaps in knowledge that exist in relation to autism, as well as the lack of resources, funding and services available to meet the needs of the autistic community (Maddox et al., 2020). I recall an early experience of working as an Assistant Psychologist, assessing a 78-year-old female for autism, who had lived in a dementia care home for over twenty years. This was despite little evidence that her presentation or trajectory over this time was indicative of dementia. The client went on to receive an autism diagnosis, which was described by client herself and her family to have been lifechanging. Following the diagnosis, I recall reflecting together with the client's family about how her life could have differed had the diagnosis come sooner. I couldn't help feeling that she had been let down by the system around her, and was left wondering how she would adjust to this new

understanding of her identity at such late stages of her life. This paved the way for a multitude of assessments to follow, whereby autistic men and women had been left undiagnosed until later stages of their adult life, more often than not having had various levels of involvement with mental health services (Camm-Crosbie et al., 2019) including inpatient admissions (Tromans et al., 2018). Compared to males, autistic females are at a significantly elevated risk of being mislabelled or undiagnosed (Lai & Baron-Cohen, 2015), and even when identified, autistic females are understood to receive diagnoses later than autistic males (Giarelli et al., 2010). My undergraduate degree exposed me to the widely cited four-to-one male to female gender ratio in autism (American Psychiatric Association, 2013). However, my early clinical observations differed from what I read, with increasing numbers of older aged females presenting to the service. Often bringing an array of mental health diagnoses with them. I began to increasingly question the gender bias. Since this time, research has shown the gender ratio to be three-to-one or perhaps slightly lower (Loomes et al., 2017). It wasn't until starting the DClinPsy and through teaching and reading became aware of how aspects including, the female autistic phenotype (Bargiela et al., 2016) and social camouflaging (Hull et al., 2017; Hull et al., 2020; Tubío-Fungueiriño et al., 2021) could potentially play a role in the underrepresentation of autistic females in the literature.

I recall initially feeling torn between two autism-related projects, both of which very much aligned with my previous experience. One involved autistic children with Duchenne Muscular Dystrophy and the other, social camouflaging in autistic adults. My decision to go for the latter project was influenced by my curiosity about the gender bias in autism, alongside a desire to increase the evidence base for autistic adults, given the bias towards child seen in the autism literature (Pellicano et al., 2014). I was also drawn to the opportunity of joining a pre-existing research team. Given my limited experience of conducting large-scale research, I felt that being a part of a research team would help guide and support me



through the thesis. The initial camouflaging study was a joint venture between myself and a PhD student, which, too, was appealing to me.

## **COVID-19 Disruptions**

### ***Methodological Impact of COVID-19***

The initial project was an online longitudinal survey on “autistic adults’ social behaviours, relationships and wellbeing” or ‘social camouflaging’. Data was to be collected at two times points over the space of a one-year period. Given my experience and interest in mental health, my thesis was due to investigate the association between mental health and social camouflaging. Prior to the World Health Organisation declaring COVID-19 a ‘pandemic’ and national lockdowns being imposed, we were in the final stages of collecting data for the first time point of our study (between February to March 2020). However, when lockdown restrictions were imposed by the UK government on 23<sup>rd</sup> March, we were struck by the harsh reality that this project would not be plausible in the current context. Social camouflaging is a conscious or unconscious use of strategies or behaviours, which minimize the appearance of autistic characteristics or traits when in social situations (Hull et al., 2017; Lai et al., 2011). Therefore in order to measure social camouflaging and its effects, some degree of social contact is required. Furthermore, given the likelihood of the pandemic impacting mental health between times 1 and 2, it was felt this plan was not plausible. With this in mind, the study required significant adaptations.

Given my clinical experience I was left wondering how autistic people, including those in our sample, were experiencing the pandemic. I was intrigued as to how autistic people, who have a strong preference for sameness and predictability were managing the uncertainty and lifestyle-changes caused by ever-changing, externally imposed regulations. Based on discussions within the research team it was decided that we would apply for an amendment to our ethics application in order to follow-up our sample of participants who had

completed the first round of data collection. Participants were asked to repeat the online survey and to answer additional COVID-related questions, which would be the focus of my thesis.

Alongside the change in focus to the thesis, due to the timely nature of our research, the team agreed that the paper would be submitted for publication as soon as possible, to allow for timely dissemination. With this in mind, I completed Chapter two during summer 2020 and submitted it for publication in January 2021 to the peer-reviewed journal, *Autism*. The paper is currently at the revise and resubmit stage of this process. I subsequently completed Chapter one following this.

### ***Personal Impact of COVID-19***

In addition to the impact of the pandemic on my research there was also a considerable personal impact. Completing the thesis during a lockdown, working to a different timescale to my peers and adjusting to the ‘new normal’ of remote teaching on the course had its own complications. With teaching based entirely from home, I struggled with the limited contact I had with my fellow peers and found myself feeling increasingly more distant from the course. This in combination with working to a different timescale to my peers and additional pressures to submit the paper for publication felt challenging. I was grateful my placements allowed for in-person work which provided a welcome change of scenery. However, working on wards with vulnerable clients, where COVID-19 had previously caused devastating consequences was highly emotive, and also elicited personal concerns relating to my own health and the health and safety of my loved ones. Combined with other challenges associated with the pandemic and the restrictions imposed, this period of time took a significant toll on me personally.

## **Working with Pre-Established Research Teams**

As noted above, given the limited amount of research experience I had relative to my clinical experience prior to the DClinPsy, working alongside researchers accustomed to completing large scale projects was an opportunity I valued. The two teams I was part of for both chapter one and two were made up of researchers with a variety of experience and professional backgrounds, including, UCL, Kings College London and the charity Autistica. Chapter one of the thesis was written as part of a pre-established wider project commissioned by NHS England and co-produced by Autistica and UCL, which aims to understand the move to telehealth services for autistic people during the pandemic. While the scoping review makes up a small contribution to this much wider project, I felt grateful to be part of research which was so actively attempting to influence systemic changes to improve health and social care for autistic people.

While joining pre-established teams was beneficial, in both cases it also brought its own challenges. Having to adapt to a variety of differences in the way in which people work, the varying timelines imposed on different researchers and the differences in expertise and experiences within the team was a challenge. Adopting the role of lead researcher for the empirical study required considerable adjustment, given my experience in comparison to other members of the team I was working alongside. These experiences required me to draw on some of my pre-existing skills and experience of working in a leadership capacity that I had developed through my placements.

## **Experience of Undertaking the Analysis**

Alongside a change in focus on my initial research, the type of data that was collected and subsequently analysed also differed from original plans. I had initially chosen to do a quantitative project, with early ideas to undertake a Cross-Lagged Panel Design (Kenny, 2014). My rationale behind initially choosing a quantitative project, was due to a wish to

develop my skills conducting statistical analyses, as well as some reservations I held about qualitative research. However, given the significant lack of understanding about how autistic adults' mental health had been effected during early stages of the pandemic, it was felt that qualitative research would provide a richer understanding.

My only prior experience of conducting qualitative analysis was during my undergraduate dissertation, where I used Grounded Theory. My experiences of this left me questioning how rigorous qualitative analysis was and how it can avoid being wholly subjective on the part of the researcher. How does one provide an entirely unbiased interpretation of data? Given these reservations, when it came to beginning the analysis I found myself feeling apprehensive and somewhat paralysed in the face of such a large dataset, questioning where to begin. At this point the breath and flexibility of the Thematic Analysis approach felt intimidating, and unlike other approaches, including Grounded Theory, I struggled with the relative lack of specific guidelines available. At this point, I was directed towards Braun and Clarke's collection of work on Thematic Analysis, which provided me the direction I was looking for and issued some welcomed feeling of containment.

The process of completing the thematic analysis, taught me many lessons and answered some of questions that had emerged from my undergraduate research. An early trap I found myself falling into during initial stages of the analysis, and to a lesser degree, throughout the analysis process was becoming wedded to codes or potential themes. Coming to terms with reflexive and recursive nature of a Thematic Analysis took time to adjust to, and on occasions left me feeling frustrated, disheartened and struggling to see the end point. Through collaborative work, I was struck by the value and necessity of involving another researcher in the analysis, as well as collating input from the wider research team along the way. This not only ensured that the coding was collaborative but also reflexive, and

allowed us to develop more nuanced themes (Braun & Clarke, 2019). Given the complexity and variability of autistic peoples experiences and the pandemic itself, this was crucial.

The flexibility of a reflexive thematic analysis, allows for different theoretical frameworks to be adopted (Braun & Clarke, 2019). Taking a critical-realistic perspective to the analysis, allowed us to acknowledge that the data was not only a reflection of the participants perspective, but of the societal contexts as whole. It also recognises the influence of the researchers interpretations on the analysis, which is cultivated by their own experiences, beliefs and knowledge. The process of reflexivity and recognising my role in the interpretation of the data was something that had been entirely absent in my undergraduate experience and helped me to move away from the simplistic assumptions I had previously held about qualitative analysis. Contrary to my previous concerns I began to recognise that qualitative analysis is not about trying to actively avoid all forms bias, but through reflexivity and working collaboratively, acknowledge them. In doing so, allowing for the development of richer, more nuanced reading of the data.

### **Navigating the Scientist-Practitioner Role**

The process of analysing the qualitative data in particular evoked conflicting feelings for me in navigating the scientist-practitioner role. The scientist-practitioner model emphasises the successful integration of both science and practice, whereby the relationship between the two are carefully considered (Jones & Mehr, 2007). In one sense, having no direct contact with participants through the use of an online survey, supported me to feel more at ease with adopting the scientist role. However, connecting with the data during the qualitative analysis made me acutely aware of the level of distress felt by many of the participants, which was so often perpetuated by lack of appropriate services in the context of the pandemic. Analysing high risk responses from participants, which at times made references to increasing incidents of self-harm and suicidal ideation, in the absence

undertaking risk assessments and safety planning, felt a far cry from my position as a practitioner. Often this conflict felt amplified during the week as I moved between placement days and research days. By this time I had started in a child trauma service, which has witnessed hugely exacerbated levels of risk in young people in the context of the pandemic and lockdown measures. Due to this, our service operates at times like a crisis service, where managing high risk cases has become part of my daily experience. This would then be followed by a research day, where I was exposed in a far more distant manner to individuals either in a risk crisis, or experiencing triggers to pre-existing mental health conditions, including complex trauma. *“It has triggered my cPTSD in ways I could never have anticipated, causing new triggers for flashbacks to appear, causing even more nightmares than usual”*. Ethical procedures had been followed to manage risk for participants, including outlining emergency information and support services on the participants information sheet. However, in the context of my training, I found it difficult not to connect to participants as I would in practice. Instead, my only response was to assign their distress to codes within my analysis.

### **Wider Limitations and Areas for Improvement**

The representativeness of the sample in the empirical paper does have its limitations. The decision to exclude participants with diagnosed intellectual disability was made in response to how cognitively demanding the online survey was to complete, which contained 112 questions in total. Autism is one of the most commonly occurring comorbid conditions for individuals with intellectual disability (Cervantes & Matson, 2015), meaning that by not including these individuals, voices from a significant proportion of the autistic community were not heard. Unfortunately, this decision also meant we contributed to the bias against intellectual disability that commonly occurs throughout autism literature (Russel et al., 2019). A further limitation coinciding with the length of the survey was the COVID-19 questions

being included at the end of the survey. This meant that prior to completing the questions which were the focus of the empirical study, participants had engaged with 90 questions. While participants were permitted to complete the survey over their own period of time, shorted surveys have been found to be more reliable and have higher response and completion rates (Kost & Rosa, 2018).

For the larger study which the empirical paper formed part of, participants were included from around the world. However, while detailed demographic information was collected, including participants nationality, the COVID-19 questions omitted to ask participants what country they had been in when lockdown had occurred. Given the large variability in lockdown measures, and different responses to the pandemic worldwide, the decision was made that in order to control for confounders, the empirical paper would only include participants from the UK. While this allowed for a more homogenous sample of data to be analysed, it meant that participants were all from a high-income, affluent country. Among an abundance of between-country differences in how autistic people are likely to have experienced the pandemic, factors including, healthcare access and access to financial support over the course of the pandemic differed hugely between countries. A further aspect that is likely to cause large variability in autistic peoples' experiences of the pandemic, is differences in how autism is conceptualised and understood in different world regions. For example, it is known that there is limited evidence regarding the understanding and impact of autism in low-and middle-income countries (Hahler & Elsabbagh, 2015).

Both Chapters one and two relied on heavily on autistic people having access to computerised software to either participate and complete the online survey in the empirical study, or access telehealth methods required to engage with service support, which were evaluated in the scoping review. This hinges on the assumption that autistic people have the means to pay for devices, software and WIFI. For many autistic people of lower socio-

economic status this may not be the case. Not only is this concerning, given the healthcare disparities discussed in both chapters one and two for autistic people (Nicolaidis et al., 2015), but in the general population individuals with lower socio-economic status are understood to experience more stress associated with mental health conditions, and experience additional barriers to accessing support services (Muntaner et al., 2007).

If I were to conduct the research again, alongside considerations for changes I have outlined above, a further area I would develop would be incorporating more community involvement from autistic people. While service-user feedback was collated for the initial longitudinal survey this was limited (only two autistic people). Due to the timely nature of the COVID research no input was gathered on the additional COVID questions. ‘Community involvement’ or ‘coproduction’ in research aims to attend to and confront dominant inequalities, and configure the power balance often seen in academia, whereby research is completed ‘about’ or ‘for’ a particularly group (Bell & Pahl, 2018). Rather than this, coproduction involves working alongside members of the community in question. Both research teams included one researcher who identified as autistic themselves. While this provided valuable insight, more input from members of the autism community at various stages of the research would have been beneficial.

### **Conclusion**

This chapter has given me the opportunity to reflect on the journey I have been on over the course of completing this thesis. The adaptations and fast pace of completing the empirical study in the context of the COVID-19 pandemic, alongside ongoing demands of the DClinPsy meant that there has been little time for reflection over the past year-and-a-half. Only by taking a step back while writing this chapter, have I been able to fully appreciate this journey.



This space for reflection has given me the opportunity to consider the skills I've learnt, from adopting new roles within research teams, to working collaboratively with different professionals, analysing and critically appraising research. Despite some of the challenges outlined throughout this chapter, I have appreciated some of the opportunities that have been brought about as a consequence of the pandemic. This thesis may not have been what I had originally envisaged three years ago, however, the research itself has achieved what I had hoped, in contributing to the evidence-base to improve health and social care for the autistic community.

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## Appendices

### Appendix A: Scoping Review Search Terms

Autism Blue: subject headings Black: key words	Telehealth Service
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<p>Asperger*, Autis*, child developmental disorders, pervasive/, child development* disor*, ASD, ASC, neurodevelopmental disorders/, neurodevelopmental dis*, Pervasive development*, autism spectrum condition*, development* dis*, development* disability*</p>	<p>Telehealth, tele-health, telemedicine/, telemedic*, tele-medic* telepractice, teletherapy, telecommunications, telerehabilitation, “remote therapy”, “remote medicine”, “remote service”, remote consultation/, remote intervention, remote rehabilitation, mobile consultation, mobile intervention, mobile rehabilitation, virtual consultation, virtual intervention, virtual rehabilitation, telecare, telepsychiatry, mhealthFh, m-health, ehealth, e-health, digital therapy, digital health, online therapy, online services, teleconsultation, tele-consultation, tele consultation videoconferenc*, video-confernc*, mobile health, telemental, electronic health, m-mental, mmental, or e-mental or emental, digital mental*, electronic mental* , computer-assisted therap*, video conferencing, teleconference, teleconference*</p>
<p>COVID exp coronavirus/, COVID-19/, SARS-CoV-2/, severe acute respiratory syndrome*, ((corona* or corono*) adj1 (virus* or viral* or virinae*)), coronavirus* or coronavirinae* or Coronavirus* or Coronovirus* or Wuhan* or Hubei* or Huanan or "2019-nCoV" or 2019nCoV or nCoV2019 or "nCoV-2019" or "COVID-19" or COVID19 or "CORVID-19" or CORVID19 or "WN-CoV" or WNCov or "HCoV-19" or HCoV19 or CoV or "2019 novel*" or Ncov or "n-cov" or "SARS-CoV-2" or "SARSCoV-2" or "SARSCoV2" or "SARS-CoV2" or SARSCov19 or "SARS-Cov19" or "SARSCov-19" or "SARS-Cov-19" or Ncovor or Ncorona* or Ncorono* or NcovWuhan* or NcovHubei* or NcovChina* or NcovChinese*), (((respiratory* adj2 (symptom* or disease* or illness* or condition*)) or "seafood market*" or "food market*") adj10 (Wuhan* or Hubei* or China* or Chinese* or Huanan*)), (outbreak* or wildlife* or pandemic* or epidemic*) and (China* or Chinese* or Huanan*)</p>	<p>2:</p>

**Appendix B: Example Search Run in OVID MEDLINE  
(Autism, Covid and Telehealth)**

Ovid MEDLINE(R) <1946 to May Week 3 2021>

- 1 Asperger\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 2538
- 2 autis\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 45297
- 3 exp Autistic Disorder/21003
- 4 exp Child Development Disorders, Pervasive/ 37837
- 5 child development\* disor\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 6588
- 6 ASD.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 20108
- 7 ASC.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 8222
- 8 Neurodevelopmental Disorders/ 2834
- 9 neurodevelopment\* dis\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 11531
- 10 Pervasive development\* disorder\*.mp. 1923
- 11 autism spectrum condition\*.mp. 349
- 12 developmental disorder\*.mp. 7934
- 13 development\* disabilit\*.mp. 23298
- 14 or/1-1392117
- 15 telehealth\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 5141
- 16 tele-health\*.mp. 158

- 17 exp Telemedicine/ 34221
- 18 tele-medic\*.mp. 146
- 19 telemedic\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 31286
- 20 telepractic\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 77
- 21 teletherap\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 5682
- 22 exp Telecommunications/ 104671
- 23 Telecommunication\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 7065
- 24 exp Telerehabilitation/ 536
- 25 Telerehabilitation\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 926
- 26 remote therap\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 66
- 27 remote consultation\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 5385
- 28 exp Remote Consultation/ or exp Videoconferencing/ 7162
- 29 remote medicine\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 80
- 30 remote servic\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary



concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 74

31 exp remote consultation/ or exp telerehabilitation/ 5741

32 videoconferenc\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 3048

33 teleconferenc\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 1050

34 remote intervention\*.mp. 48

35 remote rehabilitation\*.mp. 27

36 mobile consultation\*.mp. 11

37 mobile intervention\*.mp. 130

38 mobile rehabilitation\*.mp. 26

39 virtual consultation\*.mp. 93

40 virtual intervention\*.mp. 34

41 virtual rehabilitation\*.mp. 114

42 telecar\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 942

43 telepsychiat\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 639

44 mhealth\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 3502

45 m-health\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 496

46 ehealth\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary

concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 3210

47 e-health\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 2581

48 digital therap\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 70

49 digital health\*.mp. 1735

50 online therap\*.mp. 128

51 online servic\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 369

52 teleconsultation\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 1093

53 tele-consultation\*.mp.75

54 tele consultation\*.mp.75

55 videoconferenc\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 3048

56 video-conferenc\*.mp. 733

57 mobile health\*.mp. 7177

58 telemental.mp.208

59 electronic health\*.mp.29141

60 m-mental.mp. 7

61 mmental.mp. 2

62 e-mental.mp. 210

63 emental.mp. 21

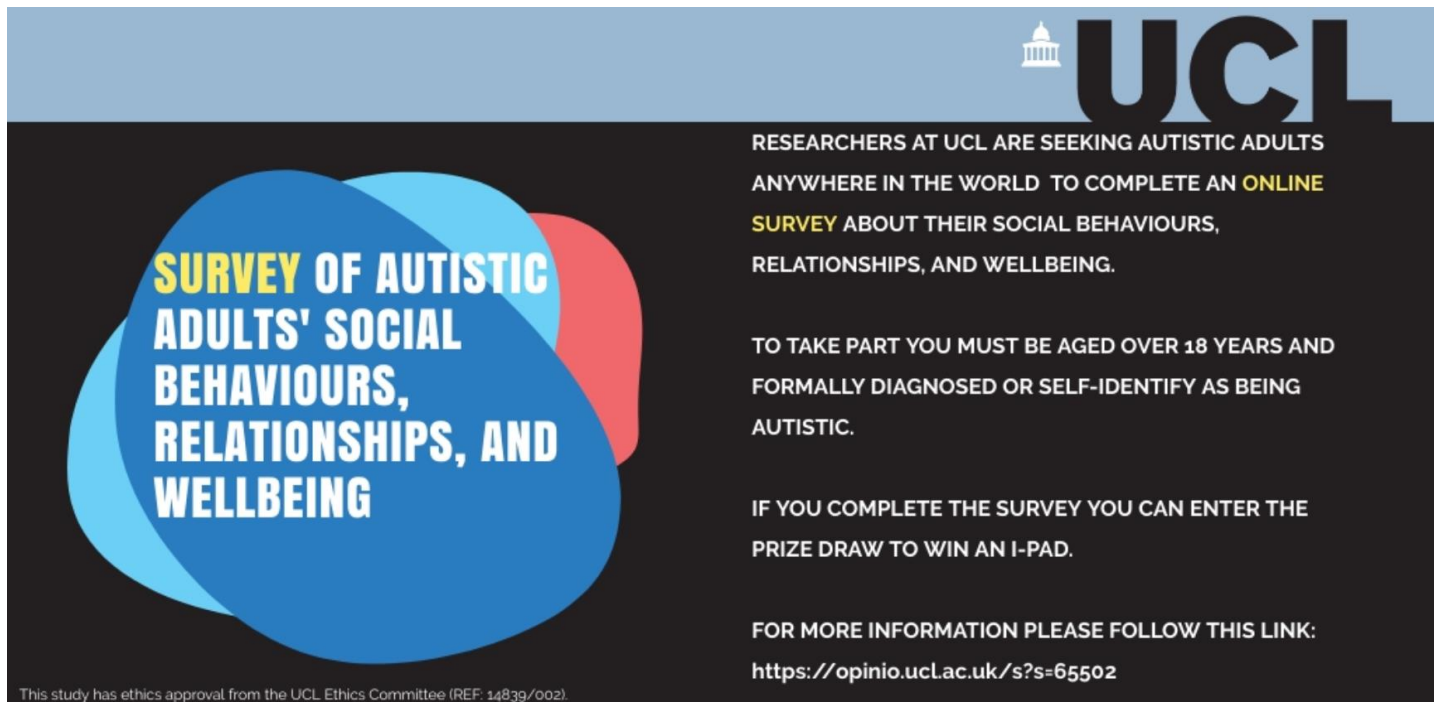
64 digital mental\*.mp. 86

65 electronic mental\*.mp. 39

- 66 computer-assisted therap\*.mp. 77
- 67 computer assisted therap\*.mp. 77
- 68 or/15-67 150481
- 69 exp Coronavirus/ 71928
- 70 exp COVID-19/ 77172
- 71 exp SARS-CoV-2/ 59521
- 72 severe acute respiratory syndrome\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 16550
- 73 ((corona\* or corono\*) and (virus\* or viral\* or virinae\*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 61126
- 74 (coronavirus\* or coronavirinae\* or Coronavirus\* or Coronovirus\* or Wuhan\* or Hubei\* or Huanan or 2019-nCoV or 2019nCoV or nCoV2019 or nCoV-2019 or COVID-19 or COVID19 or CORVID-19 or CORVID19 or WN-CoV or WNCov or HCoV-19 or HCoV19 or CoV or 2019 novel\* or Ncov or n-cov).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 97215
- 75 (SARS-CoV-2 or SARSCoV-2 or SARSCoV2 or SARS-CoV2 or SARSCov19 or SARS-Cov19 or SARSCov-19 or SARS-Cov-19 or Ncover or Ncorona\* or Ncorono\* or NcovWuhan\* or NcovHubei\* or NcovChina\* or NcovChinese\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 64076
- 76 ((respiratory\* and (symptom\* or disease\* or illness\* or condition\*)) or (seafood market\* or food market\*) or (Wuhan\* or Hubei\* or China\* or Chinese\* or Huanan\*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 706606
- 77 ((outbreak\* or wildlife\* or pandemic\* or epidemic\*) and (China\* or Chinese\* or Huanan\*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms] 17920

78	pandemic.mp. or exp Pandemics/	81663
79	or/69-78	799419
80	14 and 68	498
81	limit 80 to yr="2019 -Current"	142
82	79 and 80	44
83	14 and 68	498
84	limit 83 to yr="2019 -Current"	142
85	limit 83 to yr="2020 -Current"	78

## Appendix C: Recruitment Poster for the Original Longitudinal Survey



The poster features a dark background with a light blue header containing the UCL logo. On the left, there are three overlapping circles in shades of blue and red, with the survey title overlaid in white and yellow text. The main text on the right is in white, providing details about the survey, eligibility criteria, and a prize draw. A small line of text at the bottom left indicates ethics approval.

**UCL**

**SURVEY OF AUTISTIC ADULTS' SOCIAL BEHAVIOURS, RELATIONSHIPS, AND WELLBEING**

RESEARCHERS AT UCL ARE SEEKING AUTISTIC ADULTS ANYWHERE IN THE WORLD TO COMPLETE AN **ONLINE SURVEY** ABOUT THEIR SOCIAL BEHAVIOURS, RELATIONSHIPS, AND WELLBEING.

TO TAKE PART YOU MUST BE AGED OVER 18 YEARS AND FORMALLY DIAGNOSED OR SELF-IDENTIFY AS BEING AUTISTIC.

IF YOU COMPLETE THE SURVEY YOU CAN ENTER THE PRIZE DRAW TO WIN AN I-PAD.

FOR MORE INFORMATION PLEASE FOLLOW THIS LINK:  
<https://opinio.ucl.ac.uk/s?s=65502>

This study has ethics approval from the UCL Ethics Committee (REF: 14839/002).

## Appendix D: Ethical Amendment Application

### UCL RESEARCH ETHICS



#### Amending an Approved Application

Should you wish to make an amendment to an approved study, you will need to submit an ‘amendment request’ for the consideration of the Chair of the UCL Research Ethics Committee. Applications can only be amended **after** ethical approval has been granted.

You will need to apply for an amendment approval if you wish to:

1. Add a new participant group;
2. Add a new research method;
3. Ask for additional data from your existing participants;
4. Remove a group of participants or a research method from the project, and have not yet commenced that part of the project;
5. Apply for an extension to your current ethical approval.

If you need to apply for an amendment approval, please complete the Amendment Approval Request Form on the next page.

When completing the form, please ensure you do the following:

- Clearly explain what the amendment you wish to make is, and the justification for making the change.
- Insert details of any ethical issues raised by the proposed amendments.
- Include all relevant information regarding the change so that the Chair can make an informed decision, and submit a copy of the sections of your application that have changed with all changes highlighted/underlined for clarity.
- You do not need to submit your original application in full again. However, if the changes you wish to make alters several sections of your application form, you are advised to submit this.

Please email a signed electronic copy to the REC Administrator: [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

Amendment requests are generally considered within 5-7 days of submission.

## Amendment Approval Request Form

1	<b>Project ID Number:</b> 14839/002	<b>Name and Address of Principal Investigator:</b> Associate Professor William Mandy Psychology and Language Sciences Room 441 1-19 Torrington Place London WC1E6BT
2	<b>Project Title:</b> A Longitudinal Investigation of Camouflaging in Autistic Adults	
3	<b>Type of Amendment/s (tick as appropriate)</b> Research procedure/protocol (including research instruments) <input checked="" type="checkbox"/> Participant group <input type="checkbox"/> Sponsorship/collaborators <input type="checkbox"/> Extension to approval needed (extensions are given for one year) <input type="checkbox"/> Information Sheet/s <input type="checkbox"/> Consent form/s <input type="checkbox"/> Other recruitment documents <input type="checkbox"/> Principal researcher/medical supervisor* <input type="checkbox"/> Other <input type="checkbox"/>  <i>*Additions to the research team other than the principal researcher, student supervisor and medical supervisor do not need to be submitted as amendments but a complete list should be available upon request *</i>	
4	<b>Justification</b> (give the reasons why the amendment/s are needed) Our project investigates factors that impact upon the mental health and wellbeing of autistic participants over time, in particular the influence of 'social camouflaging'. We were in the final stages of recruiting participants for T1 of our project immediately prior to the current Covid-19 situation developing. This ongoing situation has wide-reaching impacts on individuals' personal circumstances and in turn their mental health and wellbeing. The current Covid-19 situation is very likely to affect the mental health and wellbeing of participants now and in the future. Therefore, we need to measure changes to our participants current mental health and wellbeing as well as their perceptions of Covid-19 and their views on how it is impacting their mental health and wellbeing. This will give us some capacity to tease apart effects arising from Covid-19 and the effects of social camouflaging, as stated in our original research aims. In our original project, participants who completed T1 were to be recontacted to complete T2 measures in January to April of 2021. We are seeking an amendment to add an additional data collection point to the project and thus recontact participants to recomplete T1 measures now. This will be in addition to several Covid-19 related questions. These amendments are required to allow us to pursue the original study aims, despite the recent upheavals.	
5	<i>Details of Amendments (provide full details of each amendment requested, state where the changes have been made and attach all amended and new documentation)</i>  <b>1. Re-Contacting Past Participants</b>	

We are seeking to add one additional data collection point to the current project. We wish to re-contact participants who completed T1 now, following the recontacting procedures outlined in our original ethics application. Specifically, participants who consented to being recontacted will be emailed an invitation to complete the questionnaire again via a unique access link. Participants will then access the questionnaire by clicking on their unique link at a time that is convenient to them (within a 4-week period). Upon following the link to the web page, participants will firstly be directed to a participant information sheet. Participants who confirm they have read the information sheet and who provide informed consent will then be directed to the questionnaire. Participants can decide to withdraw from the study at any time by either closing the webpage hosting the survey or not following the link to the survey.

The invitation email will read:

*Dear Participant,*

*Thank-you for recently completing the "Survey of Autistic Adults' Social Behaviours, Social Relationships, and Wellbeing." Given the current Covid-19 situation may have affected the way people's mental health and wellbeing, we are re-contacting people who completed the survey and asking them to complete the survey again, with some additional questions. Our aim is to understand better how Covid-19 has impacted your life, in particular your social relationships, and wellbeing. If you complete this additional survey, you can enter a prize draw to win an iPad. You do not need to complete this additional questionnaire; it is completely up to you to decide whether or not to take part*

*If you wish to complete the survey, please click on the below link.*

*[link]*

*If you have any questions or concerns, please contact the researchers:*

*Julia Cook (researcher)*

*University College of London Department for Clinical, Educational and Health Psychology*

*1-19 Torrington Place*

*London WC1E7HB*

*Julia.cook.18@ucl.ac.uk*

*Kind Regards,*

*Julia Cook (julia.cook.18@ucl.ac.uk)*

*Dr William Mandy, Principal Researcher (w.mandy@ucl.ac.uk)*

*Dr Laura Crane*

*Hannah Belcher*

*Rebecca Bundy*

Similar to the procedures outlined in our original ethics application, participants who complete this additional data collection point will be given the choice to enter a prize draw to win an i-pad.

## **2. We are seeking to amend the current survey in the following ways:**

Changes to Participant Information Sheet

Information regarding sensitive questions on the survey will change from:

*"Some questions in the survey ask about feelings of loneliness, anxiety, stress, and sadness.*

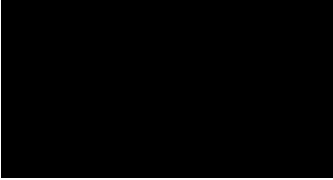


	<p>To</p> <p><i>“Some questions in the survey ask about feelings of loneliness, anxiety, stress, and sadness. Some questions ask about Covid-19 and how it is affecting you. Thinking about these questions may make some people have negative thoughts or feel upset. You do not have to answer any of these questions you do not feel comfortable answering.”</i></p> <p>Information regarding taking part in the survey will change from:</p> <p><i>“The questionnaires will probably take about 35 minutes to complete.”</i></p> <p>To</p> <p><i>“The questionnaires will probably take about 45 minutes to complete.”</i></p> <p><b>Additional information regarding support during the Covid-19 situation:</b></p> <p><b><i>More information, support, and resources for autistic people during the Covid-19 pandemic can be found at:</i></b></p> <p><b><a href="https://www.autistica.org.uk/what-is-autism/coronavirus">https://www.autistica.org.uk/what-is-autism/coronavirus</a></b></p> <p><b><a href="https://www.autism.org.uk/services/helplines/coronavirus.aspx">https://www.autism.org.uk/services/helplines/coronavirus.aspx</a></b></p> <p>Additional Questions Please see attached additional instructions and questions related to Covid-19.</p>
6	<p><b>Ethical Considerations</b> (insert details of any ethical issues raised by the proposed amendment/s) We have considered that risk that some participants may experience negative thoughts and/or distress when answering some of the additional questions. We have mitigated this risk by:</p> <ul style="list-style-type: none"> <li>• Informing participants that some of the questions related to Covid-19 may be distressing.</li> <li>• Not requiring that participants must answer any of the additional Covid-19 related questions.</li> <li>• Providing phone numbers and websites for accessing support at the beginning and end of the questionnaire/additional questions (via the Participant Information Sheet and Participant De-Brief).</li> </ul> <p>We have considered the risk that some participants may not wish to complete the survey at this additional time point. We have mitigated this risk by:</p> <ul style="list-style-type: none"> <li>• Only re-contacting participants who consented to be re-contacted to complete the survey again.</li> <li>• Informing participants in the email invitation and ensuing Participant Information Sheet that they do not have to complete the questionnaire if they do not wish.</li> </ul>
7	<p><b>Other Information</b> (provide any other information which you believe should be taken into account during ethical review of the proposed changes)</p>

responsibility for it.

- I consider that it would be reasonable for the proposed amendments to be implemented.
- For student projects, I confirm that my supervisor has approved my proposed modifications.

Signature:



Date: 28.04.2020

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## Appendix E: Participant Information Sheet

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### Participant Information Sheet

UCL Research Ethics Committee Approval ID Number: XXXX

*Survey of Autistic Adults' Social Behaviours, Social Relationships, and Wellbeing*

**Department:** *Research Department of Clinical, Educational and Health Psychology, UCL*

**Name and Contact Details of the Researcher:** *Julia Cook (E: [Julia.cook.18@ucl.ac.uk](mailto:Julia.cook.18@ucl.ac.uk))*

**Name and Contact Details of the Principal Researcher:** *Dr William Mandy (E: [w.mandy@ucl.ac.uk](mailto:w.mandy@ucl.ac.uk))*

You are being invited to take part in a research project being conducted by Julia Cook, as a part of her PhD in psychology. It is important that you understand exactly what taking part will involve and why the research is being done. Please take time to read this information sheet and discuss it with others if you wish. If anything is not clear, please do not hesitate to ask one of us. Please take time to decide whether or not you wish to take part.

**1. Why are we doing the project?**

The aim of this project is to understand better the relationships between autistic adults' social behaviours, social relationships, and wellbeing and how these may change over time.

**2. Why have I been chosen?**

We are interested in autistic adults' experiences. We are asking autistic people over the age of 18, of any gender to take part. We are hoping to recruit about 400 autistic adults.

**3. Do I have to take part?**

No - it is completely up to you to decide whether or not to take part. You can change your mind and decide to stop taking part in the study at any time without having to give us a reason and without penalty. You can end your participation in the study by closing your internet browser. If you have not completed the survey, your answers will not be recorded. If you change your mind after completing the survey (and you have provided your email address), you can ask for your data be removed until four weeks after completing the survey. If you do not provide your email address we will not be able to remove your data, as your response will be anonymous and unidentifiable.

**4. What will happen to me if I take part?**

Firstly, you will need to complete a consent form. You will then complete an online survey that contains questions about you, your social behaviours, social relationships, and your wellbeing. The questionnaires will probably take about 35 minutes to complete.

At the end of the survey, you will be asked if you would like to complete the survey again in 12- and 24-months' time. This is completely voluntary. If you would like to complete the survey again, you will be asked to enter your email address. You will then be emailed a link to complete the survey again in 12- and 24-months' time.

**5. What are the possible disadvantages and risks of taking part?**

Some questions in the survey ask about feelings of loneliness, anxiety, stress, and sadness. Thinking about these questions may make some people have negative thoughts or feel upset. You do not have to answer any questions you do not feel comfortable answering.

If you feel you distressed or in need of support, please contact:

Your GP.

Good Samaritans:  
Phone: 116 123  
Web: <https://www.samaritans.org/>

National Autistic Society:  
Phone: 0808 800 4104  
Web: <https://www.autism.org.uk/>

#### **6. What are the possible benefits of taking part?**

Each time you complete the survey (i.e. now, in 12-months' time and in 24-months' time), you can enter a prize draw to win an iPad. If you wish to enter the prize draw you will be asked to enter your email address. You may only complete the survey once at each time point.

We also hope that this research will help the autistic, research, and wider community to better understand social behaviours, social relationships, and wellbeing amongst autistic adults.

#### **7. What if something goes wrong?**

If you are unhappy or dissatisfied about any aspects of your participation, we encourage you to let us know, so we can try to resolve any concerns and find a solution. If you wish to raise a complaint, you should contact the Principal Researcher, Dr William Mandy (contact details above). However, if you feel your complaint has not been handled satisfactorily, you can contact the Chair of the UCL Research Ethics Committee at [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk) quoting the Ethics Committee Approval ID Number for this study (XXXX).

#### **8. Will my taking part in this project be kept confidential?**

All the information that we collect about you during the course of the research will be kept strictly confidential. We will de-identify your information by separating your survey responses from your personal details (your email address). Both your survey responses and your personal details (your email address) will be stored in secure conditions at UCL. You will not be able to be identified in any ensuing reports or publications.

#### **9. Limits to confidentiality**

Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

#### **10. What will happen to the results of the study?**

We plan to share our findings via publications in peer reviewed academic journals, relevant autism websites, and conference presentations. We also plan to publish tailored reports to share our findings with the autistic community and clinical professionals. You would have the option to be sent a summary of the research and be contacted at the end of the study to discuss the findings of the study with the researchers. You could also contact the researchers and ask for copies of any publications if you wish to read them.

#### **11. Data Protection Privacy Notice**

We need to tell you some important information about the way we use your personal data. We are asking you to provide us with two types of data; personal data (information about you) and special category personal data (information about your race, ethnic origin, and health).

The lawful basis that will be used to process your personal data will be performance of a task in the public interest. The lawful basis used to process special category personal data will be for scientific and historical research or statistical purposes.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudo-anonymise (de-identify) the personal data you provide we will

undertake this, and will endeavour to minimise the processing of personal data wherever possible.

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice: <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice>

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

## **12. Who is organising and funding the research?**

This research is organised and funded by University College London.

## **13. Contact for further information**

If you do not understand the above information or you have any questions, please contact the researchers:

Julia Cook (researcher)  
University College of London  
Department for Clinical, Educational and Health Psychology  
1-19 Torrington Place  
London WC1E7HB  
[Julia.cook.18@ucl.ac.uk](mailto:Julia.cook.18@ucl.ac.uk)

**Thank you for reading this information sheet and for considering to take part in this research study.**

## Appendix F: Participant Consent Form

LONDON'S GLOBAL UNIVERSITY



### CONSENT FORM

Please complete this form after you have read the Information Sheet.

**Title of Study:** *Survey of Autistic Adults' Social Behaviours, Social Relationships, and Wellbeing*

**Department:** Research Department of Clinical, Educational and Health Psychology, UCL

**Name and Contact Details of the Researcher:** Julia Cook (Julia.cook.18@ucl.ac.uk)

**Name and Contact Details of the Principal Researcher:** Dr Will Mandy (w.mandy@ucl.ac.uk)

**Name and Contact Details of the UCL Data Protection Officer:** Spencer Crouch (data-protection@ucl.ac.uk)

**This study has been approved by the UCL Research Ethics Committee: Project ID number:** XXXX

Thank you for considering taking part in this research. Please read the Participant Information Sheet for the project before you agree to take part. If you have any questions arising from the Participant Information Sheet please ask the researcher before you decide whether to join in.

**I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.**

Participant Statements:	Tick Box
I confirm that I have read and understood the Participant Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and I would like to complete the online survey.	
I understand that my participation is voluntary and that I am free to withdraw at any time whilst completing the survey, without giving a reason. I understand that if I decide to withdraw, any personal data I have provided up to that point will not be recorded.	
I understand that, if I provide my email address then I will be able to withdraw my data at any time up to four weeks after completing the survey.	
I understand that, if I do not provide my email address then my data cannot be withdrawn as my responses will be anonymous and un-identifiable.	
I consent to participate in the study. I understand that my personal information (survey response and email address) will be used for the purposes explained to me. I understand that according to data protection legislation, the lawful basis that will be used to process my personal data will be performance of a task in the public interest. The lawful basis used to process my special category personal data will be for scientific and historical research or statistical purposes.	
I understand that my information will be de-identified such that my survey responses will be separated from by personal details (my email address) and that both my survey responses and my personal details (my email address) will be stored in secure locations at UCL. It will not be possible to identify me in any ensuing reports or publications.	
I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
I understand there are no major risks to taking part in this study.	
I understand that after completing the survey at each time point (now, in 12-months and 24-months' time) I can enter the prize draw to win an iPad.	
I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researchers undertaking this study.	
I understand that I will not benefit financially from any possible outcome the study may result in in the future.	
I agree that my anonymised research data may be used by others for future research. [No one will be able to identify you when this data is shared.]	
I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No	
I hereby confirm that I understand the inclusion criteria as detailed in the Participant	

Information Sheet and explained to me by the researcher, and that I fit into this inclusion criteria.	
I am aware of who I should contact if I wish to lodge a complaint.	
I voluntarily agree to take part in this study.	
I would be happy for my anonymised data I provide to be archived at University College of London for 10 years.	

**If you would like to be sent a summary of the research and/or be contacted at the end of the study to discuss the findings of the study with the researchers, please circle the appropriate option below.**

Yes/No	I would like to be sent a summary of the research.
Yes/No	I would like to be contacted by the researchers at the end of the study to discuss the findings of the study with the researchers.

\_\_\_\_\_  
Name of participant                      Date                      Signature

\_\_\_\_\_  
Researcher                      Date                      Signature

*Appears at the end of the survey:*

I want to enter the draw to win an iPad. I confirm my email address can be retained so that the researchers can contact to me to inform me if I have won the iPad.

Yes/No

Email Address: \_\_\_\_\_

I confirm my email address can be retained so that the researchers can send me a link to complete the online survey in 12- and 24-months' time.

Yes/No

Email Address: \_\_\_\_\_

## Appendix G: COVID-19 Questions

1. Please let us know in your own words, how easy or difficult it was for you to understand government information on COVID-19

2. Please let us know in your own words, how easy or difficult it was for you to access government information on COVID-19

3. Please let us know in your own words how easy it was for you to access / receive financial related COVID-19 supports provided by your government (e.g. income support, mortgage relief)

4. How well have your usual support services (e.g., mental health services, autism support groups, social care or social services) met your needs during Covid-19?

1-----	2-----	3-----	4-----	5-----	6-----	7
My needs have been very well supported by my usual support services						My needs have been very poorly supported by my usual support services

5. Please tell us in your own words to what degree your needs have been supported by your usual support services

*N/A I do not ordinarily access any support services*



6. To what extent has your anxiety changed because of the Covid-19 virus?

1----- 2----- 3----- 4----- 5----- 6----- 7

Covid-19 has made me much less anxious			Covid-19 has not impacted my levels of anxiety			Covid-19 has made me much more anxious
--	--	--	--	--	--	--

7. To what extent has your anxiety changed because of the lockdown\* measures?

1----- 2----- 3----- 4----- 5----- 6----- 7

The lockdown measures have made me much less anxious			The lockdown measures have not impacted my levels of anxiety			The lockdown measures have made me much more anxious
--	--	--	--	--	--	--

8. To what extent has your stress changed because of the Covid-19 virus?

1----- 2----- 3----- 4----- 5----- 6----- 7

Covid-19 has made me much less stressed			Covid-19 has not impacted my levels of stress			Covid-19 has made me much more stressed
---	--	--	---	--	--	---

9. To what extent has your stress changed because of the lockdown\* measures?

1----- 2----- 3----- 4----- 5----- 6----- 7

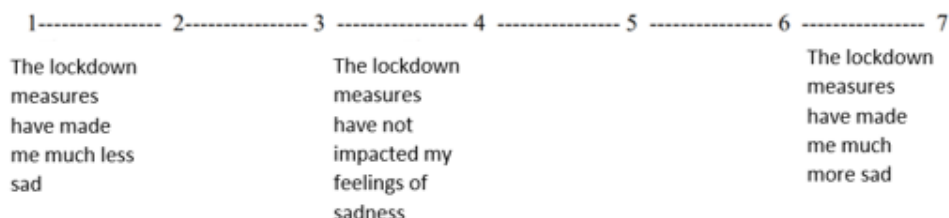
The lockdown measures have made me much less stressed			The lockdown measures have not impacted my levels of stress			The lockdown measures have made me much more stressed
---	--	--	---	--	--	---

10. To what extent have your feelings of sadness changed because of the Covid-19 virus?

1----- 2----- 3----- 4----- 5----- 6----- 7

Covid-19 has made me much less sad			Covid-19 has not impacted my feelings of sadness			Covid-19 has made me much more sad
------------------------------------	--	--	--	--	--	------------------------------------

11. To what extent have your feelings of sadness changed because of the lockdown\*  
measures?



12. Have any of the following factors impacted negatively on your mental health and wellbeing during Covid-19? (Please tick all that apply) (multiple choice – multiple selections allowed)

- a. Uncertainty about lockdown measures
- b. Current financial pressure
- c. Uncertainty about employment and financial circumstances
- d. Poor physical health
- e. Being ill with Covid-19
- f. Someone close to me being ill with Covid-19
- g. Fear about getting ill with Covid-19
- h. Fear about someone close to me getting ill with Covid-19
- i. Increases in caring responsibilities
- j. Changes to normal routine
- k. Changes to social support
- l. Feeling isolated or lonely
- m. Changes in the home (i.e. increased time at home with other members of the household)

13. Please tell us in your own words how COVID-19 has impacted your mental health

14. Have you experienced any of the following as a result of Covid-19 (Multiple choice, multiple selections allowed)

- a. Lost your job or regular income
- b. A major reduction in your income (i.e. due to being furloughed, income being reduced by your employer, being put on leave by your employer, or not receiving enough work shifts)
- c. Unable to pay bills/rent/mortgage
- d. Evicted/lost accommodation

- e. Increased caring responsibilities (i.e. caring for children, vulnerable family members or friends, or ill family members or friends)
- f. Unable to access enough/suitable food
- g. Unable to access usual support services (i.e. support group, mental health services, employment services)
- h. Unable to access medication
- i. I or someone close to me has become unwell with Covid-19

15. Please tell us in your own words how these hardships have impacted you

16. Have you found any of the following helpful in supporting your mental health and wellbeing during the Covid-19 emergency? (Multiple choice, multiple selections allowed)

- a. Spending time exercising
- b. Spending time engaging in leisure activities alone (i.e. reading, games, gardening, puzzles)
- c. Spending time engaging in leisure activities with members of your household (i.e. playing games, conversing, cooking)
- d. Spending time socialising with other people via phone calls, virtual meetings, text messages, emails etc.)
- e. Spending time on self-care for mental health (i.e., engaging in mindfulness, meditation, yoga, journaling)
- f. Creating a daily or weekly routine or sticking to an existing daily or weekly routine
- g. other

17. Please explain in your own words how these or other factors have helped your mental health and wellbeing during Covid-19

18. Has your life improved in any way as a result of Covid-19 or lockdown measures?

## Appendix H: Stages of Coding and Theme Development

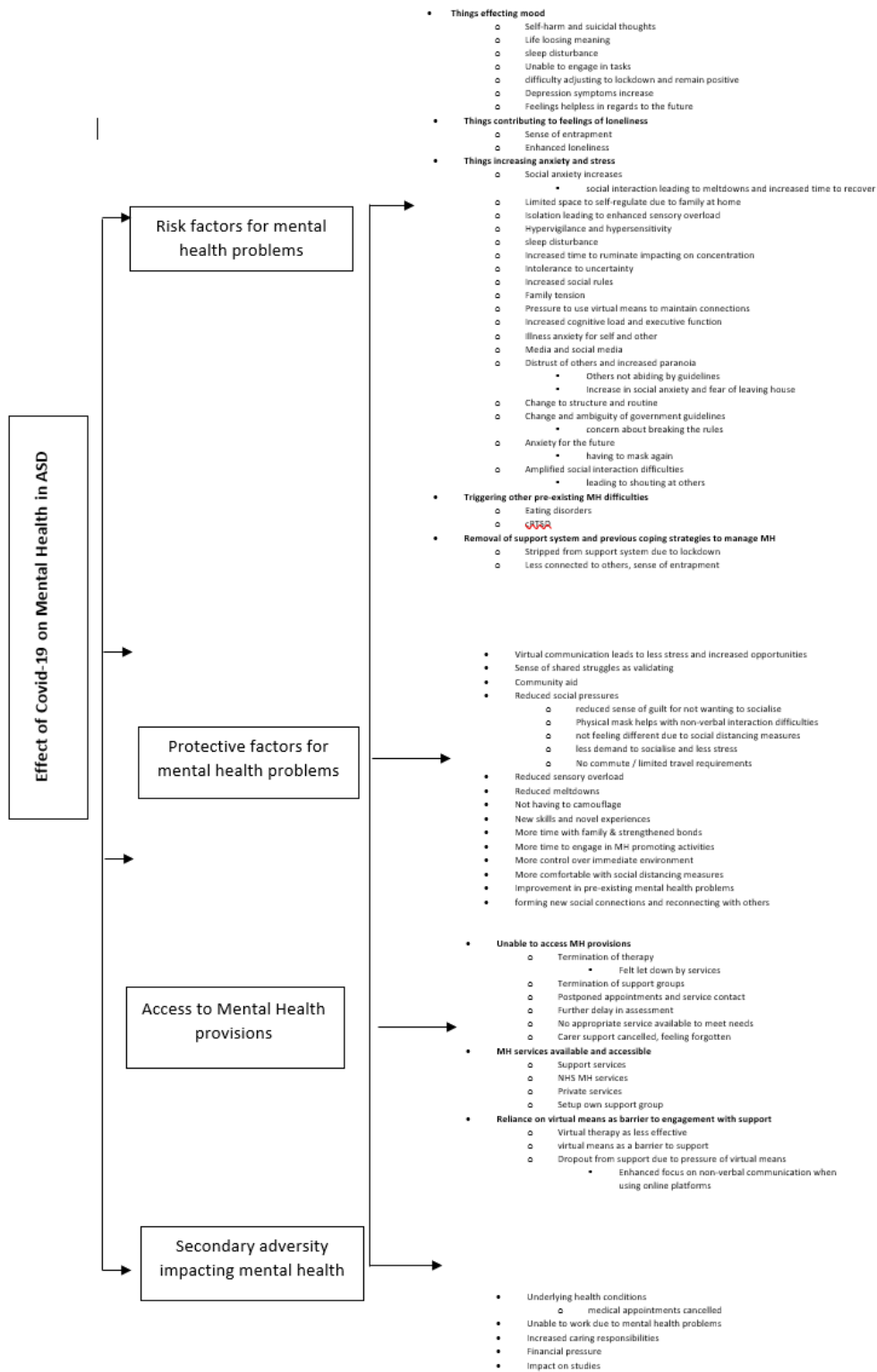
### July 2020: Early Coding in Nvivo

Name	Sources	References	Created By	Created On	Modified By	Modified On
Spending more time at home	0	0	BB	29/07/2020 12:34	BB	01/08/2020 16:47
Positive impact	0	0	BB	29/07/2020 15:47	BB	01/08/2020 15:57
Negative impact	0	0	BB	29/07/2020 15:47	BB	01/08/2020 15:57
Social distancing	0	0	BB	01/08/2020 16:59	BB	03/08/2020 21:41
Positive effect	0	0	BB	01/08/2020 16:59	BB	01/08/2020 16:59
Negative effect	0	0	BB	01/08/2020 16:59	BB	01/08/2020 16:59
Occupational, financial and academic pressures	0	0	BB	31/07/2020 10:35	BB	31/07/2020 10:36
Unable to work due to MH	1	1	BB	19/07/2020 10:21	BB	31/07/2020 13:37
More time spent at work	1	1	BB	05/08/2020 14:23	BB	05/08/2020 14:23
Impact on academic studies	6	6	BB	20/07/2020 19:26	BB	05/08/2020 14:32
Financial pressure	14	14	BB	19/07/2020 09:27	BB	06/08/2020 21:27
Employment uncertainty	9	9	BB	20/07/2020 16:08	BB	06/08/2020 21:26
Impact of Technology	0	0	BB	29/07/2020 12:00	BB	29/07/2020 12:00
Positive impact	0	0	BB	29/07/2020 12:02	BB	29/07/2020 12:02
Negative impact	0	0	BB	29/07/2020 12:02	BB	29/07/2020 12:02
Health Concerns	1	1	BB	29/07/2020 15:05	BB	04/08/2020 07:50
Worry about contracting covid or loved ones getting ill	21	22	BB	19/07/2020 09:52	BB	06/08/2020 21:42
Underlying health conditions	7	7	BB	19/07/2020 09:28	BB	04/08/2020 07:23
Change to structure and routine	0	0	BB	31/07/2020 10:14	BB	31/07/2020 10:14
Positive change	0	0	BB	31/07/2020 11:34	BB	31/07/2020 11:34
Negative change	0	0	BB	31/07/2020 11:34	BB	31/07/2020 11:34
Altered protective factors	0	0	BB	29/07/2020 15:19	BB	02/08/2020 09:32
Positive	0	0	BB	29/07/2020 16:39	BB	05/08/2020 11:24
Negative	0	0	BB	01/08/2020 17:11	BB	05/08/2020 11:24
Access to mental health provisions	0	0	BB	19/07/2020 11:40	BB	26/07/2020 20:51
Unable to access Mental Health provisions	0	0	BB	19/07/2020 09:45	BB	19/07/2020 10:20

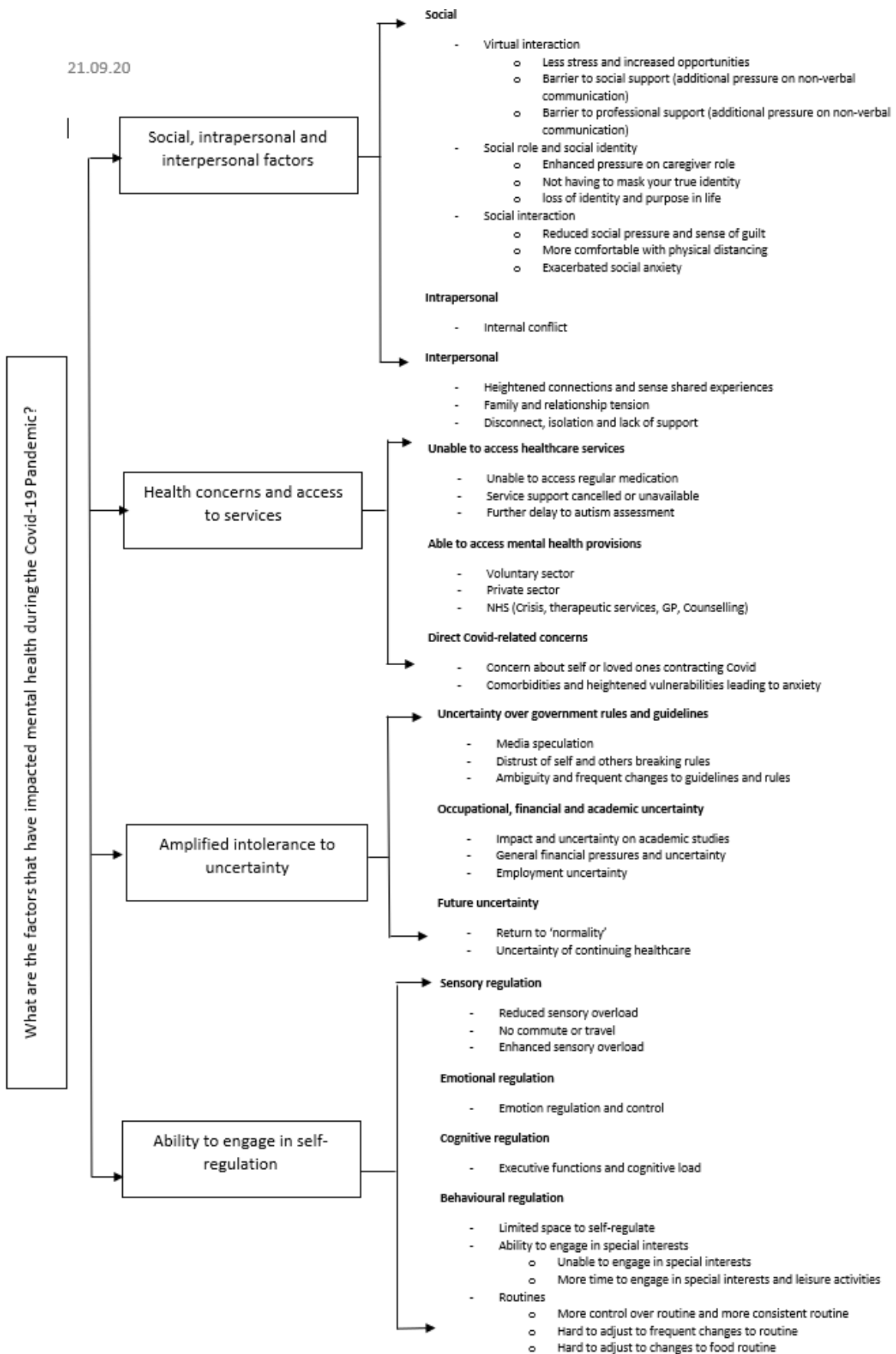
### August 2020: Coding in Nvivo

Name	Sources	References	Created By	Created On	Modified By	Modified On
Uncertainty	0	0	BB	14/08/2020 17:11	BB	14/08/2020 17:11
Occupational, financial and academic uncertainty	0	0	BB	31/07/2020 10:35	BB	12/08/2020 17:46
General media & social media causing increase in anxiety	9	10	BB	19/07/2020 10:17	BB	07/08/2020 18:45
Fear of leaving the house due to increased rules	18	21	BB	01/08/2020 16:12	BB	07/08/2020 15:34
Distrust of others	24	29	BB	01/08/2020 16:12	BB	10/08/2020 07:47
Concern about re-adapting back to 'normal'	12	14	BB	01/08/2020 16:12	BB	10/08/2020 07:47
Ambiguity of guidelines	12	14	BB	19/07/2020 10:10	BB	07/08/2020 18:43
Social, interpersonal and relational	0	0	BB	29/07/2020 12:34	BB	14/08/2020 17:04
Physical Environment	0	0	BB	14/08/2020 17:10	BB	14/08/2020 17:10
Sleep problems, restlessness, rumination	9	9	BB	19/07/2020 10:15	BB	10/08/2020 07:54
Reduced sensory input	16	16	BB	19/07/2020 09:55	BB	07/08/2020 10:51
No commute or travel	7	8	BB	19/07/2020 09:50	BB	06/08/2020 21:40
More to remember increased cognitive load and executive functions	5	5	BB	07/08/2020 18:44	BB	07/08/2020 17:49
Enhanced sensory overload	10	10	BB	20/07/2020 11:16	BB	10/08/2020 07:42
Health concerns and access to services	0	0	BB	29/07/2020 15:05	BB	12/08/2020 17:47
Unable to access Mental Health provisions	0	0	BB	19/07/2020 09:45	BB	19/07/2020 10:20
Covid related concern	0	0	BB	10/08/2020 21:17	BB	10/08/2020 21:17
Able to access mental health provisions	0	0	BB	26/07/2020 20:51	BB	10/08/2020 21:13
Ability to engage in self-regulatory behaviours	0	0	BB	14/08/2020 17:13	BB	14/08/2020 17:13
Unable to engage in special interests & previous coping strategies	12	12	BB	19/07/2020 10:21	BB	10/08/2020 08:01
More time for special interests & novel interests and skills	31	40	BB	19/07/2020 10:16	BB	07/08/2020 10:57
More control over routine & more regular routine	6	6	BB	31/07/2020 11:35	BB	10/08/2020 07:38
Limited space to self-regulate	15	18	BB	19/07/2020 11:31	BB	11/08/2020 08:04
Hard to adjust to frequent changes to routine	26	29	BB	31/07/2020 11:32	BB	10/08/2020 07:59
Change to food routine	13	13	BB	30/07/2020 07:43	BB	07/08/2020 11:17

# Flowchart A Presented at a Team Meeting



## Flowchart B Presented at a Team Meeting:



## November 2020: Coding in Nvivo

Nodes								
Name	Sources	References	Created By	Created On	Modified By	Modified On		
Repercussions of intolerance to uncertainty		0	0	BB	14/08/2020 17:11	BB	26/10/2020 15:18	
Uncertainty over government rules and guidelines		0	0	BB	09/09/2020 15:28	BB	21/09/2020 10:28	
Uncertainty for the future and enhanced vulnerability		0	0	BB	13/09/2020 13:13	BB	26/10/2020 15:19	
Missing information		0	0	BB	15/08/2020 13:27	BB	15/08/2020 13:27	
Adjusting to changes in the 'outside social world'		0	0	BB	26/10/2020 15:12	BB	26/10/2020 15:12	
Reduced in-person interactions		0	0	BB	12/10/2020 13:00	BB	12/10/2020 13:00	
Experiences of remote communication		0	0	BB	09/10/2020 15:01	BB	26/10/2020 15:14	
Altered connections and interpersonal impact		0	0	BB	26/10/2020 15:14	BB	26/10/2020 15:14	
Access to healthcare provisions		0	0	BB	26/10/2020 15:15	BB	26/10/2020 15:15	
Adjusting to changes in the 'inside social world'		0	0	BB	26/10/2020 15:13	BB	26/10/2020 15:13	
Intrapersonal effect of health concerns relating to covid19		11	11	BB	19/07/2020 10:15	BB	26/10/2020 17:48	
Increased social demands and complexity in the household unit		11	14	BB	19/07/2020 12:14	BB	26/10/2020 18:06	
Ability to engage in self-regulation		0	0	BB	14/08/2020 17:13	BB	16/09/2020 14:38	
Sensory regulation		0	0	BB	04/09/2020 15:55	BB	13/09/2020 13:22	
Cognitive regulation		0	0	BB	11/09/2020 16:43	BB	13/09/2020 13:23	
Behavioural regulation		0	0	BB	11/09/2020 16:42	BB	13/09/2020 13:23	