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Surviving Lockdown:
The experiences of neurodivergent young people and their
caregivers through the Covid-19 Pandemic

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Thesis Abstract

Neurodivergent young people and those that care for them are two groups who are vulnerable to increased risk of poor mental health. The covid-19 pandemic has been a difficult time, with many rapid changes. It is a period marked by lockdowns, the closure of schools and other services and social isolation. Neurodivergent young people presents with differences, for example; rigid and repetitive thoughts and behaviours; executive functioning differences; and emotional regulation difficulties, that may have made them more vulnerable during this time. Additionally, for their caregivers, during Covid-19 they were subjected to immense, with increased responsibilities and limited access to support. This thesis consists of a systematic review and meta synthesis and an empirical project. The meta-synthesis examines the experiences and impact of the covid-19 pandemic on the mental health and wellbeing of autistic young people and their caregivers. Thirteen qualitative papers were reviewed and the results show that the pandemic had a significant impact on these groups. Both reporting to increase anxiety, distress and burn out. As well as this, both autistic young people and their caregivers experienced negative outcomes in response to social isolation. The empirical study examines the impact of the easing covid-19 restrictions on young people with Special Education Needs and Disabilities (SENDs) and their families. The focus is to understand how the transition back to school. Interviews were conducted with 8 mothers of young people with SENDs. Analysis was conducted using an Interpretive Phenomenology methodology. The findings show that the mental health and wellbeing of children with SENDs, and their caregivers was significantly impacted by the covid-19 lockdown. Children demonstrated increased anxiety, behaviours that challenge and symptoms of low mood. Additionally, parents experienced an increased burden, with limited support, which contributed to increased psychological distress. As the restrictions were eased and the children transitioned back to school, the impact on children with SENDs was varied. Implications for future practice and research are discussed

Lay Summary

Children and teenagers with neurodevelopmental disorders like autism, ADHD and learning disabilities are more likely to have a mental health condition, such as anxiety or depression. Their parents are also more likely to have a mental health condition too. The covid-19 pandemic has been a difficult time and we experienced things like lockdown, schools closing and a lack of access to other services. Due to the difficulties that children with neurodevelopmental disorders experience, it is more likely that the pandemic affected their mental health. We conducted two studies, the first reviewed research that looked at the impact of the pandemic on the mental health on autistic children and teenagers and their caregivers. This study found that the pandemic had a negative impact on their mental health.

The second study looked at how children with special educational needs and their parents were impacted by lockdown and the transition back to school. We interviewed 8 mothers, who explained their experiences. This study found that both the children and their parents were negatively affected during lockdown. We found that their experiences with going back to school were varied. Some had bad experiences and others shared that it was a positive experience.

Chapter 1: Systematic Review

A Systematic Review and Meta-Synthesis exploring the experiences and impact of the Covid-19 pandemic on the mental health and wellbeing of autistic young people and those that care for them

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Abstract

Autistic young people and those that care for them are two groups who are vulnerable to increase risk of poor mental health. The covid-19 pandemic has been a tumultuous time and the measures put in place by governments around the world have been disruptive. Autism presents with differences, for example; rigid and repetitive thoughts and behaviours; executive functioning differences; and emotional regulation difficulties, that may have made them more vulnerable during this time. Additionally, caregivers to autistic young people experienced increased responsibilities, with limited access to support. This meta synthesis examines experiences and impact of the covid-19 pandemic on the mental health and wellbeing of autistic young people and their caregivers. This systematic review and meta synthesis reviewed 13 qualitative papers. These papers focused on the experiences of autistic young people and their caregivers during the covid-19 pandemic and the impact this had on their mental health and wellbeing. Analytic themes elicited included: The highs and lows; Change and Loss; and All things Social. Implications for future practice and research are discussed.

Introduction

The Covid-19 virus was first identified in Wuhan, China in December 2019 and due to the global spread of the virus The World Health Organisation (WHO) declared the global pandemic in March 2020. In response to the spread of the virus, governments around the world implemented public safety measures to slow the spread and over the course of the pandemic. One of the public health measures used by many governments across the world was to impose either national or regional lockdowns of their populations (BBC, 2020).

In a report by UNICEF in April 2020, it indicated that 2.34 billion children and young people under the age of 18 (henceforth referred to as young people), lived in one of the 186 countries that had some form of public health lockdown measures, due to covid at that time (Fore, 2020). The United Nations (UN) identified young people as a vulnerable group, likely to be some of those that are most affected by the disruptions caused by the pandemic. They identified that pandemic increased risk of poverty, school closures which led to educational disruption, but for many it also meant reduced access to food and nutrition (United Nations Sustainable Development Group (UNSDG), 2020). Studies completed in China, USA, Italy, Ireland and the UK have indicated that young people were at increased risk of mental health difficulties, as a result of the covid-19 pandemic, including depression, anxiety and post-traumatic stress symptoms (De Miranda & Da Silva, 2020; O'Sullivan et al., 2021; Smirni, Lavanco, Smirni, 2020)

These studies have linked increased risk of mental health difficulties during Covid-19 lockdown to, fear linked to the health crisis (fear of contamination, illness and death, illness and death of loved one), the impact of social isolation, reduced and restricted activity. Additionally, studies have indicated that other risk factors for decreased mental health were exacerbated through the pandemic, such as poverty and other social inequalities, increased exposure to domestic violence

(Lyons & Brewer 2022; UNSDG, 2020; Whitehead et al. 2021). Unfortunately, there is a lack of large scale, longitudinal studies related to the mental health impact of previous infectious disease epidemics and pandemics (Daly, Sutin & Robinson 2020), particularly with children and adolescent populations. However, some small-scale studies have demonstrated the impact that these crises have had on the mental health and wellbeing of young people (Koller et al., 2006; Page et al. 2011; Sprang & Silman, 2013).

Berger et al (2021) conducted a mixed methods systematic review evaluating the implications of exposure to infectious outbreaks on the mental health of young people. They identified that there was limited research in this area. They identified 11 studies globally; related to the Serious Acute Respiratory Syndrome (SARS) outbreak in 2003 (Hong Kong and Canada), the H1N1 outbreak (UK, USA, Mexico) and two covid-19 studies (Italy, Spain) that had been completed at the time of the review. Berger et al identified increased anxiety, stress, loneliness and depression. They further identified that increased anxiety was often linked to fear during isolation and a fear that family members would contract the illness (Koller et al, 2006). Furthermore, adolescents who had pre-existing mental health conditions such as anxiety and depression were those with the highest risk of distress (Page et al 2011).

While it is possible to draw links from these studies, there are also some limitations to their generalisability to the covid-19 pandemic. For example, in one of the H1N1 studies (Sprang & Silman, 2013), they addressed the impact of a parents' being quarantined away from the family. This is different from covid-19 where families have been required to shelter in place, together. Additionally, the majority of studies included, related to SARS, drew from samples of children who had been hospitalised, following SARS infection. With Covid-19, the risk of illness and hospitalisation was significantly lower in this population (Götzinger et al., 2020). Given the

unprecedented nature and broad reaching impact of the covid-19 pandemic, it is important to understand the impact of this on the mental health and wellbeing of specific populations, particularly those identified as more vulnerable.

One group that could be identified as more vulnerable are those diagnosed with Autism Spectrum Disorder (referred to as autism in this paper) (Toseeb et al., 2023). Autism is a neurodevelopmental disorder that is characterised by difficulty with social communication, a pattern of restricted and repetitive behaviours, interests and activities, as well as a pattern of sensory sensitivity (American Psychological Association, 2013). Young Autistic people commonly present with executive functioning differences such as cognitive inflexibility (Craig et al., 2016). This can present as: differences in transitions between behaviours, activities or thoughts; flexible problem solving; or inhibition (Murray et al., 2005; Ozsivadjan et al., 2021). Executive functioning differences such as cognitive inflexibility have been linked to increased risk of anxiety symptoms (Hollocks et al., 2014), such as the intolerance of uncertainty, and is a predictor of both internalising and externalising behaviour (Ozsivadjian et al 2021). It is also important to note that internalising and externalising behaviours can also be linked to burnout and exhaustion with maintaining masking and communication frustration of having to constantly adjust to a world designed for neurotypical people (Milner et al., 2022; Radulski, 2022). As well as this, autistic people have to manage the contextual effects of discrimination, stigma and marginalisation (Botha et al., 2022).

Additionally, Autistic young people are commonly identified as having one or more co-occurring psychiatric disorders such as: anxiety disorders including social anxiety; depressive disorders; attention deficit hyperactivity disorder (ADHD); and oppositional defiant disorder (ODD) (Simonoff et al., 2008; van Steensel et al., 2011). Autistic young people are twice as likely to be

diagnosed with an anxiety disorder or four times more likely to be diagnosed with a depressive disorder when compared to neurotypical peers (Beesdo et al.2009; van Steensel et al 2011; Toseeb & Asbury 2023).

Autistic young people are more likely to have increased risk factors for poorer mental health difficulties than neurotypical peers (Toseeb & Asbury 2022). Autistic young people are often described as being more likely to have difficulties maintaining friendships, difficulties with communication, poorer quality family relationships, and difficult school experiences (American Psychological Association, 2013; Gau et al., 2012; Petrina, Carter & Stephenson, 2014; Preece & Jordan, 2010). Additionally, autistic people are more likely to experience health inequalities. These inequalities include increased risk of developing health conditions, such as, gastrointestinal problems, epilepsy, abnormal immune function and are more likely to have reduced access to health care (Chaidez, et.al 2014; de Sousa Lima et al., 2020; Weir, Allison & Baron-Cohen, 2022). These differences in experiences can be explained as features of autism; linking them to social communication, rigid and repetitive behaviours or behaviours that challenge.

The “double empathy problem” (Milton, 2012), proposes that autistic and non-autistic people, have difficulty understanding each other. The implication is that within the wider social context, in which the neurotypical perspective is prioritised, the social context is made disabling only for autistic people. Considering, how health services are designed and offered, they may not be as accessible to neurodivergent people. For example, they often require increased communication demands, are unpredictable environments or challenging sensory experiences (Doherty et al., 2023).

Given the pattern of difficulties presented, autistic young people often rely upon established routines and a network of supports, including school and mental health services, that are adapted

to meet their individual needs (Toseeb et al., 2023). When governments around the world implemented lockdown measures in response to the growing threat from covid-19, these routines and supports were abruptly disrupted as schools and other services were closed (Banerjee et al., 2021). As discussed above, a feature of autism is a difficulty with sudden changes and transitions as well as the intolerance of uncertainty. Considering this and the rapid changes and uncertainty during this period, it is highly likely that this was a period of increased stress and anxiety for autistic young people. The growing body of research in this area indicates that autistic young people have been significantly impacted by the pandemic. Studies have reported that autistic young people have experienced an increase in symptoms related to anxiety, depression and stress (Alhuzimi, 2021; Colizzi et al, 2020; Humphrey et al., 2023).

Research prior to the covid-19 pandemic demonstrated that parents/carers of autistic young people are at increased risk of poorer mental health than parents of children with other additional support needs (Hayes & Watson, 2013; Pisula, 2007; Ruiz-Robledillo et al., 2014; Taylor & Warren 2012) or parents of neurotypical young people (Hoffman et al 2009). Additionally, it has been reported that parents of autistic young people are more likely to experience mental health conditions, such as depression and anxiety, than the general population (Bitsika & Sharpley, 2004; Friesen et al, 2022). Mental health difficulties and psychological distress in caregivers to autistic young people have been linked to challenges in accessing supports for their child and themselves, social isolation, managing their child's behaviours that challenge e.g., aggressive, self-harming or destructive behaviour, assistance with daily life skills, difficulties associated with comorbid diagnoses and situational stressors (Catalano et al., 2018; Friesen et al, 2022). Given the sudden changes as a result of government-imposed lockdown measures, which has led to increased responsibilities placed on parents with managing schooling, reduced access to supports and heightened anxiety in

relation to the pandemic, it is likely these difficulties have been exacerbated as a result (Bentenuto et al., 2021; Toseeb & Asbury, 2021).

With the broadening of diagnostic criteria and a growing understanding of the female phenotype and understanding masking behaviour, increasing numbers of adults, in particular women, are receiving a diagnosis of Autism (Lai & Barron-Cohen, 2015). While there is limited research looking at the experiences of autistic parents, there is evidence that growing numbers of parents are self-identifying as autistic after their children have gone through the diagnostic process (Crane et al., 2021; Lilley et al; Heyworth et al., 2023; Pohl et al., 2020). It is likely that autistic parents experience similar risks to mental health addressed above (Heyworth et al. 2023); however, it is also important to consider the differences they experience, e.g., with executive functioning, which may increase risk to mental health difficulties (Demetriou et al., 2018; Heyworth et al. 2023). Additionally, autistic adults are more at risk of co-occurring mental health difficulties, such as anxiety and depression (Lai et al., 2019), as well as the pressure to conform to a neurotypical world. However, it is also important to consider that autistic parents may have more of an understanding of the differences experienced by their neurodiverse children, than neurotypical parents. Consequently, they may have more insight into how to support their needs, and this may act as a protective factor with the stresses of parenting and autistic child (Crane et al, 2021).

Evidence from both quantitative and qualitative studies have suggested that parents of autistic young people have been negatively impacted by the covid-19 pandemic (Asbury, 2021; Adams, 2022; Creswell, 2021; Stadheim, 2022; Wang et al, 2021). A mixed methods review of peer reviewed articles and grey literature conducted by Lee et al. 2021, looked at the impact of the pandemic on the mental health and wellbeing of caregivers of autistic young people. The majority of studies highlighted that during lockdown, caregivers experienced increased distress and mental

health symptoms including anxiety and depression. Additionally, they highlighted that caregivers experienced increased caregiving demands, social isolation and were required to manage increased challenging behaviour from their children and other stressors, such as financial instability.

There is a growing body of evidence, mostly quantitative, that aims to identify the impact that the covid pandemic on the mental health and wellbeing of young people and their caregivers. Searches of PROSPERO indicate that a number of systematic reviews and meta-analysis of quantitative data are underway. However, to the author's knowledge there has been no meta-synthesis of the qualitative data in this area. The aim of this review is to understand the qualitative experiences of autistic young people, and their caregivers during the covid-19 pandemic and the impact this has had on their mental health and wellbeing.

Method

Inclusion/Exclusion or Eligibility Criteria

This meta synthesis will focus on the experiences and impact of the covid-19 pandemic on the mental health and wellbeing of autistic young people and their caregivers. Only studies that have used qualitative methods including, but not limited to, Thematic Analysis (TA), Interpretive Phenomenological Analysis (IPA) and Grounded Theory (GT) will be included. The studies included were those that include autistic young people, under the age of 18, and their parents/carers. Studies that included autistic young people who were older than 18 were included, if it was clear where the origins of the contributions were from, those from older young people were not included in extraction. This included studies where young people participated themselves, or caregivers reporting on their observation on their children's experiences in lockdown and the impact that it

had. Additionally, papers relating to parents/carers of autistic young people, responding on their experiences of parenting autistic young people through the pandemic and the impact that this has had on their mental health and wellbeing were included. Studies including mixed participant populations, such as parents and young people, were included if it was clear where the origins of the contributions were from. Papers were included from December 2019 to current date, this coincides with the first detection of the Covid-19 virus.

The inclusion criteria were as follows:

- Published since December 2019
- Using qualitative methodology
- Including young people 0-18 who have a diagnosis of ASD.
- Parents/carers of young people 0-18 who have a diagnosis of ASD
- English Language
- They were primary empirical studies – not reviews, meta-analyses or case studies.

Search Strategy

The search strategy for this review was devised by the author and a librarian at the University of Edinburgh. Database searches were conducted, using APA PsychARTICLES, APA PsychInfo, Embase and Ovid Medline and Applied Social Science Index and Abstracts (ASSIA). These databases were searched simultaneously, using the Ovid interface, except ASSIA which was searched through ProQuest. Additionally, a search for grey literature was conducted through a search with ProQuest Dissertations and Theses Global Database. This

was to allow for data that is not available in peer reviewed journals to be included in this review.

Search terms included:

Autis* OR asperger* OR ASD AND covid* OR “SARS-CoV*” AND teen* OR adolescen*
OR child* OR schoolchild* OR “emerging adult” OR “young people” OR “young person*”

Initial scoping searches were conducted using these terms and it was felt that other terms related to experience or impact significantly limited the search and was found to exclude studies known to be relevant, so it was decided to keep the search to these terms only, to avoid the exclusion of these and potentially other relevant articles. This search returned 1848 papers, which were then screened, in order to apply the inclusion/exclusion criteria.

Screening process and data extraction

Once database searches had been conducted, the RIS files associated with each search were uploaded to Covidence Data Management Software in order to screen articles and extract data. The Preferred Reporting Items for Systematic Reviews (PRISMA) protocol was used (Page et al, 2021). From the search 1848 records were added to Covidence. Following deduplication, 663 records were removed, leaving 1185 records to be screened. The next stage was to conduct title and abstract screening, applying inclusion and exclusion criteria. A second rater screened 118 (approx. 10%) of the papers in this initial phase. At this point, 1143 records were excluded, leaving 42 papers for full text review. Following the full text review, 29 papers were excluded, leaving 14 papers for data extraction. Of the papers that underwent full text review 8 papers (approx. 20%)

were screened by a second reviewer. There was 100% agreement between both raters. See figure 1 for an outline of this process. During extraction, descriptive information was taken from each of the papers included, see table 1. It is understood that two of the papers included, may have been drawn from the same sample, however as they had different aims, they were both included.

A quality appraisal was conducted on all 14 papers identified for data extraction. This was conducted using the 10 item Critical Appraisal Skills Program Qualitative Study Checklist (CASP 2018) tool for evaluating the quality of qualitative studies. The CASP was adapted to provide each study a score out of 10 (Lee et al., 2021). The responses on the CASP qualitative study check list are “yes”, “can’t tell” and no. For a yes response, a score of 1 was applies; “can’t tell”, a score of 0.5 and “no”, a score of 0. A second reviewer also conducted a quality appraisal of 30% of the papers. There was 97% agreement between raters. Although quality varied, no paper was excluded from this review.

Figure 1.

Prisma Flow Diagram (Page et al. 2021)

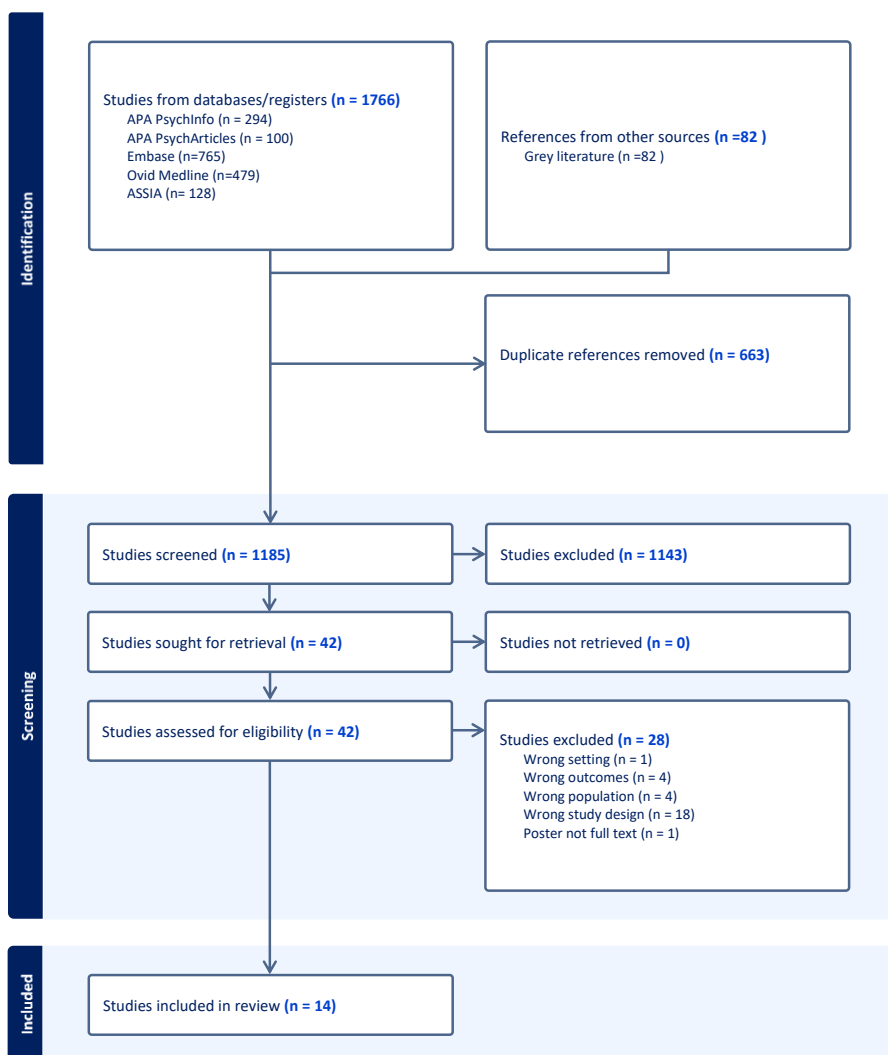


Table 1.***Descriptive Data Table***

Author, year	Title	Aim	Participants (N, gender, ages, ethnicity/ nationality)	Participant group	Setting	Country of origin	Data collection and analysis	Analysis	Main Themes
Adams, (2022)	Life under lockdown for children with autism spectrum disorder: Insights from families in South Africa	Explored caregivers perspectives on the experiences of children with ASD, during Covid-19 lockdown	12 families consisting of 21 caregivers to children with ASD aged between 4-10 years old (10 mothers, 6 fathers, 4 Grandmothers, 1 great grandmother) 18 South African 3 Zulu	Autistic Children and Young People	University, peer reviewed	South Africa	Semi-Structured interview	Framework method for Thematic Analysis	1. The lockdown breakdown: Negative reactions to the disruptions in routine 2. Unmanageable frustration resulting in dysregulation of emotions 3. Loss of previously acquired skills 4. Improved social interactions
Asbury (2023)	A longitudinal study of the mental health of autistic children and adolescents and their parents during COVID-19: Part 2, qualitative findings	Explored the impact of the first of the covid-19 pandemic on the mental health and wellbeing of children with an ASC and their parents and if this is different from children with other SENDs	Parents/carers of 517 autistic young people (75%) and other SENDS. Time 1: 282 parent/carers Time 2: 211 parent carers Time 3: 104 parent carers Time 4: 183 parent carers UK	Both	University, peer reviewed	United Kingdom	Open ended questionnaire	Content Analysis	1. Worry 2 Psychological distress 3. Wellbeing

Bozkus-Genc (2022)	How parents of children with autism spectrum disorder experience the covid-19 pandemic: perspectives and insights on the new normal	Explored parents' experiences of Covid-19 and the impact this has had. Additionally, explored the impact of covid-19 on parenting skills	8 parents (7 mothers, 1 father) of children and young people with ASD (aged 6-26), Turkish, Turkey	Parent	University, peer review	Turkey	Semi Structured Interview	Content Analysis	1. Positive Aspects 2. Negative aspects
Canning (2021)	Blurring the boundaries: the invasion of home as a safe space for families and children with SEND during Covid-19 Lockdown in England	Explored the opinions, experiences and motivations of families with a child diagnosed with ASD, during lockdown	8 families (10 children with ASD aged 5-11 years) UK	both	University, peer review	United Kingdom	Semi-structured interview	Thematic Analysis	1. School work demands 2. Use of Technology 3. Interactions (family/other agencies)
Dogan (2022)	Views and experiences of individuals with autism spectrum disorder and their mothers during the Covid-19 pandemic	Explored the perspectives and experiences of the pandemic, of children and young people with ASD and their mothers from March 2020 to November 2021	16 participants 8 Children and young people with ASD (aged 8-21) 6 male, 2 female 8 mothers (aged 41-46 years) Turkish, Turkey	both	University, peer review	Turkey	Semi Structured Interview	Thematic Analysis	CYP with ASD: 1. The meaning of the pandemic for them 2. Pandemic activities 3. measures taken during the pandemic 4. Reflection of the Covid-19 Pandemic on School Mothers: 1. The impact of the pandemic 2. Changes in Children with ASD during the pandemic
Heyworth* (2023)	"I'm the Family Ringmaster and Juggler": Autistic Parents' Experiences of Parenting	"To understand autistic parent' parenting experience	35 autistic parents (aged 32-54) of	Parents	University, peer reviewed	Australia	Semi-structured interview	Reflexive Thematic Analysis	1. Regular life "can be really hard at times"

	During the Covid-19 Pandemic	during the initial phase of the Covid-19 Pandemic”	autistic children (aged 4-25 years) 95% female						2. Lockdown created new pressures 3. “My mental health just tanked” 4. Distinctive autistic insights supported family life
Humphreys (2023)	The impact of Covid-19 Lockdown on parents and young people with Autism Spectrum Disorder (ASD)	Explored the experiences, challenges and opportunities identified by parents of children and young people with ASD during covid-19 lockdowns	117 Parents/ Caregivers of CYP with ASD 112 females 5 males 93 Australian 24 Other 86 parents respond to open ended questions. 12 parents completed interview	both	University, peer reviewed	Australia	Open ended questionnaire & Semi Structured interview	Thematic Analysis	1. Accessing support services 2. Receiving Support Services and school via online modes 3. observing changes in behaviour 4 Experiencing levels of conflict at home 5. Impacting the health and relationships of carers and their families
Lew-Koralewicz (2022)	Psychosocial Functioning and the Educational Experiences of Students with ASD during the Covid-19 pandemic in Poland	Explored the impact of the covid-19 restrictions on the psychosocial functioning of adolescents with ASD	10 Young People with ASD (aged 16-18 years old 9 males 1female	Autistic Children and Young People	University, Peer reviewed	Poland	Semi-Structured Interview	IPA	1. Emotional Functioning 2. Social Functioning
Ozsvadjian (2023)	Autistic and non-autistic young people’s and caregivers’ perspectives on Covid-19 related schooling changes and their impact on emotional wellbeing: An opportunity for change?	Explored autistic and non-autistic Young people’s experience of school changes and the relationship between these changes and their everyday lives and well-being/mental health, during the COVID-19 pandemic	71 Caregiver 45 caregivers of autistic young people (39 mothers, 3 fathers, 3 other) 26 caregivers of non autistic young people (25 mothers, 1 father)	Autistic Children and Young People	University, Peer reviewed	United Kingdom	Open ended questionnaire	Thematic Analysis	1. Difficulties faced in school pre-lockdown 2. Benefits of lockdown learning 3. Challenges faced during lockdown learning 4. General changes to well-being during lockdown 5. Thoughts and attitudes towards return to school after lockdown 6. Caregivers’ and youths’ hopes for future changes to education

		from both caregiver's and young people's perspectives	18 autistic young people 12 non autistic young people (aged 11-18) United Kingdom						
Pellicano (2022)*	Covid-19, social isolation and the mental health of autistic people and their families: A qualitative study	Explored how autistic people and their families experienced and responded to increased social isolation during lockdown and the impact this had on their mental health	84 Parents (aged 23-65) of autistic children 16 Autistic Young people aged 12-18) Gender: 5 female 8 male 1 non binary, 1 other Ethnicity: 12 White European, 1 White Australian/New Zealand, 2 Other White, 1 Chinese	Both	University, Peer reviewed	Australia	Semi-Structured Interview	Reflexive Thematic Analysis	1. a release from conventional social challenges 2. a deep sense of social loss 3. a deterioration in mental health
Saliverou (2021)	The impact of Covid-19 Pandemic Containment Measures on Families with Moderate and High Functioning ASD	Explored the impact of lockdown and subsequent government measures impacted the lives of children with ASD and their families	10 caregivers (aged 33-52 years) of children with ASD (aged 6-15 years) 7 mothers, 3 fathers Greek, Greece	both	University Peer reviewed	Greece	Semi-Structured interview	Thematic Analysis	1. The Educational Framework 2. The management of daily life 3. The construction on the new daily routine

Stadheim (2022)	The qualitative examination of the impact of the Covid-19 pandemic on children with autism and their parents	Explored the experiences and community needs of children with ASD and their families during the covid-19 pandemic	122 parents of 122 children and adolescents with ASD (aged 3–18 years) American, USA	both	Research Centre, peer reviewed	USA	Open ended questionnaire	Grounded Theory	1. public health measures yielding new challenges and unexpected gains, Experiencing abrupt changes across developmental domains 3. Changing family dynamics 4. Protective factors
Tokatly Latzer (2021)	Core experiences of parents of children with autism during the Covid-19 pandemic	Explored in-depth experiences of parents and children with autism and the implications of lockdown	31 parents of 25 children with autism Parents: 25 female, 6 male Children: age 4-6 years 22 male, 3 female Israel	both	University, peer reviewed	Israel	Semi-Structured interview	Immersion-Crystallisation	1. shutting down of special education system 2. crude logistics of a pandemic induced lockdown 3. Chronicles of regression and evolution 4. Coping strategies
Vanderlick (2023)	Parent Perspectives on how the COVID-19 Pandemic Affected Symptoms of Autism Spectrum Disorder in Their Children	Explored how parents describe their experience during the covid-19 lockdown, while managing their children's ASD related behaviour	7 parents of children with ASD 5 female, 2 male USA	parents	Doctoral Dissertation	USA	Semi-Structured interview	Narrative Analysis	1. Experience of raising a child with ASD 2. Differences with quarantine 3. Transition back to routine was successful 4. Advice and changes for the future

Synthesis Method

This meta-synthesis was conducted, using the Thematic Synthesis Method (TS) that was proposed by Thomas and Harden (2008). This method involves the reading and re-reading of individual papers and identifying the constructs and themes within the primary data. In order to do this analysis, data was extracted from the sections of the papers titled “findings” or “results”. This was then uploaded to Nvivo 14 Software to conduct the analysis. Quotes from participants were excluded from the analysis in order to reduce bias and to stay as close as possible to the author’s text. Text was read and re-read, and coded line by line according to context and meaning. As analysis moved on to subsequent papers, codes can be adapted and changed, or new codes could be added. This process created a “Codebook” of relevant codes of concepts that have been translated across papers, with associated quotes. Codes were reviewed for similarities in order to group them into descriptive themes. Once these descriptive themes had been identified, they were reviewed further in order to identify analytical themes. See table two for an overview of identified themes. In order to address validity, codes from 3 papers (20%) were discussed with a second reviewer. There was a general agreement about the codes, between reviewers.

Findings

The data for this meta synthesis was extracted from 14 different qualitative studies conducted across the globe. These included studies from the UK (Asbury, 2023; Canning, 2021; Ozsivadjan, 2023), Australia (Heyworth, 2023; Humphreys, 2023; Pellicano, 2022), Turkey (Bozkus-Genc, 2022; Dogan, 2022); USA (Stadheim, 2022; Vanderlik, 2023) Greece (Saliverou 2021); Poland (Lew-Koralewicz 2022); Israel (Tokatly Latzer, 2021); and South Africa (Adams, 2022). Participants included both autistic young people and their caregivers. Autistic young people's ages ranged from 5-18 years. Study participants were either caregivers only, caregivers and autistic young people or autistic young people only. Ten were completed with only caregivers as participants. In six caregivers provided responses about their own experience and their perspective on their autistic young people's experience (Asbury 2023; Humphreys, 2023; Saliverou, 2021; Stadheim, 2022; Tokatly Latzer, 2021). Additionally, three of these studies only looked at the experiences of the parents/caregivers (Bozkus-Genc, 2022; Canning, 2021; Heyworth, 2023) and one looking only at caregiver perspective of the experiences of their autistic young people (Adams, 2022). The remaining studies included autistic young people in their samples; three included both caregivers and autistic young people (Dogan, 2022; Ozsivadjan, 2023; Pellicano 2022) and one included only autistic young people (Lew-Koralewicz (2022)). All studies, except two, focused on the experiences during the first lockdown. The other two included experiences during and post lockdown (Asbury, 2023; Ozsivadjan, 2023).

Analysis produced 25 codes that have been organised into 9 descriptive themes and 3 analytic themes. These codes and themes are displayed in tables 2 and 3. The following narrative will examine these themes.

Table 2.

Themes and codes

Code Names	Descriptive Theme	Analytic Theme
Increased anxiety and stress The burden of juggling everything Low mood Changes in Behaviour	Emotional impact	The highs and lows
Feeding difficulties Sleep	Physical Health	
Relationships in the family Skill development Impact of reduced demands Ability to Adapt	Positive aspects	
School Closure Change in mental health service provision Wish to return to normal	Loss of services	Change and Loss
Boredom/Frustration Sensory Stimulation	Loss of freedom	
Regression in development Academic performance	Loss of skills	
Adapting new routines Managing new public health measures	Managing Change	
Missing connection with family and friends Loneliness Nothing has changed for me	Social Isolation	All Things Social
Loss of Social Skill Helpfulness of technology	Social Skills	

Theme 1: The Highs and Lows

1.1 The Emotional Impact

Participants reported that lockdown was difficult for autistic young people and that it had a significant impact on their mental health and wellbeing. In all papers it was highlighted that young people experienced an increase in anxiety related symptoms. There were a number of different reasons attributed to this, but all highlighted the sudden change in routine as a result of the implementation of public health safety measures as a trigger. It appears that autistic young peoples' understanding of the changes, impacted the intensity of the symptoms. Furthermore, young people experienced heightened anxiety specifically related to the pandemic, including: fears of contamination, that a family member or friend would become unwell or die.

“the autistic young people also reported worsened mental health including anxiety, low mood, and worsened self-esteem” (Ozsivadjian, 2023 pp. 1486)

Linked specifically to features of autism, children experienced anxiety due to rigid and literal interpretations of public health measures such as social distancing rules. This could include anxiety around how they or others follow these rules.

“children’s anxiety was triggered by the abrupt change in routine, fear of themselves or a loved one becoming ill and overly literal interpretations of social distancing rules.” (Asbury, 2023, pp194)

As well as increased anxiety, participants reported that some autistic young people experienced significantly lowered mood and symptoms of depression, including increased experiences of self-harm and suicidal ideation.

“Parents described their child [feeling down], being [emotional] or [unhappy], with some depicting the changing mood symptoms as depression” (Stadheim, 2022, pp6).

Participants indicated that emotional distress was observed through changes in behaviour, such as increased repetitive behaviours or compulsive behaviours (Lew-Koralewicz, 2022; Tokatly-Latzer, 2021). Additionally, parents reported that they observed increased behaviours that challenge, such as aggressive and destructive behaviour (Adams, 2022; Asbury, 2023; Humphreys 2023; Stadheim, 2022; Tokatly-Latzer 2021).

While participants largely reported that autistic young people experienced increased difficulty with anxiety and emotion regulations, some did report that during lockdown, they either experienced no change or improved anxiety, compared to what they experienced before lockdown measures were implemented. Participants attributed this to a reduction in demands being placed on the young people, with reduced social interaction and avoiding stressful environments, such as school (Asbury, 2023; Dogan, 2022)

“children had difficulty in regulating their emotions; this was evident with [participant] when his child got so angry that he became very destructive.” (Adams, 2022)

Parents also reported to experiencing increased anxiety and stress, and described lockdown as “really hard” (Pellicano, 2022). Parents also reported to anxiety around transmission of covid, particularly if they were the ones who were mostly leaving the home, for example if they still had to go out to work.

“some worried about bringing the virus home from work, as is likely to have been the case for many parents working outside the home” (Asbury 2023, pp. 194)

Fear of transmission of the virus, led parents to worry. Some of this worry was linked specifically to having a child with additional needs. Parents reported heightened worry about what would happen to their child, if they were to die particularly if there was not someone who understood the specific needs of their child. As well as this, parents drew a comparison that they likely faced higher stress and anxiety than parents of neurotypical young people. They described having to deal with anxiety and stress around disablist public health safety measures such as “do not resuscitate” orders for people

with intellectual disabilities, implemented in the UK, increased barriers to support, and the risk of developmental regression due to the closure of schools and specialist services (Asbury, 2023; Canning, 2021; Stadheim, 2022; Vanderlick, 2023).

Heyworth (2023) focused on the experience of autistic parents of autistic young people. In this paper, parents highlighted that they had pre-existing difficulties, that contributed to elevated anxiety and difficulty with low mood. This included managing their own difficulty with managing sudden change, their restricted and repetitive behaviours and sensory difficulties.

When governments implemented lockdown measures, parents suddenly found themselves having to take on many more roles than normal, all at the same time; for example, being responsible for home schooling, childcare, still working (either from home or going out to work), managing therapeutic input and supporting the family's needs.

“Parents experienced anxiety and burn out from taking on all caring and educating responsibilities for their child” Humphreys, 2023).

With the closure of schools and other support services, such as therapeutic services, parents were required to take on these roles, with limited support from formal systems. Additionally, due to social distancing rules, they also had limited access to more informal supports, such as the support they would normally receive from family and friends. As mentioned previously, many of their children experienced difficulty with regulating their emotions and some experienced an increase in behaviours that challenge. Parents were required to manage these with limited access to support, which further contributed to difficulty with stress, anxiety and burn out. Autistic parents shared that difficulty with executive functioning had a significant impact on their ability to manage everything.

“This was especially the case for those with prior executive function difficulties who “already had trouble being organised, and staying on top of chores and family admin, including arranging support for [child]” (Heyworth, 2023 pp30).

1.2 Physical Health

Some of the autistic young people experienced some “physical changes” (Dogan 2022) during the pandemic. Many parents reported that the young people experienced increased feeding difficulties during lockdown. Some of this was attributed to limited access to preferred foods and as a result of restrictive behaviour and/or sensory sensitivity around foods, autistic young people struggled to eat alternatives. Lack of access to preferred foods led to increased distress in young people, and parents observed behaviours such as refusal to eat, linked to elevated anxiety. Some parents described going to great lengths to attempt to track down or recreate foods that their children ate before the pandemic, to varying degrees of success.

“Families reported that children either refused to eat or experienced significant emotional distress as they were unable to eat their preferred food or meals... Parents found it difficult to find alternatives or disguise food and packaging in order for children to eat and to reduce their emotional distress” (Adams, 2022, pp 1012)

Not only was the lack of access to preferred foods distressing for the young people, but also a source of worry and stress for their parents as well. They wanted to make sure that their children’s nutritional needs were being met, and as mentioned previously, were required to juggle many different responsibilities, including attempting to locate foods for their children and manage the consequences of the lack of access, including managing challenging behaviours.

Additional to feeding difficulties, autistic children experienced changes in sleep.

“Sleep was also a common topic. Many children found it difficult to fall asleep and/or suffered from frequent awakenings and night terrors” (Tokatly-Latzer,2021, pp 1052)

Autistic young people’s difficulty with sleep contributed to increased worry by parents about their children.

1.3 Positive aspects

Autistic young people and their parents shared that despite all of the challenges caused by the pandemic and lockdowns, there were also a number of different positive aspects that were important to highlight. Many participants highlighted that they enjoyed spending time with their families, that they would not normally be able to spend together. This contributed to a sense of connectedness with each other, that they may not have previously had.

“adolescents with ASD had an increased feeling of security and were able to strengthen their relationships with relatives, which was definitely a positive effect of the pandemic” (Lew-Koralewicz, 2022)

With the additional time at home, autistic young people and their parents observed that they had time to focus on skill development. Some parents highlighted that they were able to support their children with learning life skills. Many autistic young people reported that they were able to take up a new hobby or focus on learning a new skill.

“flexible schedules also meant that they could pursue their passions, which ranged from reading. Chess, sewing, playing Animal Crossing, Minecraft, World of Warcraft, baking, choir, singing, painting, sculpting, gardening, building Lego to renovating the house. Some attended online groups that were the highlight of [their] week” (Pellicano, 2022).

Another positive aspect that was reported, as mentioned previously, was that lockdown provided some autistic young people with reduced demands. For example, the reduction of social interactions, and exposure to stressful situations, such as school, meant that they had either reduced anxiety, or in

increased capacity to manage things that they were not able to manage before the lockdown (Ozsivadjian). Autistic parents reported that they also shared that the reduced demands helped to reduce their anxiety and that many felt less anxious during lockdown than they had before.

“Not having to compete with other children resulted in positive experiences and greater self-confidence” (Canning, 2021)

Autistic young people and their parents reported that despite the beginning of lockdown being challenging, and many struggled to manage the sudden change. It is evident that that many of the autistic young people and their parents were able to eventually adapt to new routines and patterns. This is an indication that for some anxiety may have decreased over time as they got used to the change, enabling them to adapt to new routines.

Theme 2: Change and Loss

2.1 Loss of services

Autistic young people and their parents reported that the closure of schools was disruptive for most of the autistic young people. They highlighted that the changes in their routine and rigid understanding of what school involved and where learning happened, meant that they struggled to engage in educational activities. Many schools utilised technology to continue to provide schooling. They offered lessons in varying ways online. Parents mostly reported that when lessons moved online, the academic provision was not sufficient to meet the complex needs of their children. Many observed increased anxiety, frustration and challenging behaviour. Some reported that online learning could be demanding sensorily and led to their children becoming over stimulated and struggle with sensory regulation.

“a growing number of parents expressed concern that they were not doing a good enough job of home education and learning at home was causing high levels of anxiety for their children” (Asbury, 2022).

Parents reported that the closure of school increased the burden of what they had to manage, as they were required to support their children to access learning, many felt that they “did not have the knowledge” to meet their child’s developmental needs” (Tokatly-Latzer, 2021). This contributed to parents’ feelings of hopelessness and increased anxiety and worry about their children. Additionally, parents reported varying levels of support from schools and highlighted that without the support of schools it was difficult to encourage their children to engage.

While most participants indicated negative experiences of home schooling and learning online, some participants felt that moving schooling online made it more accessible, as it removed the social aspect of school and young people felt more able to engage (Ozsivadjian, 2023).

“Young people reported that remote learning is a lot better actually than school [due to the] peace and quiet” (Pellicano, 2022)

As mentioned previously, the reduced demands helped some to have experiences of success in things that would previously have been more stressful for them (Dogan, 2022; Lew-Koralewicz, 2022). Additionally, some explained that having schooling online meant that they were able to engage with classmates, which helped reduce feelings of social isolation.

Therapeutic services were either not available or they attempted to move them online, this led to difficulties engaging online, parents reported that the difficulties with learning at home and lack/difficulty of access to therapeutic services contributed to increased challenging behaviour and they observed decline – developmental and academic. This loss of skill will be further discussed below.

2.2 Loss of skills

Parents of autistic young people shared that they observed their children to experience a decline in academic and other developmental skills over the course of lockdown. Additionally, some parents highlighted that they observed their child to have reduced coping skills.

“Regressions in previously mastered skills or behaviors were reported across multiple domains, including social communication (i.e., regression of speech, communication of needs, social skills, and non-verbal communication skills like eye contact), self-care, executive functioning, emotional control, and fine motor skills” Stadheim (2022).

Much of this was attributed to reduced educational provision, as well as the cessation of specialist support services, for example; speech and language or mental health services (Adams, 2022; Saliverou, 2021; Stadheim, 2022; Tokatly-Latzer, 2021)

As discussed previously, parents shared that despite schools and other services attempting to provide input online, parents identified that the provision was not sufficient to meet the complex needs of their child.

“All caregivers in the current study reported on their child’s loss of and degradation of previously acquired skills during the lockdown period. Caregivers felt that a reason for the degrading of skills may be attributed to the cessation in their child’s education and therapy (Adams, 2022)”.

Parents were concerned about the current regression and loss of skills and also worried about the future and the impact that this regression will have on their children’s development as things start to return to normal, post covid (Tokatly-Latzer, 2021; Vanderlick, 2023).

2.3 Loss of freedom

With the implementation of lockdown measures, autistic young people and their parents reflected on the impact of the loss of freedom, particularly around the freedom to leave the house and to engage in activities for enjoyment. Participants highlighted that this change in freedom impacted on their mood and led to young people becoming bored, frustrated and dysregulated. Parents attributed an increase in behaviours that challenge to a number of things, including “lack of access to preferred

activity” (Stadheim, 2022)

Some autistic young people indicated that their rigid interpretation of what it meant to be at home for a stretch of time, e.g. school holidays, led to frustration, particularly around not being able to engage in leisure activities and also being required to engage in structured activities.

“Children were frustrated as they associated being home with specific activities, such as being on holiday, but not able to do what they wanted” (Adams 2022)

Additionally, autistic young people shared that they became bored, which in turn affected their motivation to organise themselves and to maintain previously established routines.

“Some people felt bored, which resulted in the inability to organize their time with regard to their previous habits” (Lew-Koralewicz 2022).

Participants described the impact of being locked down on sensory regulation. Some autistic young people benefit from physical exercise in order to help regulate their sensory systems. Lockdown meant that this was sometimes not possible to achieve, particularly with stay-at-home orders. Participants reported that difficulties in achieving this meant that autistic young people became dysregulated and that this in turn had an impact on their mood.

“One of the most frequently mentioned challenges was the lack of means and space for children to expend energy, leading to various levels of psychomotor agitation... Feelings of helplessness are being used to describe the suffering of being in a small space (Tokatly-Latzer, 2021)

Autistic parents described a similar experience regarding sensory regulation. Additionally, they

highlighted that lack of space, and being around others at home, with limited escape, also provided a challenging sensory experience.

“[autistic parents] found lockdown to be such an intense sensory thing for me, especially the intensity of constantly being in each other’s presence (Heyworth, 2023)

2.4 Managing change

When governments implemented PHSM and lockdown measures, it was a period of rapid change that significantly shifted people’s every day activities and routines. Autistic young people and parents reported that for them, lockdown resulted in a loss in their routines, which significantly impacted both the young people’s and their parents’ mental health and wellbeing, particularly in the initial stages of the pandemic.

“families were called upon to formulate a new daily routine adapted to the new measures and health restrictions. For most families, this was a great difficulty, especially in [lockdown 1], which was an unfamiliar situation, and there was neither preparation or assistance” (Saliverou 2021).

While the initial changes were challenging, many reported that, as time went on, they were eventually able to adapt to the situation and implement new routines in their daily life.

“While they experienced the loss of routine, many found that they were able to adapt” (Pellicano, 2022).

While many participants reported that they were able to adapt, parents and young people expressed a wish for life to return to the pre-pandemic normal (Saliverou, 2021; Tokatly-Latzer, 2021; Vanderlick) when lockdown measures ended, many had difficulty adjusting again with the easing restrictions (Stadheim, 2022).

As well as managing changes to routine, some participants shared their experiences managing the new public health safety measures. Some parents shared that their children had significant difficulty complying with social distancing rules and wearing masks. They particularly highlighted that wearing masks was a difficult sensory experience. Difficulty with managing these new measures had an impact on both the young people and their parents, and in some instances, prevented them from accessing the community.

“[participant described] instances where their child was unable to comply with the public safety measures, which added to their family’s isolation to the home environment difficulty tolerating a mask or face covering” (Stadheim, 2022).

Theme 3: All Things Social

3.1 Social Isolation

Many autistic young people included in these studies experienced social isolation as a result of lockdown and social distancing measures that were implemented in their countries. They reported to feeling a sense of loneliness, missing the connection that they had with family or friends, who they were not able to see. It appears that the increased sense of loneliness and social isolation may have contributed to feelings of sadness and low mood in autistic young people.

“Parents were also acutely aware of how much their children really missed their friends and reflected on how much the lockdown may have impacted quite seriously with those friendships” (Heyworth, 2023 pp 32).

For some they were able to use technology, for example using video calling, as a way of keeping in touch with family and friends. However, for many this was challenging, and did not facilitate social access. Participants reported that being online could be overwhelming, as it was a new way of

communicating and they had difficulty with managing the change of approach to social interactions. As well as this, many struggled with sensory difficulties when engaging in social activity online.

“[autistic adolescents] point out that they do not have enough competence to build satisfactory, remote contact with their peers, although they feel the need for such contact. Their lack of skills makes it difficult for them to engage in a relationship, and the pandemic exacerbated these difficulties” (Lew-Koralewicz, 2022, pp8)

Parents of autistic young people also reported experiencing social isolation during lockdown. Parents lost access to many of their more informal support systems, including family and friends. Additionally, they experienced burn out from managing all of the responsibilities that they were juggling, for many it felt too much to reach or have the capacity to engage in social interactions, due to the mental load. Autistic parents shared that they felt a real loss of access to the neurodivergent community, as they felt it was difficult to manage social interactions online, again highlighting that mental load and burn out made it difficult for them to reach out to each other.

3.2 Social Skills

Parents of autistic young people highlighted that they were worried that as their children were not practicing social skills, their skills in this area would regress. Furthermore, some parents and autistic children highlighted that they did lose some ability to engage in social skills. Many autistic young people “became increasingly tentative to engage in social interaction” (Humphrey, 2023, pp7) and increasingly avoiding social situations and more likely to engage in solitary activity such as playing computer games or watching TV (Humphrey, 2023; Lew-Koralewicz, 2022; Stadheim, 2022).

Discussion

The mental health of autistic young people was negatively impacted by the covid-19 pandemic. They experienced elevated levels of anxiety and symptoms of low mood (Asbury, 2022; Ozsivadjian, 2023; Stadheim, 2022). Additionally, caregivers observed increased rigidity and behaviours that challenge, including aggressive and destructive behaviour (Adams, 2022; Asbury, 2023; Humphreys 2023; Lew-Koralewicz, 2022; Stadheim, 2022; Tokatly-Latzer, 2021). Autistic young people struggled to manage the changes that occurred as a result of the pandemic. They experienced disruptions in routines, education and therapeutic input, as well as social isolation. As well as the emotional impact, caregivers also reported physical changes that autistic young people experienced due to the disruptions of the pandemic. Caregivers reported changes in sleep patterns and feeding difficulties associated with restrictive behaviour and/or sensory sensitivity around foods, due to limited access as a result of the restrictions. This is consistent with findings reported by systematic review of quantitative data, that identify that autistic young people experienced increased anxiety and emotional dysregulation, changes in behaviour and disturbances with sleep as a result of the covid-19 pandemic (Dal Pai et al 2022; Lewis et al 2023).

The closure of schools and services was disruptive for many autistic young people, who struggled to adapt to the changes and to the reduced or curtailed supports. Many schools and services attempted to adapt and move their provision online; however, for many autistic young people, the provision was not adequate to support their complex needs. With this disruption, autistic young people's emotional distress appeared to increase in severity. This is supported by similar findings in quantitative studies (Colizzi et al., 2020; Lim et al., 2021). Caregivers reported that they observed the young people to experience regression in academic and developmental skills, including social communication, self-care, executive functioning, emotional regulation, speech and language and fine motor skills (Adams, 2022; Humphreys et al., 2023; Saliverou; 2021; Stadheim, 2022; Tokatly

Latzter, 2021; Vanderlick, 2023). Caregivers attributed this decline in skills to the lack of access for education and other therapeutic services.

Much of the theoretical understanding of autism highlights that autistic people experience reduced social communication skills and reduced social motivation (Baron-Cohen, 1995; Chevallier et al., 2012; Dawson et al., 2005). Based on this theoretical understanding, it might have been possible to hypothesise that autistic people would not have experienced negative outcomes from the social isolation as a result of lockdown restrictions. Despite this, the studies represented in this meta synthesis do not support this. Autistic young people experienced social isolation and loneliness during lockdown, which contributed to feelings of sadness and low mood (Heyworth, 2023; Humphreys, 2022; Lew-Koralewicz, 2022; Pellicano, 2022; Stadheim, 2022). Additionally, it was highlighted that differences with social skills made it difficult for autistic young people to find alternative methods, for example video calling, to connect with family and friends (Lew-Koralewicz, 2022).

Lockdown was equally difficult for caregivers, particularly due to the large demand placed on them. Caregivers had to juggle a huge load. This included things like family care, home education or online learning and addressing their children's complex needs; which includes managing their increases anxiety and behaviours that challenge (Asbury, 2023; Bozkus-Genc, 2022; Heyworth, 2023; Humphreys, 2023). Caregivers had to navigate this while attending work (remote or out of the home) and many other things. Parents had limited support from the schools, government agencies or other therapeutic services (Canning, 2021; Humphreys, 2023; Heyworth, 2023; Pellicano, 2022). Additionally, parents were significantly impacted by the loss of more informal supports such as family and friends (Asbury, 2023; Bozkus-Genc, 2022; Heyworth, 2023; Humphreys, 2023, Vanderlick, 2023). Autistic parents highlighted the loss of their community of neurodiverse parents (Heyworth, 2023). These studies highlight that caregivers had significantly more to contend with, with limited support, which worked to increase psychological distress and burnout. This is consistent

with the findings from systematic review of quantitative data, that identify that the caregivers of autistic young people experienced increased stress and decreased psychological wellbeing (Alonso-Esteban et al. 2021)

This is consistent with pre-covid evidence that links autistic young people's outcomes to the mental health and wellbeing of their caregivers (Hayes & Watson, 2013; Pisula, 2007; Ruiz-Robledillo et al., 2014; Taylor & Warren 2012). It has been identified that managing behaviours that challenge e.g., aggressive, self-harming or destructive behaviour, assistance with daily life skills, difficulties associated with co-occurring diagnoses, and difficulties in accessing supports for their child were linked to increased risk of psychological distress and burn out in caregivers to autistic young people. (Catalano et al., 2018; Pisula, 2007; Quintero & McIntyre, 2010). Caregivers to autistic young people are more at risk of negative outcomes than caregivers of young people with other additional support needs (Pisula, 2007). Heyworth et al (2023) and Pellicano et al. (2022) highlighted the additional difficulties faced by autistic parents to autistic young people, e.g. differences in executive functioning, pre-existing mental health conditions, managing sensory sensitivity. There is currently a paucity of research aiming to understand the experiences of autistic parents. Given the growing numbers of parents to autistic young people self-identifying as autistic (Crane et al., 2021; Lilley et al; Pohl et al., 2020), more research is needed to understand how best to support these families, not only in the event of another public health crisis, but also under more regular circumstances.

Whilst the majority reported negative outcomes; many autistic young people and their caregivers shared some positive experiences through the pandemic. It is important to acknowledge these differences in experiences. For many, they enjoyed being able to spend time together, they would not normally get. This additional time together enabled them to strengthen their relationships (Adams, 2022; Bozkus-Genc, 2022; Lew-Koralewicz). Additionally, some caregivers and autistic young people felt that lockdown offered them time to learn new skills or take up hobbies (Lew-Koralewicz, 2022; Pellicano, 2022). To some extent, this was attributed to reduced demands, like

reduction in social demands and less exposure to stressful environments e.g. school (Canning, 2021; Ozsivadjian, 2023; Pellicano, 2022). This reduced demand opened up the opportunity to experience successes, where they might not normally be able to. This may have also facilitated the ability to eventually adapt to new patterns and routines (Pellicano, 2022; Saliverou 2021; Stadheim, 2022). The beginning of lockdown was challenging, and many struggled to manage the sudden change. However, for some autistic young people they were able to eventually adapt accordingly.

The individual differences in experiences highlights the complexities of supporting autistic young people and demonstrates their need specific individualised support (Asbury et al. 2021).

Ozsivadjian et al. (2023) outlined participants hopes for the future, highlighting their wish for the continuation of social distancing measures beyond covid restrictions. They felt benefits from measures such as one-way systems, staggered start times and smaller group sizes. These measures worked to reduce anxiety and sensory load. Additionally, they expressed the need for individualised strength-based approaches and for teachers to have training in these methods. This demonstrates the impact of navigating a world designed by neurotypical people, on autistic young people. It supports the evidence that the fact that neurodivergent people need to constantly adjust to neurotypical norms, communication differences, and masking behaviours are exhausting and can lead to psychological distress and burnout (Milner et al., 2022; Radulski, 2022).

Limitations and Implications

There are a number of limitations to this meta-synthesis. The studies included in the synthesis are studies that have been conducted across the globe. This synthesis does help to understand the experiences of young autistic people and their caregivers during the pandemic, identifying similar patterns of difficulty, globally. What was not considered in this synthesis was the differences in the restrictions that were imposed by governments; neither were the specific supports that were available within each country. As a result, there is limited scope for understanding contextual differences that may have contributed to the difficulties faced by autistic young people and their

caregivers; or indeed, the positive experiences too. As the evidence base grows, it would be helpful to conduct reviews of the qualitative data based within individual countries. This would help to understand the experiences within the context of the restrictions that they faced. This may help to inform public policy in individual countries, by understanding the sort of support that is needed by autistic young people and their caregivers, particularly in the event of future public health emergencies.

It has now been over two years since the WHO declared the covid-19 pandemic and the virus still exists in the community. Additionally, it has not been a straight trajectory out of the crisis. For example, in the United Kingdom, there were multiple lockdowns between 2020-2021 (Baker et al., 2021; Senedd Research, 2022; SPICe Spotlight, 2022). The majority of the papers included in this synthesis are focused on experiences early on in the pandemic and thus only provides an understanding of the experiences, limited to that time frame. Further, longitudinal research is needed to understand the long-term impact of the pandemic on the mental health and wellbeing of autistic young people and their caregivers.

In many of the studies included, young people's experiences have been sought through parent report. In order to develop a richer understanding, it would be beneficial to conduct further qualitative research with autistic young people as participants. This may help us understand, on a deeper level, the impact that the pandemic has had on them and may help to provide more insight into what has driven individual differences. A deeper understanding would facilitate public policy in addressing accessibility of education and support services and the continuity of care.

The studies included in this meta synthesis analysed their data using varying different methods of qualitative analysis, which may raise concerns about the homogeneity of the review sample and may be considered a limitation of this study. Despite the differing methods of analysis, the sample was considered to be homogenous given that there is a common experiences and differences of the groups represented by the participants prior to the covid 19-pandemic. Namely, the differences that

are experienced by those with an ASC, that meets the diagnostic criteria for ASC (APA, 2011) and evidence shows that caregivers of autistic young people are faced with similar stressors (Hayes & Watson, 2013; Pisula, 2007; Ruiz-Robledillo et al., 2014; Taylor & Warren 2012).

Conclusion

Prior to the pandemic, autistic young people and their caregivers were already identified as populations at increased risk of poorer mental health. The findings of the studies included in this meta synthesis highlight that populations were significantly impacted by the disruption of lockdown. Additionally, that the differences associated with an autism diagnosis or being a caregiver, made them more vulnerable to negative outcomes. Autistic young people experienced increased anxiety, behaviours that challenge and symptoms of low mood. Caregivers were required to manage significantly during the pandemic, with limited supports. This contributed to elevated anxiety, psychological distress and burn out. Additionally, both groups experienced the effects of social isolation. While there were some positive experiences, linked to reduced demands, the majority experience was of negative outcomes. These studies provide a helpful understanding of the experiences of these groups during the earlier stages of the pandemic; however, more longitudinal research is needed to understand the long-term impacts, which will help to inform public health safety policy.

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Appendices

Appendix A: Submission Guidelines for Journal of Autism and Developmental Disabilities

Retrieved from: <https://www.springer.com/journal/10803/submission-guidelines>

Instructions for Authors

Editorial procedure

Double-Anonymous Peer Review

MANUSCRIPT FORMAT

Title Page

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

The name(s) of the author(s)

The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country

A clear indication and an active e-mail address of the corresponding author

If available, the 16-digit [ORCID](#) of the author(s)

If address information is provided with the affiliation(s) it will also be published.

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

Purpose (stating the main purposes and research question)

Methods

Results

Conclusion

For life science journals only (when applicable)

Trial registration number and date of registration for prospectively registered trials

Trial registration number and date of registration followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

Competing Interests: Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

Use a normal, plain font (e.g., 12-point Times Roman) for text.

Use italics for emphasis.

Use the automatic page numbering function to number the pages.

Do not use field functions.

Use tab stops or other commands for indents, not the space bar.

Use the table function, not spreadsheets, to make tables.

Use the equation editor or MathType for equations.

Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Body

The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:

Introduction (The introduction has no label.)

Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)

Results (Center the heading.)

Discussion (Center the heading.)

Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

Footnotes

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

Terminology

Please always use internationally accepted signs and symbols for units (SI units).

Scientific style

Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.

Please use the standard mathematical notation for formulae, symbols etc.: *Italic* for single letters that denote mathematical constants, variables, and unknown quantities **Roman/upright** for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) **Bold** for vectors, tensors, and matrices.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

Negotiation research spans many disciplines (Thompson, 1990).

This result was later contradicted by Becker and Seligman (1996).

This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author’s name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. “<https://doi.org/abc>”).

Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture*, 8(3), 207–217. <https://doi.org/10.1037/ppm0000185>

Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. <https://doi.org/10.1097/PHM.0000000000001435>

Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.

Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.

Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from <https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view>

Tables

All tables are to be numbered using Arabic numerals.

Tables should always be cited in text in consecutive numerical order.

For each table, please supply a table caption (title) explaining the components of the table.

Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.

Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Artwork and Illustrations Guidelines

Electronic Figure Submission

Supply all figures electronically.

Indicate what graphics program was used to create the artwork.

For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.

Vector graphics containing fonts must have the fonts embedded in the files.

Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Line Art

Definition: Black and white graphic with no shading.

Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.

All lines should be at least 0.1 mm (0.3 pt) wide.

Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.

Vector graphics containing fonts must have the fonts embedded in the files.

Halftone Art

Definition: Photographs, drawings, or paintings with fine shading, etc.

If any magnification is used in the photographs, indicate this by using scale bars within the figures themselves.

Halftones should have a minimum resolution of 300 dpi.

Combination Art

Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.

Combination artwork should have a minimum resolution of 600 dpi.

Color Art

Color art is free of charge for online publication.

If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.

If the figures will be printed in black and white, do not refer to color in the captions.

Color illustrations should be submitted as RGB (8 bits per channel).

Figure Lettering

To add lettering, it is best to use Helvetica or Arial (sans serif fonts).

Keep lettering consistently sized throughout your final-sized artwork, usually about 2–3 mm (8–12 pt).

Variance of type size within an illustration should be minimal, e.g., do not use 8-pt type on an axis and 20-pt type for the axis label.

Avoid effects such as shading, outline letters, etc.

Do not include titles or captions within your illustrations.

Figure Numbering

All figures are to be numbered using Arabic numerals.

Figures should always be cited in text in consecutive numerical order.

Figure parts should be denoted by lowercase letters (a, b, c, etc.).

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Chapter 2: Empirical Study

Parents perceptions of children with Special Education Needs and Disabilities returning to school during Covid-19 transition phases

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Abstract

This paper examines the impact of the easing covid-19 restrictions on young people with Special Education Needs and Disabilities (SENDs) and their families. The focus is to understand how the transition back to school impacted on their mental health and wellbeing. Young people with SENDs and their caregivers are two groups who were already identified as vulnerable, with increased risk of mental health conditions, before the pandemic. The current study analyses interviews with 8 mothers of young people (10 males and 8 females aged between 5-19 years old) with SENDs. They were interviewed about the impact of lockdown and the transition back to school, on the mental health and wellbeing of their children and themselves. Analysis was conducted using an Interpretive Phenomenology methodology. Analysis of the data produced 5 superordinate themes: Managing home-schooling and everything else, Impact on young people, process of transition, effect of the transition, Impact on family. The mental health and wellbeing of children with SENDs, and their caregivers was significantly impacted by the covid-19 lockdown. Children demonstrated increased anxiety, behaviours that challenge and symptoms of low mood. Additionally, parents experienced an increased burden, with limited support, which contributed to increased psychological distress. As the restrictions were eased and the children transitioned back to school, the impact on children with SENDs was varied. Implications for future practice and research are discussed

Introduction

Special Educational Needs and Disabilities (SENDs) are defined by the UK governments in the SEND code of practice 0 to 25 years (Department for Education, 2014) as a child or young person of compulsory school age who has a learning difficulty or disability. Specifically, that the learning difficulty or disability leads to a significantly increased difficulty in learning than the majority of same aged peers. Alternatively, has a disability that prevents them from accessing educational facilities that are provided for same aged peers in mainstream schools or post-16 institutions. There is a broad range of different types of SENDs that young people can experience, these can include, but not limited to, specific learning difficulties, such as dyslexia; behavioural and emotional difficulties; speech and language or communication difficulties, autism spectrum disorders (henceforth referred to as autism) or Intellectual Disabilities (McCoy et al 2011). The UK government reported that in 2022 that 16.5% of children present with special educational needs (Department for Education, 2022).

Given that there is a broad range of difficulties associated with SENDs, there is a broad spectrum of differing support needs required by these young people, which are based on their specific difficulties (Toseeb & Asbury 2021). Despite the heterogeneity, research shows some common experiences. Evidence shows that children and young people with SENDs are identified as a group who are more vulnerable to mental health conditions, such as depression and anxiety (Al-Yangon, 2012; Matteucci et al 2019, Mungnani et al, 2009). For example, autistic children are twice as likely to be diagnosed with an anxiety disorder or four times more likely to be diagnosed with a depressive disorder when compared to neurotypical peers, as well as one or more co-occurring psychiatric disorder (Beesdo et al.2009; Simonoff et al., 2008; van Steensel et al 2011; Toseeb & Asbury 2023).

Additionally, Emerson & Hatton (2007) reviewed the Office of National Statistics (ONS) report on the mental health of children and adolescents with learning disabilities. Their review based on the

ONS data shows that 1 in 3 children and adolescents with learning disabilities have a diagnosable psychiatric disorder and are six times more likely to have a diagnosable psychiatric disorder, such as anxiety, depression and conduct disorder, than peers without a learning disability (Totskia, Liew, Absoud & Adnams 2022). This indicates a significant risk of mental health difficulties in children and young people with learning disabilities. However, these findings should be interpreted with caution as it does not appear to consider other potential risk factors to mental health difficulties. People with SENDs are more likely to have increased risk factors to mental health difficulties, this includes poorer health (e.g. increased risk of endocrine disorders, epilepsy, gastrointestinal problems) poverty, family dysfunction as well as expressive and receptive language difficulties (Allerton et al., 2011; Chaidez, Hansen & Hertz-Picciotto, 2014; Emerson & Einfeld, 2010; de Sousa Lima et al., 2020; Totsika et al., 2022; Wallander et al., 2006, Weir, Allison & Baron-Cohen, 2022).

As well as increased risk for mental health difficulties, people with SENDs are also more likely to present with executive functioning differences (Craig et al., 2016; Smith-Spark et al., 2016). This includes working memory, self-control including emotional regulation and cognitive inflexibility. Differences with cognitive flexibility can lead to difficulties with transitions between behaviours, activities or thoughts; flexible problem solving; or inhibition (Murray et al., 2005; Ozsivadjian et al., 2021). Executive functioning differences such as cognitive inflexibility have been linked to increased risk of anxiety symptoms (Hollocks et al., 2014), such as the intolerance of uncertainty, and is a predictor of both internalising and externalising behaviour difficulties (Ozsivadjian et al 2021). In addition to cognitive differences, internalising and externalising behaviours can also be linked to other contextual differences faced by people with SENDs. This includes burnout and exhaustion associated with communication differences, maintaining masking and the frustration of having to constantly adjust to a world designed for people without SENDs (Milner et al., 2022; Radulski, 2022). In addition to this, people with SENDs have to having to contend with the contextual effects

of discrimination, stigma and marginalisation (Botha et al., 2022) which can further compound internalising and externalising behaviours.

Pre covid-19, caregivers of children with SENDs are at increased risk of poor mental health and wellbeing, including increased risk for anxiety, depression and poorer quality of life (Hoffman et al., 2009; Quintero & McIntyre, 2010). Mental health difficulties and psychological distress in caregivers who have children with SENDs has been linked to burn out from managing challenging behaviour e.g. aggressive, self-harming or destructive behaviour, assistance with daily life skills, difficulties associated with co-occurring diagnoses, and difficulties in accessing supports for their child. (Catalano et al., 2018; Eisenhower et al., 2005; Friesen et al, 2022; Pisula, 2007; Quintero & McIntyre, 2010). Additionally, the severity of their child's disability and the availability of social supports for caregivers are also factors that contribute to psychological distress in caregivers (Blacher & McIntyre, 2006; Unwin & Deb, 2011; Weiss, 2002; White & Hastings, 2004). When governments imposed lockdown measures, this led to increased responsibilities placed on parents with managing schooling, reduced access to supports and heightened anxiety in relation to the pandemic, it is likely these difficulties have been exacerbated as a result (Bentenuto et al., 2021; Toseeb & Asbury, 2021).

Covid-19

The Covid-19 virus was first identified in Wuhan, China in December 2019 and due to the global spread of the virus The World Health Organisation (WHO) declared the global pandemic in March 2020. In response to the spread of the virus, governments around the world implemented public safety measures to slow the spread over the course of the pandemic. In the United Kingdom (UK), the government implemented a UK wide lockdown on 23rd March 2020, implementing Public Health Safety Measures (PHMS) to slow the spread of the covid-19 virus (Cabinet Office 2020).

Across the UK, the national governments of Scotland, Wales and Northern Ireland were responsible for implementing PHSM and lockdown restrictions within their respective countries. While there

were some differences in the timings and the rules, the restrictions were largely similar, including limiting movement, social gathering and limiting services (Ferguson et al., 2021). The initial UK wide lockdown started in March 2020 and was ended in June 2020. Due to rising infection rates subsequent regional lockdowns were implemented as follows: In Wales from October 2020 until November 2020; England and Northern Ireland from November 2020 until December 2020 (Baker et al., 2021; Senedd Research, 2022; SPICe Spotlight, 2022). A final round of regional, full lockdown measures, were implemented in late 2020/early 2021. These were as follows: Wales and Northern Ireland from December 2020 to March 2021. England and Scotland implemented lockdown measures from January 2021 until March 2021 (Baker et al., 2021; Senedd Research, 2022; SPICe Spotlight, 2022).

Across the UK, government guidance stated that those identified as ‘vulnerable learners’ should attend school throughout the pandemic. Despite this, many went through long periods of time without access to education provision. A report from Ofsted (2021) indicated that some of the reasons for this included: parental choice, schools’ risk assessments indicated the risk was too high, or staffing issues. For many young people who present with complex health needs, this meant they did not have access to essential health services such as physiotherapy and/or speech and language therapy (Ofsted, 2021)

In the UK, the transition back to school was not smooth, particularly given the multiple lockdowns. At the start of the autumn term in 2020, schools were meant to open fully to all pupils. However, not all of the schools were able to do this, and when they did, not all pupils returned (Ofsted, 2021). School attendance was poor, and most notably, in England, those with SENDs. The Department for Education (2023) has largely attributed this to illness, including covid-19. Within the SEND population, attendance was significantly below whole school attendance (Ofsted, 2021). As well as covid infection, low attendance was also linked to parents choosing not to send their children to school, anxiety around Covid-19 infection, particularly considering that this population is at increased risk of health concerns (Sibieta 2020).

Research that has emerged following the start of the Covid-19 Pandemic has shown that the impact of restrictions has had a significant impact on mental health and wellbeing (Daly et al 2020). In a report by the United Nations Sustainable Development Group (2021), children and young people were identified as a vulnerable group and potentially some of the most affected by the disruption caused by pandemic restrictions. They identified that the pandemic increased risk of poverty, school closures which led to educational disruption, and additionally, for many it also caused reduced access to food and nutrition (United Nations Sustainable Development Group (UNSDG), 2020). Research that has been conducted since the start of the Covid-19 pandemic indicates that children and young people were at increased risk of mental health difficulties such as depression, anxiety and post-traumatic stress symptoms (De Miranda & Da Silva, 2020; O'Sullivan et al., 2021; Smirni et al., 2020). A rapid systematic review by Loades et al (2020) found that not only are children and young people more at risk of anxiety and depression during enforced isolation but also after the isolation ends. This indicates that the ongoing risk is likely to continue beyond the lifting of social distancing measures. These global studies, conducted in China (Wang et al 2020), Italy (Colizzi et al. 2020), Ireland (O'Sullivan, 2021) and the UK (Cresswell et al. 2021), have linked increased risk of mental health difficulties during Covid-19 lockdown to a number of factors. This includes, fear linked to the health crisis (fear of contamination, illness and death, illness and death of loved one), the impact of social isolation, reduced and restricted activity. Additionally, studies have indicated that other risk factors for decreased mental health were exacerbated through the pandemic, such as poverty and other social inequalities, increased exposure to domestic violence (Lyons & Brewer 2022; UNSDG, 2020; Whitehead et al. 2021).

Impact of Covid on children with SENDs and their families

Given that children and young people with SENDs are more at risk of developing mental health conditions (Al-Yangon, 2012; Matteucci et al 2019), it is likely that this population may have been disproportionately affected by the disruption of the pandemic (Banerjee et al 2021). Additionally, considering children with SENDs are more likely to struggle with sudden transitions, the rapidly changing landscape of lockdowns and PHSMs likely contributed to psychological distress in these children and young people. Parents of children and young people with SENDs, in the UK have, reported changes to emotional wellbeing and increased anxiety during lockdown (Asbury et al, 2021; Creswell et al 2021; Toseeb et al, 2023). The Co-space project is a longitudinal study that has tracked the mental health of school aged children, from the general population, aged 4-16 years in the UK, throughout the Covid-19 crisis. Findings from this study have identified that when restrictions were eased in March 2021, children experienced a reduction in mental health symptoms. However, this excluded those who were identified with SENDs or neurodevelopmental disorders, who continued to show elevated emotional, behavioural and attentional difficulties (Creswell et al 2021). Unfortunately, it is not clear which SENDs have been represented within their sample.

Qualitative studies, focusing on the impact of lockdown on autistic young people indicates that they have been observed to have increased anxiety, linked to specific fears about the pandemic, such as fears of contamination, that family and friends might become unwell or die (Asbury et al 2021). Increases in anxiety have also been attributed to difficulty with managing the changing rules, the impact of social isolation, reduced activity; difficulties associated with home education and lack of access to therapeutic services (Adams et al, 2022; Asbury et al. 2021; Stadheim 2022). Parents have observed increases in behaviours that challenge, such as aggressive and destructive behaviour (Adams, 2022; Asbury, 2023; Humphreys 2023; Stadheim, 2022). Additionally, they observed regressions in developmental skills including communication skills, self-care, executive functioning, emotional

control, and fine motor skills (Stadheim, 2022). A report by Ofstead (2021) indicated that despite the restrictions being eased, when children and young people returned to school, there were delays in the resumption of services in schools and in the community that they had previously been receiving. For example, access to CAMHS, speech and language, occupational therapies or physiotherapy. Additionally, they reported that children and young people with SENDs were disproportionately affected by these delays since they relied on these services to a greater extent.

With the implementation of lockdown measures, the closure of schools, clinical services and respite put significant pressures on the parents of children with SENDs (Banerjee 2021). Parents who were suddenly required to take on new roles and responsibilities and juggle everything including, additional childcare responsibilities, home learning and remote working, as well as meeting the child's SEND specific needs, with little or no external support (Asbury et al 2021; Pellicano 2021). There is a small amount of research which indicates that during the first covid-19 lockdown, parents of autistic children were more likely to report a decline in mental health, than parents with neurotypical children (Wang et al 2022). Qualitative studies of parents of young people with SENDs have indicated that parents reported increased anxiety and burn out. They attribute this to anxiety related to covid, restricted activity, social isolation, as well as the pressured of juggling home learning, remote working from home and childcare. Additionally, they highlighted difficulty associated with managing to meet their children's specific needs and increases in behaviours that challenge, such as aggression and destructive behaviour, with little or no external support (Adams, 2022; Asbury et al 2021; Heyworth, 2023; Pellicano, 2021) Parental stress can influence the behaviour of children with SENDs and research indicates that reductions in parenting stress can lead to improvements in the behaviour of children with SENDs (Bitsika and Sharpley 2000; Harris, 1994; Harris et al 2000; Osbourne et al., 2007).

Given the difficulties identified, it is important to understand the impact of the pandemic on both the young people and their families. The transition back to school was a pivotal time for children with

SENDS after the pandemic with many families reporting the difficulties managing the child's anxiety and change of routine (*Health, Social Care and Sport Committee's Inquiry into the Health and Wellbeing of Children and Young People, 13th May 2022*).

The current study aims to further understand how children and young people with SENDs and their families coped and their understanding of the easing restrictions and their experiences of their return to school. It is hoped that insights can be gained through this investigation allowing better support to be developed for families who have children with SENDs as the children attempt to resume old routines and school schedules.

Current Study

The current study aims to use Interpretive Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2022) to further understand how children and young people with SENDs and their families coped and their understanding of the easing restrictions and their experience of their return to school. Through this study, we aim to answer the following questions:

1. How did the transition back to school, post Covid-19 lockdown, impact the mental health and wellbeing of children with Special Educational Needs and Disabilities according to their parents?
2. How did the transition back to school, post Covid-19 lockdown, impact the mental health and wellbeing of the families of children with Special Educational Needs and Disabilities?

Method

Participants

Participants consisted of eight mothers of children and young people with SENDs who were interviewed and included in the analysis. Interviews reported on the experience of 18 children and young people with SENDs. This included 10 males and 8 females aged between 5-19 years old. Children attended either mainstream school or have been placed in a special needs school. Diagnosed SENDs include, Dyslexia, Autism Spectrum Disorder (ASD), Attention Deficit/Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), Pathological Demand Avoidance (PDA), Tourette Syndrome, Global Developmental Delay (GDD) and Learning Disability (LD), see table 1 for a breakdown of demographic information. Participants were from two different counties in the west of Scotland. Participants were recruited by the original researcher, by placing adverts placed on Twitter and Facebook.

Table 1.

Participant demographics

Participant Pseudonym	CYP Demographics (gender/age)	Diagnosed SEND	Education Placement
Jane	male /15 years	ASD/ADHD	Mainstream school
	female / 8 years	ASD	Mainstream school
	female/ 5 years	ASD, ADHD, ODD, PDA	Special needs school
Rachel	female/19 years	ASD	Mainstream school
	male/ 16 years	ASD, ADHD	Mainstream school
	male/14 years	ASD, ADHD	Special needs school
Carol	female/ 15 years	ASD, Dyspraxia	Mainstream school
	males/ 9 years	Dyslexia	Mainstream school
Sarah	male/ 13 years	ASD	Mainstream school
	females/9 years	ASD	Mainstream school
Jennifer	male/8 years	ADHD	Mainstream school
	female/8	Dyslexia	Mainstream school
Helen	male/14 years	ASD/ Global Developmental Delay/Severe Learning Disability	Special Needs School
Ann	male/ 5 years	ASD	Mainstream school
	female/12 years	ASD	Mainstream school
Lana	male/5 years	ASD	Mainstream school
	female/12 years	ASD	Mainstream school
	male/11	ASD, Tourette Syndrome, Learning Disability	Mainstream school

Ethics

This study used secondary data that had previously been collected by a student at the University of West of Scotland (author 2) and had remained unanalysed. Ethical approval was sought and granted for the original study from the University of West Scotland (UWS) in 2021 under the supervision of Dr Carrie Ballantyne as part of a larger collaborative project with the current researcher's supervisor (who co-owns the data). Due to Covid-19 restrictions all communication with participants was remote. Participant information sheets, consent forms and the interview schedule were sent to participants before the interview. Participants were advised that they could withdraw at any time. Additionally, they were sent a debrief sheet after the interview. All documents were sent electronically via email due to Covid-19 restrictions and participants gave their informed written consent, also via email, before interviews were carried out. Any identifying information that was included in the interviews were omitted during transcription. Following transcription by the original researcher, records were destroyed, and the transcripts have been stored on a secure server. For this study, ethics approval was originally sought from the University of Edinburgh to analyse the data by the study supervisor. The current researcher was added to this ethics application. The study supervisor transferred the data securely. Please see appendix B and C for the research proposal and ethical approval.

Data Collection

Due to Covid-19 restrictions, interviews had to take place remotely. Signed consent was sought from participants via email. Participants were called on the phone by the researcher at a pre-arranged date and time. Interviews were conducted on the phone over loudspeaker, and this was recorded by the researcher on a Dictaphone. The original researcher conducted semi-structured interviews, to understand participant's perceptions about how their children with SENDs and their families coped with and understood the easing restrictions and the return to school. The interview schedule is included in Appendix D

Fifteen interviews were originally conducted; however, seven interviews were excluded from the study, due to the quality of transcription. At the time of interview, the original researcher had used transcription software, and saved these transcriptions in a word document. Due to their personal circumstances, they were not able to go through all of the transcripts to ensure they matched the audio recordings and correct incorrect transcription. At the time of completing this study, audio recordings had been destroyed in accordance with ethical obligations, so it was not possible to correct the transcripts.

Data Analysis

Data was analysed using an IPA approach, using the method laid out by Smith, Flowers and Larkin (2022). Given that this study is attempting to understand the participant's idiosyncratic and individual lived experience of the easing Covid-19 restrictions and the return to school, IPA was deemed to be the most suitable method of analysis. IPA is a method of analysing qualitative data that is theoretically rooted in phenomenology, ideography and hermeneutics. The focus of this method is to provide a deeper understanding of participant's lived experience, how they make sense of it on a case-by-case basis, rather than generalising across a population (Smith 2011). Additionally, IPA takes into consideration how the researcher makes sense of how the participants make sense of their experience, the double hermeneutic. Other methods of analysis were considered and ruled out. Grounded Theory and Thematic Analysis were deemed inappropriate as these methods utilise codes that are imposed by the researcher, instead of code being grounded in the experiences of the participants (Smith et al 2022). Additionally, these methods generalise findings across a specific population rather than understanding the individuals experience (University of Auckland 2022).

The analysis was completed using the six steps to IPA analysis, as suggested by Smith et al (2022) these steps include:

1. Reading and rereading the transcripts one by one in order to immerse oneself into the original data, prior full analysis of each interview in turn.

2. Initial exploratory noting, which involves the examination of semantic content and the language used on an exploratory level.
3. Constructing experiential statements by coding the researchers' exploratory notes
4. Searching for connections across personal experiential statements, clustering interconnected experiential statements. This groups them into themes for the individual interview.
5. Moving to the next transcription and repeating the previous steps
6. Looking for patterns across cases once all interviews have been analysed to identify group experiential themes. Themes are grouped into Group Experiential Themes and Sub Themes.

Following this analysis of the interviews, quotes were extracted from the data as examples to support each theme, forming a "codebook", to ensure that analysis was grounded in the data (Smith et al 2022) and the most relevant were selected for inclusion in the results.

Quality and Reliability

In the current study, a method of inter-rater reliability of the qualitative data was not used. The guidelines for IPA methodology do not tend to employ these methods (Smith et al 2009). Given the inherent subjectivity of IPA, considering both the experience described by the participant and the double hermeneutic of the researchers' experience, including other raters may dilute the analysis as no two researchers will have the same experience with the data. As a result, they are unlikely to be able to precisely replicate each other's analysis (Gauntlett et al 2017). Steps were taken to maintain this subjectivity, whilst also taking steps to implement validity and quality control. Coding procedures, generated codes and themes, and relevant quotes from the data were shared and discussed in supervision. This was to ensure the analytic process was adhered to and that interpretation was logical, transparent and reflexive.

Reflexivity

Given the emphasis on the researcher's experience of the data, when using IPA methodology, reflexivity is highly important. In order to promote transparency of interpretation, it is important to understand the background of the researcher and anything that may have influenced their understanding and interpretation.

The researcher has a specific interest in the experiences of children and young people with SENDs. Prior to taking a place on the Doctorate in Clinical Psychology program, the researcher trained and worked as a qualified Educational Psychologist. In this role they worked with children and young people with different SENDs. In their role, they assessed children and young people to identify and diagnose SENDs. Additionally, they worked directly with the children and young people, their schools, families and other systems involved to support their needs in the educational setting. In their role as an assistant psychologist, they worked in a specialist Autism service. In this role, they conducted autism assessments as part of a multi-disciplinary team. The researcher was mindful of the experiences of the people that they have worked with, many of whom had had long and difficult journeys to diagnosis or access to care.

As a trainee clinical psychologist, they worked through the pandemic and has a knowledge about the context of the services that may have been available to participants. Indeed, the researcher also lived through the pandemic and had their own experiences with lockdowns and easing restrictions. The researcher reflected on how these experiences may have led them to hold assumptions about the experiences of participants, for example that most experiences would be negative, which may have framed the initial experience of reading transcripts.

Findings

Analysis of the data produced 6 superordinate themes that have been organised by time through two overarching themes 1. Managing lockdown and home schooling 2. Transition back to school. The superordinate themes have been broken down further into 14 subordinate themes. These themes are displayed in table 2.

Table 2.

Themes elicited from participants

Master Theme	Overarching Theme	Group Theme	Experiential	Sub Themes
Experiences through covid and beyond	Experiences during Lockdown	Managing Home-schooling and everything else	Impact on YP	Resources
				Support from school
	Back to school	Process of transition	Effect of the transition	Making it through best we can
				Positive aspects
				Mental health
				Social
				Getting ready
				The journey through transition
				Emotional
				Social
				Impact of new rules
		Impact on Family		Daily living
				Mental Health of parent
				Impact on Siblings

Experiences during Lockdown

Participants described their experiences during lockdown. The first theme that was identified focuses on how parents experienced being managing home schooling during lockdown and how they

understand the impact that has had on their children. The following narrative will examine these group experiential themes by focusing on the sub themes individually. All names included are pseudonyms.

1. Managing home schooling and everything else

1.1 Resources

All participants identified that they felt that at some point during the lockdown that they did not have the appropriate resources to manage home schooling. All participants reflected that they did not feel that they had physical or practical resources to meet the needs of their children.

“It was just the whole resources went. When you're at school you have proper resources, that you didn't get” (Ann).

Within this sub theme the group shared their experiences in relation to different types of resource were highlighted, including, financial resource:

“I had to fight social work to be able to, because we have self-directed support. We have a budget for both boys, but I wasn't allowed to use them, but we weren't getting the support that we would normally get, and I had to fight with them for about six weeks” (Rachel)

and internal resource such as academic capacity:

“*** was given work that I can't understand that much, and when I was young, the way we were taught to learn things was different from how they do it now” (Lana)

Or emotional resource:

“I felt at breaking point. There was times where I was like I can no longer do this because I'm trying to keep all the kids happy. I'm trying to boost all of them back up. I'm trying to accommodate all their needs and there's just absolutely nothing.” (Jane)

1.2 Support from schools

In conjunction with discussing limited resources, most participants described feeling as though their children's schools did not provide them with enough support. Participants had differing levels of communication and experiences of support from their schools throughout lockdown. However, all participants expressed some anger or frustration at what felt like they had not received enough support from their children's schools, during the lockdown, which left them feeling abandoned during a time of collective difficulty. Rachel's statement below really embodies this, particularly as she emphasises "no actual support".

"There wasn't really any help from the school. The start we got a bundle of stuff, and they would send homework tasks through the expressions at, but no actual support to get them done."

(Rachel)

Jane and Ann spoke about their experience of being dismissed by the school after they requested additional support from their children's schools.

It was kind of just "schools are closed, you have to do it. Just get on with it, fling him in front of a computer which doesn't work for ***." (Jane)

Lana reflected that despite a lack of support overall, once she contacted the school, they were able to offer a bit more support:

"There was no one to talk you through that. I phoned his school and spoke to them, and then the teacher, she did do a zoom call with ***. Like he very much needs the person here, and it was like he was talking to that lady. He could make a connection with the teacher about what he was doing." (Lana)

Lana's reflection here considers the importance of social connection in learning, particularly in the absence of being able to see and talk to teachers. The perceived impact of the lockdown on the social development of participants children with SENDS, will be discussed later on in this analysis.

Sarah shared that the school her child attended had a plan to support families with home schooling through lockdown. However, she did not find it to be sufficient support.

"Yeah. I got a call once a week to check in, but that was it". (Sarah)

Scottish government guidelines during lockdown meant that some children were still able to attend school. This included children of key workers and those with SEND needs who were considered vulnerable. Some of the participants in this study had this option available to them. Parents had difficult decisions about the risks of sending their children to school in the midst of the pandemic, weighing up the support they may need. Jane, who was a key worker thought the risk of exposure to covid-19 was too high.

“I know I was a key worker, so that they could’ve went there, but I was too scared in case he got infected” (Jane)

On the other hand, Helen felt that due to her child’s significant additional needs, the benefits of sending them to school outweighed the risk of exposure. However, she reflected that she had to fight with her child’s school, for them to be able to attend.

I had to follow up with the school 'cause I had to demand that ***came to school. ..., but they were they were picking which kids who they deemed to be most vulnerable.... Yeah, wasn't fairly judged at all (Helen).

Participants’ experiences of communication and access to schools varied significantly during lockdown, while attempting to home school. Despite this, they consistently describe feeling as though they did not have sufficient support, and in many cases experiencing unsatisfactory responses from schools when they have asked for help.

1.3 Making it through the best we can

In the face of feeling as though there was a lack of support from school, many of the participants described feeling as though the burden was placed on them to find a way through and to manage everything themselves.

“The kids weren't supported from anybody other than the parents. I think it's all been put on the parents to support the kids. There's not been any help from any other resource” (Rachel).

Many participants reflected that it was difficult to engage their children in academic work due to the lack of support from school.

“The biggest challenge we had and we're trying to teach *** with home learning was we didn't have his support package that the school had at home, so getting him to do any type of school work was it was non-existent because we didn't have. We didn't have any strategies that they use”. (Jane).

As well as managing home schooling, participants had to juggle things like childcare for younger children who are not yet school age. Jane reflected on having to manage home schooling for her two school aged children as well as looking after her toddler, all while being expected to work from home too.

“... two of them doing the schoolwork and then *** because the nursery was closed as well. And then I was still working the whole way through.” (Jane)

Ann shared that as a key worker, she had a lot to manage. During the day she had to go to work, and once she was done with that, had to come home and work with her children on home schooling.

“I'm a part time cleaner at the high school. So, before the kids went back to school I would stop and we were still having to go and clean the school. But then I was having to come home and do home learning.”
(Ann)

Jennifer highlighted that she ended up not doing a lot of the tasks that were being sent by school, “We actually abandoned most of the actual stuff coming from the schools” and that her children responded better to the activities that she created instead, “*** definitely responded to it a lot better than doing the actual stuff from the school”

Lana and Jane both found that spending time on life skills was more helpful for their children than much of the work that was sent from their schools, so adapted to build this into their day to day.

“We did a lot of cooking and we did a lot of home economics and because he found that a de-stressor. He found that enjoyable, so we'd let him do the research and find the recipes. And, you

know, write down what he needed, and we'd spend all day in the kitchen, cooking... He wasn't willing to be sat in front of teams doing anything else" Lana

Rachel's approach to adapting home learning was to try and make it as enjoyable as possible, when her children struggled to engage with academic work:

"I tried making it into games and making into fun. Yeah, they just weren't interested. Not engaging at all". (Rachel)

Participants shared their experiences of home schooling and how they tried to improve the situation as best they could, in the face of their experience of limited support from school. Additionally, it highlights their attempt to improve the situation in the context of the collective challenges people faced as a result of the pandemic and lockdown. This was summed up by Lana, when she said, "I think everybody was in such a shock when this covid thing happened".

1.4 Positive aspects

Some of the participants highlighted that while there were a lot of challenges with managing lockdown with their families, they also identified that there was something positive about their experience too. Sarah and Rachel both shared that they enjoyed the closeness and the amount of time that they were able to have with their families that they would not otherwise have together, if they were going about their lives in the way they did pre-covid.

"I think you know it was extra quality time with the kids that we wouldn't normally have got."
(Rachel)

As well as this, Sarah shared that she enjoyed knowing what their daily experiences were and the new role as "teacher" that she had as a result of home learning.

"I loved having them at home, I did. I like knowing where they really are, I like knowing what they're doing. Actually, when the school gave the stuff to do, I liked being the teacher." (Sarah)

2. Impact on YP

Most of the participants reflected on the impact that the covid-19 lockdown had on their children. Their responses highlighted different ways in which their children were impacted. During analysis, these fell within two different subordinate themes: emotional and social. The narrative below addresses these themes individually.

2.1 Emotional

Jennifer and Carol both shared that during lockdown, they observed their children to begin to have difficulty managing their emotions. Jennifer highlighted that her daughter had increased levels of stress, and was highly distressed, particularly when completing academic activities. This was highlighted when she shared:

“She would just take a tantrum every five minutes because it was too hard for her. Very difficult for them. Really too hard. It's just that she because she struggled so much with her reading that she would just end up having a meltdown” (Jennifer)

Carol shared that she observed both of her children's mental health to have deteriorated over the lockdown. She described her son, that it had “definitely affected him more about his germ phobia,” and described her daughter to have low mood, difficulty sleeping and low appetite.

“I've never seen her like that before, but she just stared at a wall for hours and hours on end and then I would try and ask her what was wrong. She couldn't explain it to me but then she was just crying. So eventually I said look, we can't have this. We need you. She stopped eating stopped drinking and after two days of me trying to just get her to say what's wrong. I was like, we're gonna have to take her to the GP.” (Carol).

Helen observed a change in her child's behaviour, which may indicate a deterioration in his mental health. She felt that this was due to the change in his normal routine, which is why it was so important for her to make sure he continued to access school as a vulnerable person. She described this when she said:

“It’s distressing! He’s back to being in pull up nappies and his behaviour was come back, he was having meltdowns, he was just getting dead frustrated. He wasn't sleeping at night. I knew that would happen. I knew that would happen, and so that's why I had to, you know ummm fight, I guess” (Helen).

Helen identified that the change in routine with lockdown contributed to her child’s deterioration in mental health and it’s possible to speculate the many other potential contributing factors, that could have impacted the children’s mental health, such as social isolation or the change in daily living, or the anxiety around health and safety and so on. However, this was not explored with these participants and may be an area for further research in the future.

2.2 Social

Participants reflected on different aspects of the covid lockdown, such as social isolation and social distancing, and the impact that this has had on the social development of their respective children. As mentioned above, when Lana was reflecting on the support they received from the school, (quote is included in the Support from School section above) her response considers the importance of social connection, and the impact of its absence on her child’s learning.

Ann, Carol and Sarah shared similar thoughts, that the children not being able to see their friends has been difficult and had an impact on them.

“I think not being able to see their friends. Not being able to see their friends has had an impact on them.” (Sarah)

Carol reflected on this a bit further and discussed the impact that following the rules, social distancing and anxiety has impacted her son’s mental health.

“I think the social distancing impacted the children's mental health. And anyway, and I would say that my son he was really upset about not seeing his grandparents and because of the grandparent’s health issues we really did need to keep away from them. But when we're going

out in like public or whatever, my younger one just sticks next to me and he kind of worries and then he shouts at people for being too close.” (Carol)

Transition back to school

This overarching theme aims to explore the experience and impact on the mental health and wellbeing of young people and their families following the transition back to school post lockdown. In this area, four Group Experiential Themes were identified. These include: The process of transition, the impact on young people, the impact of change and the impact on families. Within each of these Group Experiential Themes, a number of sub themes have been identified. In the following narrative, the Group Experiential Themes will be explored through each identified sub themes individually.

3. Process of transition

This Group Experiential Theme explores the experience of going through the transition back to school, whereas later themes aim to understand the impact of the transition back to school.

3.1 Getting ready

This sub theme relates to the experience of the period once they knew children would return to school and their experience of the preparations that were made for this. Most participants shared that this was a period of heightened anxiety for themselves. Many shared that they were concerned about the risk of exposure to covid.

“I was very nervous at first, and I really didn't know whether I wanted to send them back” (Jennifer).

Additionally, it was felt that the amount of time that they had to prepare themselves and their children to go back to school was insufficient.

“There was no time to prepare him for the changes that were going to be put in place for him.

Going back to school, it was thrown at him” (Nora)

For Nora, note that school was “thrown” at her child, indicating how unsupported they felt. Jennifer’s description of her worry does not go as far referring to the act of returning to school; however, they both highlight the anxiety and uncertainty that they experienced around having to manage the changing situation.

Participants described different levels of support from the school to prepare for the transition back. The support given by school is also linked with the “Journey through theme”, and it is helpful to evaluate this in the context of their journey through the transition and will be included in the next section.

3.2 Journey through

Participants described different experiences with the transition back to school; however, a common theme between most participants was that it was a period of inconsistency. One inconsistency was school attendance. Due to ongoing requirements to socially isolate after exposure to covid, many children were not attending school consistently.

“Going back after the pandemic my main concern was my daughter’s got asthma. Severe asthma and we were concerned about how this, how the covid would affect her. Any emails that we got for the school saying covid had been in the school we, wanted to keep her off. Yeah, obviously as a precaution.” (Ann)

Participants shared that their schools attempted to support the transition back to school for their children with SENDs; however, their experience of this has been mixed. Lana described receiving support from the school in preparation for the transition; however, once her child had returned to school, the plan was not followed through, and they were not supportive once her child began to struggle as a result.

“we took him up for many hours induction...he was quite reassured. At the end he said yes, I'm quite happy to come back to school as long as nobody touches me.

“his teacher had taken a new post and he had a different teacher in place. Not the teacher he spoke to the day we went up. I definitely preferred that teacher and allegedly she would touch him and he got in trouble for making the noise [anxiety related vocal tic]”. (Lana)

Rachel described receiving no support from the school with the transition.

“There was no plan and there was no transition. They were off for months and then they were back.” (Rachel)

Sarah had a different experience to the other participants and described a positive experience with the transition, and that the schools have provided good support with it.

“The two schools that we are involved with are brilliant, like they were really good, I honestly couldn't fault them and how they managed to do the transitions” (Sarah).

While Jennifer’s son had difficulty with the transition, which will be discussed later, she felt that his teacher provided them with the support they needed.

“They were really good, and his teacher has been really good... Honestly, I think they're amazing to be able to handle all.” (Jennifer)

Participants highlighted that there were other factors that made the transition difficult, such as navigating school and work when other services were not accessible to support them outside of school.

“It's been a lot easier, but then it was still really difficult in the beginning when they first went back because the after school wasn't on and I was back at work. So, like back doing my normal hours so I had to try and get up the road before they came in and I found that that was difficult. Trying to get them, Work and then without the extra childcare support.” (Jennifer)

4. Effect of the transition

4.1 Emotional

Participants described that the children had experiences when they returned to school. Jennifer, Rachel and Carol all reflected that they observed significant change in some of their children’s

emotions. Carol shared that her daughter's "mental health [had] definitely deteriorated" and reflected that her daughter's low mood had been better managed at home. This suggests that the stressors provided by school have worked to worsen her mood; however, it is not clear if this is directly related to a specific feature of the transition e.g. if there is support available at school, change in environment, increased demands etc.

Rachel reflected that her two children had different experiences, one of her son's was happy to return to school. However, her other son struggled with increased anxiety.

"he doesn't have full understanding of what's going on, so he is very anxious and very upset"

Rachel

Jennifer's children also managed the transitions differently, she shared that her daughter managed school well; however, her son struggled with difficulty transitioning into school in the mornings.

"Oh my Lord, it was so hard! The teachers were having to peel him off of me. He was going in little corners in the playground and wouldn't move. They had to have two teachers like coax him in the school" (Jennifer).

Lana and Jane both observed a change in their children's behaviour, which indicated to them that they had elevated anxiety, after returning to school post lockdown. Lana shared that her son had an increase in symptoms linked to his diagnosed ASD.

"*** makes a lot of noises when they get stressed out. He makes whooping noises, it's part of the spectrum thing. When he was at home, he hardly made any noises. It's anxiety, it was so much better at home actually, though not a cure. I thought "Oh my God, he's so much better" it's anxiety that triggers it. Yeah, stressful environments, yeah so yeah, at school it started again."

(Lana)

Jane's son demonstrated increased anxiety through increased aggressive behaviour, which she also linked to a lack of understanding about the changes that were happening at school, and the increased demands that were placed on him.

“Even if his guidance teacher could take that time to try and explain things to him or any teacher that was around him so you know, try and explain things when he went back.... Give him that time and explain things to him, it would have would have helped and he never even got that. It was just constant demands that he had to conform to” (Jane).

Sarah shared that she did not notice a change in her children social and emotional difficulties, which remained consistent with how their difficulties presented pre-pandemic, and Helen and Ann, similarly felt that the transition back to school had not had an impact on the emotional wellbeing of their children. Ann further highlighted that, lockdown had been a difficult time, but that the children had been resilient in the face of the difficulties.

“I think it's been tough for them to, although they're resilient” (Ann).

While, some parents have shared that the transition back to school has not had an impact on their children’s emotional wellbeing, it is clear that for some, there has been a significant impact. Parents highlighted difficulties with low mood and anxiety. Participants who indicated this, made attributions about the causes of the increased anxiety, namely, difficulty with transitioning and an intolerance of uncertainty. These difficulties are also consistent with the difficulties associated with neurodevelopmental disorders. Given that children with neurodevelopmental disorders are more at risk of experiencing these sorts of difficulty, it is possible that this has led to an increased risk of heightened anxiety as they transitioned back to school.

4.2 Social

Some participants discussed the social impact of the transition back to school. Ann reflected that this had a positive impact, as it ended her daughter’s social isolation.

“she was glad to be able to see her friends again” (Ann).

Jane, Jennifer and Sarah shared that the opposite was true for their children. They reflected on how social distancing rules led their children to experience social isolation, despite being back at school surrounded by other people.

“socially he's now feeling very secluded, and we were at a point post COVID that he was starting to feel like people were accepting him and now because of all the distancing, he's not allowed close to people that he's now feeling pushed away and he segregated from everybody right” (Jane)

The impact of the social distancing rules links directly to the “Impact of the new rules” theme. As a result, it is helpful to evaluate this in the context of their experience with the new rules and will be addressed in the next section.

4.3 Impact of the new rules

Five participants shared how their children were impacted by the changes in the school setting after returning post covid lockdown. This has been broken down into the impact of the new rules and the impact of new routines.

When children returned to school after the lockdown, new rules such as social distancing and mask wearing were introduced as safety measures to reduce risk of covid exposure (Baker et al, 2021). Sarah shared that her two children responded differently to the new social distancing rules within their schools.

“My daughter, she struggled a lot with it because she's saying segregated from a lot of her friends, so when they're in the playground they can't get close over certain parts of the playground...she's really struggled with that.”

“My son...for him the rules and structure that let you know you can only go one way and you need to do it this way and see he copes with that really well. So actually, this environment suits him right.” (Sarah)

Rachel shared that her son struggled with mask wearing, as it impacted the way in which he understands other people's communication.

“*** needs to see your whole face to get an indication of what you're saying. He needs that reassurance. He needs to see the smile.”

Similarly, Jane shared that her son also struggled with masks as he was not able to see people's full face.

“***didn't like it because he couldn't see people faced and teachers just right and he couldn't see the full face of other people in his class.” (Jane)

Carol also shared that her two children have responded differently to the new rules. Carol shared that her daughter has felt a benefit from wearing masks in school.

“she actually liked having the mask on her face, which I thought she maybe wouldn't, but she prefers to have it on 'cause she feels like it's like a mask for her. She can stand behind.” Carol

Whereas her son has struggled with the masks.

“My youngest won't wear a mask. He said he can't wait. It really makes him not be able to breathe properly, but I think he panics to be honest.” (Carol)

Lana shared that her son struggled with anxiety about the prospect of the new rules not being followed.

“*** said I'm quite happy to come back to school as long as nobody touches me Part of our problems was the media coverage of COVID and like through having his iphone would listen to things on Tiktok.... Yeah listen to Nicola Sturgeon and Boris Johnston and he was constantly like “we shouldn't be doing this” or “You know people shouldn't be nearer than two meters”

5. Impact on family

This Group Experiential Theme focuses on the impact of the children and young people with SENDs transitioning back to school had on their families. This is divided into three sub themes, daily living of parents, mental health of parents and the impact on siblings.

5.1 Daily living

Participants found that when their children went back to school, there was a change in their daily living and routines. Many shared that managing everything became much easier.

“Oh, it's been much easier now that they're back at school.” (Sarah)

Ann and Rachel described feeling more relaxed and had more time for self-care.

“I was having to come home and do home learning. In that since the kids went back, Uhm I just need, I don't need to do the home learning and now so it's a lot more relaxed. I can come home and go for a sleep.” (Ann)

“It's helped know that they're back at school because before I couldn't do anything. I had no time for myself. I couldn't even go to the bathroom. You know I had no time. (Rachel)

Carol explained that the children returning to school, has had a positive impact on her ability to work from home.

“I'm still working from home. It's really good and them being at school has really made a big difference for me.” (Carol)

These participants outlined that since their children have returned to school, it was “really good” and had a positive impact on their daily living. Additionally, it has meant that they have more time for themselves to carry out even basic functions, as well as improve their capacity for work. This has not been the experience for all participants, further exploration of the impact of children and young people with SENDs returning to school, on their parents continues in the next section and discussed within the subordinate theme around parental mental health.

5.2 Mental health of parent

Participants shared the impact of the transition of their children back to school. Three participants shared that the transition back to school has had a significant impact on their mental health.

Jane shared that she had anxiety about how her child would cope during the transition.

“I had a lot of fears around, more so around *** and how he would cope with the changes because there wasn't enough time to prepare him for the changes that were going to be put in place for him. Going

back to school, it was thrown at him, so my I've not been sleeping and I'm still not sleeping because it's still all new.” Jane

Jennifer explained that her child had difficulty with separation anxiety once he returned to school She shared that this had a significant impact on her mental health at the time.

“It definitely affected my mental health in the morning. Yes, yes. So I think it affected both me and my oldest child and quite a bit during that period.” Jennifer

Lana who enjoyed the closeness described a sense of loss after her children returned to school.

“I feel quite lost. Yeah, 'cause they're not here.” (Lana)

Conversely, Sarah shared that her mental health has improved since the children have transitioned back to school,

“My mental health has improved since they've gone back to school”. (Sarah)

The impact on mental health of parents is linked to how their children have managed the transition back to school. It appears that those who have had more challenging transitions may have led to poorer reported mental health in parents.

5.3 Impact on siblings

The analysis of the interviews highlighted that not only were the children with SENDs and their mothers impacted by the transition back to school, but other family members were also impacted too.

“Yeah, it's just the thing is that he's in amongst our family. It has a knock on effect on the whole family, doesn't it?” (Lana)

Jane explained that other family members have experienced the brunt of challenging behaviours, from her son, since he transitioned back to school.

“It's not just being me that's had it and his younger sisters have and his step-dad has. His dad has seen the changing behaviours and his mental health declined to the point that he's not willing to participate

in things, and he's more aggressive, confrontational, so yeah. Very much. It's impacted we're in a family of seven there is not one of us that have escaped it. Yeah, that's terrible. I mean really, it's had a terrible impact" (Jane)

Jennifer, who has two children with SENDs highlighted that one of her children's difficulties with the transition has affected the other child

"It was really affecting my oldest daughter because all *** wanted was her. And the playground and everything else, she wasn't allowed near friends because he was over, because he just wanted to cuddle... she doesn't understand where he's coming from... It was affecting her hard because she didn't want it."
(Jennifer)

Discussion

This study aimed to understand the impact of the transition back to school, post lockdown, on the mental health and wellbeing of children and young people with a diagnosed SEND, and their families. Throughout this study, participants highlighted that they and their children were significantly impacted by the covid-19 pandemic. Parents highlighted that their children experienced negative outcomes during the period of lockdown, and many varied outcomes following the transition back to school. During lockdown, parents reported that their children experienced increased levels of anxiety, symptoms of low mood and observed more behaviours that challenge, including aggressive and destructive behaviour.

Autistic children have been shown to have worse outcomes, with higher rates of anxiety and psychological distress than neurotypical peers, and peers with other SENDs (Asbury & Toseeb, 2021). This increased risk has been linked to features of autism, such as: cognitive flexibility, intolerance of uncertainty, sensory sensitivities and differences associated with rigid and repetitive behaviours (Asbury et al 2021; Adams; 2022). Considering that the majority of the children represented in this study are diagnosed with autism, it is possible to see similar patterns in experience during lockdown. In this study, children particularly struggled with the change in routine and adapting to the covid

restrictions. This difficulty led to increased anxiety and behaviours that challenge, and developmental regression e.g., toileting. This is consistent with the findings of other studies that have looked at the impact of lockdown on autistic children (Adams, 2022; Asbury, 2023; Dogan, 2022; Humphreys 2023; Stadheim, 2022).

Parents shared that the experience of lockdown was equally difficult for them. Studies addressing the impact of covid on those who parent any child indicate that parents were at increased risk of burnout, anxiety, depression (Christie et al. 2022; Kerr et al., 2021; Skripkauskaite et al. 2023). Additionally, that parents were more likely to face extra stressors that were not faced by those without children (Christie et al., 2022). However, when comparing the experience of parents with different circumstances, being a younger parent or having a child with SENDs predicted greater overall mental health symptoms (Skripkauskaite et al. 2023). In this study, parents shared that they were required to juggle a huge load, managing home schooling, family care, , working and many other things, in the context of having to manage their children's complex needs. Parents shared that they felt that they had limited support from the schools or other services. As a result, things like home schooling were more challenging. They felt that schools had given limited consideration to their children's additional needs, either online or other forms of home learning. Parents shared that they did not feel skilled enough to meet their child's additional needs. Most participants reported that learning online was challenging, and often inaccessible, given their complex needs. As a result, their children struggled to engage with learning and navigating this, was reported to be a contributing factor to increased anxiety in both children and their parents.

On return to school, parents reported variable support from schools, as well as inconsistent implementation of school based social distancing rules. This caused difficulties associated with rigid patterns of thinking for their children working to increase their experience of anxiety. Navigating a community that was designed for neurotypical people, and difficulty accessing appropriate supports is something that people with SENDs and their caregivers have to contend with on a regular basis

(Milner et al., 2022; Radulski, 2022; Botha et al. 2022). This contributes to the increased risk of internalising and externalising behaviour in the young people; as well as contributing to increased risk of mental health difficulties in their caregivers (Catalano et. al, 2018; Eisenhower et. al, 2005; Friesen et al., 2022). It appears that these inequalities have remained, in part, due to the varying available support to these families through lockdown and transition back to school.

The experience of the transition back to school for the young people was variable. Parents shared that there was very little time to prepare their children, and themselves for the transition back to school. As mentioned previously, there were differing levels of support for different children from different schools. As well as this, some reported their children experiencing significant anxiety and observed increases in behaviours that challenge. It was hypothesised that those who had more support would have an easier transition back to school. However, some of the participants who reported to have the most support with the transition, their children also experienced significantly increased anxiety after returning to school. As a result, it is difficult to interpret why this might be. There is limited information in relation to the severity of the young people's disability and the specific supports that they were offered, as well as other potential environmental stressors.

The impact of the transition on the mental health of parents appears to be linked to how their children have managed the transition back to school. Most parents reported anxiety around transmission of covid. However, the parents who reported their children to have had a more challenging transition, have reported to having significantly increased anxiety as their children returned to school. This is consistent with pre-covid evidence that links children with SENDs outcomes to the mental health and wellbeing of the parents who care for them (Hayes & Watson, 2013; Pisula, 2007; Ruiz-Robledillo et al., 2014; Taylor & Warren 2012). As mentioned previously, this includes managing behaviours that challenge e.g., aggressive, self-harming or destructive behaviour, assistance with daily life skills, difficulties associated with co-occurring diagnoses, and difficulties in accessing supports for their

child. (Catalano et al., 2018; Eisenhower et al., 2005; Friesen et al, 2022; Pisula, 2007; Quintero & McIntyre, 2010).

This study identifies the complexities of supporting young people with SENDs; who present with their own individual needs (Toseeb et al., 2023). This demonstrates the needs for specific individualised support, both during lockdown and through the transition. A number of participants reported benefits to the new social distancing measures, including one-way systems and the use of masks. It appears that the Covid-19 measures worked to reduce anxiety, sensory overstimulation and differences in social anxiety. This is consistent with the findings by Ozsivadijian et al., (2023), which indicated that autistic young people highlighted that they would like for some of these covid related restrictions to remain in place for them. This included the one-way systems, staggered starts to the school day and smaller class sizes. They further highlighted the need for individualised strength-based approaches, involving teachers receiving more training in how to support autistic people in a way that focuses on strengths and not their differences. One participant in this study highlighted that face masks were helpful in reducing social demand. Tentatively, this may draw a link to camouflaging behaviour in autistic females, (Hull et al 2017a; Lai et al., 2011), which can contribute to burn out and exhaustion (Hull et al., 2020). It is possible that the use of face masks has been helpful in reducing the demands of camouflaging and worked to reduce anxiety.

The impact of wearing masks in schools provides some interesting considerations for young people with SENDs. In this study, while some reported them to be beneficial, others reported face masks to be a hinderance. Some reported that their children struggled with the sensory experience of wearing a mask and their children were then exempt from wearing them. It was also reported that some children had difficulty, with learning, when their teachers were required to wear mask. It is possible that this demonstrates the need for facial cues in learning for young people with SENDs (Massaro & Bossler 2006). However, caution should be taken with this interpretation, since the parents were not in the classroom directly observing this, therefore, it still remains unclear what is driving this. It is

possible that the teacher using the mask affects communication, or it is possible that this could be linked to social communication or cognition. There is a paucity of published research looking at the impact of face mask on young people with SENDs. However, some evidence suggests that the use of masks distorts speech, which impacts both receptive and expressive language of children who are listening to that speech (Nobrega et al., 2020). This can be mitigated by using transparent facemasks, indicating the importance of the non-verbal cues in communication (Massaro & Bossler, 2006; Nobrega, 2020). Additionally, research conducted with autistic adults suggests that autistic people over rely on the lower half of a face, avoiding the eyes, in order to interpret emotion of others (McCrakin et al., 2023). When they are observing an image or actor with a mask, autistic adults demonstrated poor emotion recognition (McCrakin et al., 2023, Neumann et al., 2006; Spezio et al., 2007a, 2007b; Madipakkam et al., 2017). This suggests that, with mask wearing, they may not have access to the non-verbal cues that they may rely on more heavily than eye contact.

Limitations and future research

The majority of the children represented within this sample, have a diagnosis of autism. As a result, while it provides a helpful understanding, this is largely limited to the experiences of autistic children and their caregivers, from the West of Scotland. As a result, these findings are difficult to generalise to children with SENDs in other parts of the UK and those with other SENDs, e.g. those with intellectual disabilities, developmental language disorder and other types of neurodiversity. However, it is important to note that some of the findings of this study are consistent with those that have looked at the impact of lockdown on autistic children within the UK (Asbury et. al, 2021; Toseeb et al., 2023).

In this study, it is hard to draw specific conclusions about causes for emotional difficulties in young people post transition. Some present with increased difficulties that can be linked to their diagnosis e.g., difficulty with transition, rigid patterns of thought, changes in routine, emotional regulation, which are consistent with a diagnosis of autism (APA, 2011). However, the data does not necessarily reflect the severity of the children's disabilities and specific supports that they received. As a result,

we can demonstrate the differences in experiences; however, it is difficult to draw conclusions that understand why those differences have occurred. Additionally, some parents only spoke about one of their children and did not reflect on the experiences of their other children with SENDs, so this makes it more difficult to understand any contextual difficulties that may have been experienced by individual families, that contributed to their experiences with the transition back to school. For example, if their children attended different schools and if there were different supports between children.

Covid-19 still exists in the community and the transition through lockdowns has not been straightforward. The data from this study was collected following the transition back to school after the first lockdown. As mentioned previously, there were subsequent lockdowns, and as a result multiple transitions into lockdown and back to school (Baker et al., 2021; Senedd Research, 2022; SPICe Spotlight, 2022). This study provides an understanding that is limited to that first transition. In order to have a deeper understanding of the impact of these transitions on children with SENDs and their caregivers, more longitudinal research is needed. Additionally, further research is needed to understand the benefits and implications of the implementation of safety measures within the school context. The difference in experiences of these poses interesting questions about how to support children with SENDs. For example, the benefits and wider consequences of social distancing measures and the use of masks in schools.

There are a large number of themes identified within this study, which attempted to capture the experiences of both parents and young people with SENDs. As the parents were sharing their experiences, as well as their perspective on the experiences of their children, the understanding of their experiences was felt to be intertwined. As a result, the approach taken was to explore this along the timeline of lockdown to transition back to school. However, this may have led to some overlap in themes, particularly when making a distinction on experiences within lockdown vs transition back to

school. It may be possible to synthesise some themes if analysis was separated out to have a set of themes related to the experiences of caregivers and for young people, independently of each other.

The use of qualitative methods in this study has allowed for a rich understanding of the experiences that these families have experiences through lockdown and the impact that the transition back to school has had. This has allowed the participants to have a real voice in the research. There is a growing campaign to involve the voice of participants in the evidence base that is used to understand their experiences (Fletcher-Watson et al., 2019). It is important to note that this study could have gone further by engaging participants in member checking (Birt et al., 2016) not simply as a method of ensuring validity, but to further embed their voice and lived experience into the data.

Implications

The findings of this study pose several implications for professionals who work with children with SENDs and their caregivers. It has highlighted the complexities of supporting young people with SENDs and emphasised that they present with their own individual needs (Toseeb et al., 2023). In the event that there is another global pandemic, which results in similar PHSMs being implemented, it is important to address the accessibility of education and support services, so that continuity of care is possible. Due to the complexities presented by working with this populations, and the variability of experience it is evident that this population do not benefit from a one-size-fits-all approach (Asbury et al. 2023; Ozsivadijian et al., 2023, Pellicano, 2021). Participants in this study felt the absence of good communication with schools and other services. In planning for potential future pandemics, it is crucial that concrete plans should be established for how services will be able to maintain good communication with families.

The social model for disability (Oliver, 1996; Levitt, 2017) outlines that people are disabled by barriers created by a society built around those without a disability, making a distinction between impairment and disability or environments that are disabling. If we consider the findings of this study through this lens we can see how the restrictions put in place likely led to increased risk of poor

outcomes. The withdrawal of everyday individualised supports and services had a significant impact on young people with SENDs and their families. This demonstrates the needs for specific individualised support, both during lockdown and through the transition.

As a population who are at increased risk of mental health disorders, it is important that these vulnerabilities are not perpetuated in a post covid world. It is interesting that number of participants reported benefits to the new social distancing measures, this provides some insight into some of the supports that may be beneficial, in the event of future pandemics. Additionally, their positive experience with the safety measures also presents as an opportunity to learn new ways of supporting autistic children outside of a public health crisis. By creating environments that developed keeping neurodiversity in mind, this may work towards reducing the impact of the stress of having to fit into a neurotypical world (Milton, 2012), thus making the environment less disabling. It appears that these measures have worked to reduce anxiety, sensory overstimulation and differences with social anxiety. The findings by Ozsivadijian et al., (2023) add to this, and goes further in highlighted the need for individualised strength-based approaches and providing training to teachers to autistic people in a way that focuses on their strengths.

Conclusion

The mental health and wellbeing of children with SENDs, and their caregivers was significantly impacted by the covid-19 lockdown. Children demonstrated increased anxiety, behaviours that challenge and symptoms of low mood. Additionally, parents experienced an increased burden in managing their children's difficulties, as well as juggling their own covid anxiety, home-schooling, working and any other responsibilities that were required of them. Parents reported a significant lack of support from school and other services, which negatively impacted both the children and their parents. As the restrictions were eased and the children transitioned back to school, the impact on children with SENDs was varied. For some, the transition provided limited challenge. However, other children experienced significant difficulty and distress as a result in the change in routine and

difficulty with adjusting to new social distancing rules. Parents outcomes were also varied and appear to be dependent on their children's experiences. Those whose children had the most difficulty with the transition, presented with significantly more psychological distress and anxiety. This study highlights that complex presentation of children with SENDs and demonstrates the needs for specific individualised supports, both during lockdown and through the transition.

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Appendices

Appendix A: Submission Guidelines for Journal of Autism and Developmental Disabilities

Retrieved from: <https://www.springer.com/journal/10803/submission-guidelines>

Instructions for Authors

Editorial procedure

Double-Anonymous Peer Review

MANUSCRIPT FORMAT

Title Page

Title Page

Please make sure your title page contains the following information.

Title

The title should be concise and informative.

Author information

The name(s) of the author(s)

The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country

A clear indication and an active e-mail address of the corresponding author

If available, the 16-digit [ORCID](#) of the author(s)

If address information is provided with the affiliation(s) it will also be published.

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

Purpose (stating the main purposes and research question)

Methods

Results

Conclusion

For life science journals only (when applicable)

Trial registration number and date of registration for prospectively registered trials

Trial registration number and date of registration followed by “retrospectively registered”, for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

Competing Interests: Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to "Competing Interests and Funding" below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

Use a normal, plain font (e.g., 12-point Times Roman) for text.

Use italics for emphasis.

Use the automatic page numbering function to number the pages.

Do not use field functions.

Use tab stops or other commands for indents, not the space bar.

Use the table function, not spreadsheets, to make tables.

Use the equation editor or MathType for equations.

Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Body

The body of the manuscript should begin on a separate page. The manuscript page header (if used) and page number should appear in the upper right corner. Type the title of the paper centered at the top of the page, add a hard return, and then begin the text using the format noted above. The body should contain:

Introduction (The introduction has no label.)

Methods (Center the heading. Use un-centered subheadings such as: Participants, Materials, Procedure.)

Results (Center the heading.)

Discussion (Center the heading.)

Headings

Please use no more than three levels of displayed headings.

Level 1: Centered

Level 2: Centered Italicized

Level 3: Flush left, Italicized

Footnotes

Center the label “Footnotes” at the top of a separate page. Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lowercase letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes. Type all content footnotes and copyright permission footnotes together, double-spaced, and numbered consecutively in the order they appear in the article. Indent the first line of each footnote 5-7 spaces. The number of the footnote should correspond to the number in the text. Superscript arabic numerals are used to indicate the text material being footnoted.

Terminology

Please always use internationally accepted signs and symbols for units (SI units).

Scientific style

Generic names of drugs and pesticides are preferred; if trade names are used, the generic name should be given at first mention.

Please use the standard mathematical notation for formulae, symbols etc.: *Italic* for single letters that denote mathematical constants, variables, and unknown quantities Roman/upright for numerals, operators, and punctuation, and commonly defined functions or abbreviations, e.g., cos, det, e or exp, lim, log, max, min, sin, tan, d (for derivative) **Bold** for vectors, tensors, and matrices.

References

Citation

Cite references in the text by name and year in parentheses. Some examples:

Negotiation research spans many disciplines (Thompson, 1990).

This result was later contradicted by Becker and Seligman (1996).

This effect has been widely studied (Abbott, 1991; Barakat et al., 1995; Kelso & Smith, 1998; Medvec et al., 1999).

Authors are encouraged to follow official APA version 7 guidelines on the number of authors included in reference list entries (i.e., include all authors up to 20; for larger groups, give the first 19 names followed by an ellipsis and the final author’s name). However, if authors shorten the author group by using et al., this will be retained.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

Reference list entries should be alphabetized by the last names of the first author of each work.

Journal names and book titles should be *italicized*.

If available, please always include DOIs as full DOI links in your reference list (e.g. “<https://doi.org/abc>”).

Journal article Grady, J. S., Her, M., Moreno, G., Perez, C., & Yelinek, J. (2019). Emotions in storybooks: A comparison of storybooks that represent ethnic and racial groups in the United States. *Psychology of Popular Media Culture*, 8(3), 207–217. <https://doi.org/10.1037/ppm0000185>

Article by DOI Hong, I., Knox, S., Pryor, L., Mroz, T. M., Graham, J., Shields, M. F., & Reistetter, T. A. (2020). Is referral to home health rehabilitation following inpatient rehabilitation facility associated with 90-day hospital readmission for adult patients with stroke? *American Journal of Physical Medicine & Rehabilitation*. Advance online publication. <https://doi.org/10.1097/PHM.0000000000001435>

Book Sapolsky, R. M. (2017). *Behave: The biology of humans at our best and worst*. Penguin Books.

Book chapter Dillard, J. P. (2020). Currents in the study of persuasion. In M. B. Oliver, A. A. Raney, & J. Bryant (Eds.), *Media effects: Advances in theory and research* (4th ed., pp. 115–129). Routledge.

Online document Fagan, J. (2019, March 25). *Nursing clinical brain*. OER Commons. Retrieved January 7, 2020, from <https://www.oercommons.org/authoring/53029-nursing-clinical-brain/view>

Tables

All tables are to be numbered using Arabic numerals.

Tables should always be cited in text in consecutive numerical order.

For each table, please supply a table caption (title) explaining the components of the table.

Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.

Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Each table should be inserted on a separate page at the back of the manuscript in the order noted above. A call-out for the correct placement of each table should be included in brackets within the text immediately after the phrase in which it is first mentioned. Copyright permission footnotes for tables are typed as a table note.

Artwork and Illustrations Guidelines

Electronic Figure Submission

Supply all figures electronically.

Indicate what graphics program was used to create the artwork.

For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.

Vector graphics containing fonts must have the fonts embedded in the files.

Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Line Art

Definition: Black and white graphic with no shading.

Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.

All lines should be at least 0.1 mm (0.3 pt) wide.

Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.

Vector graphics containing fonts must have the fonts embedded in the files.

Halftone Art

Definition: Photographs, drawings, or paintings with fine shading, etc.

If any magnification is used in the photographs, indicate this by using scale bars within the figures themselves.

Halftones should have a minimum resolution of 300 dpi.

Combination Art

Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.

Combination artwork should have a minimum resolution of 600 dpi.

Color Art

Color art is free of charge for online publication.

If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.

If the figures will be printed in black and white, do not refer to color in the captions.

Color illustrations should be submitted as RGB (8 bits per channel).

Figure Lettering

To add lettering, it is best to use Helvetica or Arial (sans serif fonts).

Keep lettering consistently sized throughout your final-sized artwork, usually about 2–3 mm (8–12 pt).

Variance of type size within an illustration should be minimal, e.g., do not use 8-pt type on an axis and 20-pt type for the axis label.

Avoid effects such as shading, outline letters, etc.

Do not include titles or captions within your illustrations.

Figure Numbering

All figures are to be numbered using Arabic numerals.

Figures should always be cited in text in consecutive numerical order.

Figure parts should be denoted by lowercase letters (a, b, c, etc.).

If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures, "A1, A2, A3, etc." Figures in online appendices [Supplementary Information (SI)] should, however, be numbered separately.

Figure Captions

Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.

Figure captions begin with the term **Fig.** in bold type, followed by the figure number, also in bold type.

No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.

Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.

Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Figure Placement and Size

Figures should be submitted within the body of the text. Only if the file size of the manuscript causes problems in uploading it, the large figures should be submitted separately from the text.

When preparing your figures, size figures to fit in the column width.

For large-sized journals the figures should be 84 mm (for double-column text areas), or 174 mm (for single-column text areas) wide and not higher than 234 mm.

For small-sized journals, the figures should be 119 mm wide and not higher than 195 mm.

Permissions

If you include figures that have already been published elsewhere, you must obtain permission from the copyright owner(s) for both the print and online format. Please be aware that some publishers do not grant electronic rights for free and that Springer will not be able to refund any costs that may have occurred to receive these permissions. In such cases, material from other sources should be

Appendix B: Thesis Proposal



Doctorate in Clinical Psychology

Thesis Research Proposal

(For Methodological Review Only)

This form is for methodological review of projects that are **not** being submitted as assessed work for Research 1. (e.g. where a trainee has already received a pass mark for Research 1, but subsequently changed the intended thesis project)

The form will be reviewed by a member of the academic team and will receive feedback including an evaluation of the viability of the project and any recommended adjustments. Significant concerns about viability will be flagged to the Programme Director and Research Director and a decision made about whether the project can proceed in its current form.

We expect 2-3 pages A4 for sections 1-8

Trainee Name
Catherine Coales

Provisional Thesis Title
Parents perceptions of children with Special Education Needs and Disabilities returning to school during Covid transition phases

Proposed Setting

Allocated Thesis Project Supervisors

Clinical	Katrina Johnston
Academic 1	Karri Gillespie-Smith
Academic 2	
Others Involved	

Anticipated Month / Year of Submission (Usually May of final year)
August 2023

Date Form Submitted / Version
17/03/2023

Please Note: Whilst this is not an ethics review process, where questions have some similarities to questions contained in the NHS IRAS Research Ethics form, the corresponding IRAS question numbers are given in parentheses. This is intended to facilitate completion of NHS ethics where such approval is needed.

Section 1: Introduction
Provide a brief overview of the rationale and scientific justification for the research 500 words maximum <i>Relevant to IRAS A12</i>
<p>Research that has emerged following the start of the Covid-19 Pandemic has shown that the impact of restrictions has had a significant impact on mental health and wellbeing (Daly et al 2020). In a report by the United Nations Sustainable Development Group (2020), children and young people were identified as a vulnerable group and potentially some of the most affected by the disruption caused by pandemic restrictions. Research carried out since the start of the Covid-19 pandemic indicates that young people were at increased risk of mental health difficulties such as depression, anxiety and post-traumatic stress symptoms (De Miranda & Da Silva, 2020; Qi, Liu, Chen et al., 2020; Smirni, Lavanco, Smirini, 2020). A rapid systematic review by Loades et al (2020) found that children and young people were more at risk of anxiety and depression during enforced isolation and that this continued also after the restrictions eased. This highlights that mental health issues are likely to continue in child groups beyond the lifting of social distancing measures.</p> <p>Children and young people with (Special Educational Needs and Disabilities (SENDs) are identified as a group who are particularly more vulnerable to mental health conditions (Al-Yangon, 2012; Matteucci et al 2019), which have been further compounded during the pandemic (Banerjee 2021). Parents of children and young people with SENDs reported changes to emotional wellbeing and increased anxiety during lockdown (Gillespie-Smith et al., 2021).</p>

Co-space project is a longitudinal study that has tracked the mental health of school aged children with and without SENDs aged 4-16 years in the UK, throughout the Covid-19 crisis. Findings from this study have identified that when restrictions were eased in March 2021, children experienced a reduction in mental health symptoms, except those with SENDs, who continued to show elevated mental health symptoms (Creswell et al 2021). A report by Ofstead (2021) indicated that despite the restrictions being eased, when children and young people returned to school, there were delays in the resumption of services in schools and in the community. This included access to CAMHS, speech and language, occupational therapies or physiotherapy.

The closure of schools, clinical services and respite put significant pressures on the families of children with SENDs (Banerjee 2021). Family functioning, can influence the behaviour of children with SENDs and research reports that reductions in parenting stress can lead to improvements in the behaviour of children with SENDs (Bitsika and Sharpley 2000; Harris, 1994; Harris et al 2000; Osbourne, McHugh & Reed 2007). Given this, it is important to understand the impact of the pandemic on both the young people and their families. The transition back to school was a pivotal time for children with SENDs after the pandemic with many families reporting the difficulties managing the child's anxiety and change of routine (*Health, Social Care and Sport Committee's Inquiry into the Health and Wellbeing of Children and Young People, 13th May 2022*).

The current study aims to further understand how children and young people with SENDs and their families coped and their understanding of the easing restrictions and their experiences of their return to school. It is hoped that insights can be gained through this investigation allowing better support to be developed for families who have children with SENDs as the children attempt to resume old routines and school schedules.

Section 2: Research Questions / Objectives

What are the principal and secondary research questions / objectives?

IRAS A10

How did the transition back to school, post Covid-19 lockdown, impact the mental health and wellbeing of children with Special Educational Needs and Disabilities

How did the transition back to school, post Covid-19 lockdown, impact the mental health and wellbeing of the families of children with Special Educational Needs and Disabilities

Section 3: Methodology

Give a summary of your design and methodology

This should be clear enough for reader to know what will happen at each stage of the project. Include **principal inclusion and exclusion criteria and how data will be collected or identified.**

Research Design:

This study will evaluate the findings of a pre-existing data set, using a qualitative approach. The original research consists of 15 semi structured interviews with the mothers of children with SEND needs.

Settings

Due to the Covid-19 pandemic, all interviews were carried out over the telephone. Interviews were then transcribed and anonymized.

Procedure for recruitment

Participants were recruited through the original researcher, through adverts placed on Twitter and Facebook

Procedure for interviews

Due to Covid-19 restrictions, interviews had to take place remotely. Signed consent was sought from participants via email. Participants were called on the phone by the researcher at a pre-arranged date and time. Interviews were conducted on the phone over loudspeaker, and this was recorded by the researcher on a Dictaphone.

Ethical approval was sought and granted for the original study from the University of West Scotland (UWS) in 2021 under the supervision of Dr Carrie Ballantyne as part of a larger collaborative project with Dr Karri Gillespie-Smith (therefore both CB and KGS own the data). Participant information sheets, consent forms and the interview schedule were sent to participants before the interview. Additionally, they were sent a debrief sheet after the interview. All documents were sent electronically via email due to Covid-19 restrictions and participants gave their informed written consent, also via email, before interviews were carried out.

Participants:

There are 15 participants included in this data set. Participants in this study were 15 mothers of children with Special Educational Needs and Disabilities (SEND). The demographics of their children are as follows:

Sex: 16 males and 10 females

Diagnoses: ADHD (11) Dyslexia (2), Autism Spectrum Disorder (8), Pathological Demand Avoidance (2), Autism (9), Learning Disability (2), Oppositional Defiance Disorder (1), Aspergers (1), Global Developmental Delay (1)

Type of School attended: Mainstream (23), Special needs school (3)

Ages of children and young people range from 5-19 years

Section 4: Sample Size

What sample size is needed for the research and how did you determine this?

For quantitative projects, outline the relevant Power calculations and the rationale for assuming given effect sizes. For qualitative projects, outline your reasoning for assuming that this sample size will be sufficient to address the study's aims. If data is to be collected outline reasons for your confidence in being able to achieve a sample of at least this size.

IRAS A59 and IRAS A60

A preexisting dataset will be used. 15 participants were interviewed as part of the existing study.

Section 5: Analysis

Describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative methods) by which the data will be evaluated to meet the study objectives

IRAS A62

The analysis of data will occur using the steps to IPA suggested by Smith, Flowes & Larkin (2009). They proposed the following six steps

1. Reading and rereading the transcripts to immerse oneself into the original data
2. Initial noting, which involves examining the semantic content and language used on an exploratory level. The researcher notes anything of interest within the transcript, making descriptive, linguistic and conceptual comments.
3. Developing emergent themes. This involves identifying themes that are emerging from the researchers notes, that are also grounded in the original data.
4. Searching for connections across emergent themes
5. Moving to the next transcription and repeating the previous steps
6. Looking for patterns across cases.

An important part of IPA research is to acknowledge the researcher’s experience with the data. It acknowledges that the researcher will have a natural bias based on their own experience (Smith et al, 2009). In order to mitigate this, the researcher will use supervision to reflect on their experience and reactions to the data and how this may impact on data analysis. This is considered to be an important process, providing a deeper level of interpretation of the data and identified themes (Smith et al, 2009).

Section 6: Project Management / Timetable

Outline a timetable for completion of key stages of the project
 E.g. ethics submission, start and end of data collection, data analysis

	Mar- April	April- May	May- Jun	Jul- Aug	Sept- Oct
Submit Proposal					
Submit Ethics Application					
Ethics Approval (Estimate)					
Data Analysis					
Write Up - Introduction					
Write Up - Methods					
Write Up - Results					
Write Up - Discussion					
Systematic Review (Ongoing)					
First Full Draft					
Second Draft					
Submit					
Viva					

Section 7: Management of Risks to Project

Please summarise the main potential risks to your study, perceived likelihood of occurrence of these risks, and how you will respond to identified risks if they should occur (you do not need to repeat information provided in section 4).

Risk	Likelihood of risk manifesting			Severity of harm		
	Remote	Possible	Probable	Minimal	Significant	Severe
Identifiable due to data linkage	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifiable due to low participant numbers	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifiable due to geographical location	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Identifiable due to transfer of data	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifiable due to access of data	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Data Management

There is a low risk to any breach in data security. Transcripts are kept on the University of Edinburgh online server and will not be downloaded to the researcher's personal computer. Participant's identifying information is not available to the researcher, all documents with identifying information were destroyed following completion of the interviews.

Risk to the study

There is a low/medium risk that researcher may experience a flare up of a pre-existing disability which may impact write up time for the August 2023 deadline. In this instance it is possible to request an extension as part of University of Edinburgh students with disabilities adjustments.

The researcher has a young child at home, difficulties with illness brought home from nursery, balancing work, placement and any childcare issues could present a risk to the research timeline. Any issues that come up in relation to this will be managed through supervision.

Section 8: Are there any potential costs for the project?

Outline any potential financial costs to the project and justify why these are necessary; including how costs will be met. Please separate these into potential costs for the University and potential costs for your NHS Board. You should ask your NHS Board to meet stationery, printing, postage and travel costs.

No

Section 9: Confirmation of Supervisors' Approval

“I confirm that both my Academic and Clinical Thesis Supervisors have seen and approved this research proposal and have both completed the supervisors’ appraisal forms below.”

Delete as appropriate

Yes	
-----	--

Main Academic Supervisor’s Appraisal of Project Risk

Supervisor’s Name

Karri Gillespie-Smith

Date

04/04/23

Do you consider that the project should proceed in broadly its current form?

Delete as appropriate

Yes		
-----	--	--

Outline the reasons for the above response

Highlight any areas of risk to the completion of the project that have not been fully addressed within the proposal and any steps that could be taken to reduce risks

Low risk – existing dataset with ethical approval to be analysed.

Appendix C: Ethics Approval

07/08/2023, 16:20

Email - Catherine Coales - Outlook

Re: CLPS202 - Ethics application

HiSS Research Ethics <ethics.hiss@ed.ac.uk>

Thu 02/03/2023 10:39

To: Karri Gillespie-Smith <Karri.Gillespie-Smith@ed.ac.uk>

Cc: Catherine Coales <C.Coales@sms.ed.ac.uk>

Thanks for this Karri! We noted this.

Zsofia

Dr Zsofia Garai-Takacs

Lecturer in Applied Psychology

Ethics and Integrity Lead

From: Karri Gillespie-Smith <Karri.Gillespie-Smith@ed.ac.uk>

Sent: 27 February 2023 15:24

To: HiSS Research Ethics <ethics.hiss@ed.ac.uk>

Cc: Catherine Coales <C.Coales@sms.ed.ac.uk>

Subject: Re: CLPS202 - Ethics application

Dear Ethics Committee

Hope you are well. I am just emailing to ask that the DClin student Catherine Coales S2007800 cc'd above is added to the study CLPS202 which aims to look at existing anonymized data set that is owned by myself. If there is anything further you require please do let me know.

Best wishes

Karri

Dr Karri Gillespie-Smith

Senior Lecturer in Applied Psychology | Department of Clinical and Health Psychology

School of Health in Social Science | University of Edinburgh

Old Medical School, Doorway 6 | Rm 2.9 Teviot Place

Edinburgh, EH8 9AG | Tel: +44 (0)131 651 3932

Email: Karri.Gillespie-Smith@ed.ac.uk | Twitter: Follow me @Karri_G_Smith

Principle Investigator of ESRC/UKRI funded project - 'Road to recovery: Understanding the impact of COVID and recovery phases on children and young people with Intellectual Disabilities and their families.' For more information or project updates please visit our webpage -

<https://www.ed.ac.uk/health/subject-areas/clinical-psychology/research/research-groups/road-to-recovery>

***Please note that due to child care I may send emails outside normal office hours and that I do not expect a response at these times.**



THE UNIVERSITY
of EDINBURGH

School of Health in Social Science Research Ethics Application

The supervisor or primary investigator must complete and sign this form after checking that all relevant sections are completed, and relevant documents are attached. For all undergraduate (UG) and MSc student projects, it is the supervisor's responsibility to submit this form and all attachments. Please note that failure to do this will result in the application being returned (and not processed) causing your research to be delayed.



Supervisor (name and UUN): Dr Karri Gillespie Smith	
Primary Investigator (name and UUN): Emy Nimbley	
List of all collaborators (with affiliated institutions in brackets): Claire Morris , Dr Carrie Ballantyne, University of the West of Scotland.	
Student's programme of study (if applicable): PhD in Clinical Psychology	
Project Title: Parents perceptions of children with Intellectual Disabilities returning to school during covid transition phases.	
Case Number (if known – assigned by Administrator at time of 1st submission):	
Proposed Project Start Date: TBC	Proposed Project End Date: 31st December 2022

Please indicate whether the primary investigator on this project is staff or student and select your subject area:

- Staff UG or MSc Student DClin Student PhD Student
 CPASS Clinical Psychology Nursing Studies

This is a:

- New application for ethical review – first submission
 Resubmission following reviewer comments
 Resubmission with requested amendments

Has been reviewed by an external ethical board, such as NHS IRAS or a UK HEI (multi-site studies only) with a favourable opinion? Level 1 *

- IRAS (NHS research ethics) Other: Ethics Committee of University of West Scotland

Please tick one option that best describes your application:

- Collecting or generating new data involving other people: Level 2
 Extracting, re-coding and analysing existing data that contains sensitive information (i.e. identifiable information): Level 2
 Analysing secondary (archival) data that is routinely collected or is an existing anonymised dataset: Level 1
 Collecting new data BUT an external ethical review board (such as NHS IRAS; UK HEI – for multi-site studies; etc) has fully reviewed this project and generated a favourable opinion: Level 1

This application is complete with the following attachments (tick all that apply):

Advert/flyer <input type="checkbox"/>	Caldicott application stating what data was requested <input type="checkbox"/>	Caldicott signed approval <input type="checkbox"/>		Consent form/s <input type="checkbox"/>
Data collection tools (e.g. interview guides) <input type="checkbox"/>	Debrief with signposting <input type="checkbox"/>	IRAS application <input type="checkbox"/>	IRAS opinion letter <input type="checkbox"/>	NGO or local authority letters <input type="checkbox"/>
Participant Information Sheet/s <input type="checkbox"/>	Participant Information Sheet (young person version) <input type="checkbox"/>	R&D application <input type="checkbox"/>	R&D approval <input type="checkbox"/>	Researcher Checklist (C-19) <input type="checkbox"/>
Risk assessment <input type="checkbox"/>	Standardised recruitment email <input type="checkbox"/>	Sponsorship Letter OR Email to confirm no sponsorship needed / statement explaining why sponsorship is not needed. <input type="checkbox"/>		

Other attachments (please specify):

To be completed by primary investigator or project supervisor

By signing this front sheet, I confirm that I have prepared and/or reviewed this ethics application and related documents in accordance with ethical guidelines. I also confirm I have checked that all relevant sections of the application form are completed and relevant documents are attached.

Supervisor or/PI Signature:

Student signature:

Date: 06/04/22

On completion, this Word document along with the relevant attachments should be submitted to ethics.hiss@ed.ac.uk.

Note: Please note all undergraduate and MSc applications MUST be signed and submitted by the project supervisor.

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LEVEL 2 ONLY – Participant Risk and Information	Error! Bookmark not defined.
Section 6: Potential risks to participants and researchers	Error! Bookmark not defined.
Section 7: Participants and data subjects.	Error! Bookmark not defined.
Section 8: Participant or data subject information and consent	Error! Bookmark not defined.

This section is to be completed after review only

ISSUES ARISING FROM THE PROPOSAL – to be completed by Ethics Reviewer

Thank you for your application. We have completed the review process and can provide a favourable opinion.

Signature: Ingrid Obsuth (sig)

Position: Ethics & Integrity Lead

Date: 12 April 2022

APPLICANT'S SIGNATURE FOLLOWING REVISIONS – to be completed by applicant

I confirm that I have addressed all of the queries generated during the ethical review process of my application. I have outlined in the box above underneath each comment how each request was addressed and/or provided further clarification.

Supervisor/PI Signature:

Student signature:

Date:

CONCLUSION TO ETHICAL REVIEW – to be completed by Ethics Lead

The applicant's response to our request for further clarification or changes has now satisfied the requirements for ethical practice and the application has therefore been given a favourable opinion.

OR

Thank you for providing responses to our comments. Some outstanding questions remain:

Signature:

Position:

Date:

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

If you are applying for amendments to a previously reviewed and processed project, please use the below form to detail the amendments you wish to make:

This section is to be completed for amendments only

AMENDMENT/S: REQUEST FOR APPROVAL – to be completed by applicant

I would like to apply for the following amendments to this previously processed project which had generated a favourable opinion:

Supervisor/PI Signature:

Student signature:

Date:

CONCLUSION TO ETHICAL REVIEW OF AMENDMENT – to be completed by Ethics Lead

The requested amendment satisfies the requirements for ethical practice and it has therefore received a favourable opinion.

OR

Additional information is required related to:

Signature:

Position:

Date:

NOTE: Once reviewed please include the page on which this box appears as a formal document demonstrating that favourable opinion has been provided for this project (for example as an attachment to MSc dissertations).

LEVEL 1 and 2 – Confidentiality and Handling of Data

Section 1: Introduction

External Research Ethics Approval:

Does your research project require the approval of any other institution and/or ethics committee, nationally or internationally?

Note: It is each researcher's responsibility to check whether their project requires Sponsorship, Caldicott Approval, R&D approval, and/or IRAS (see <https://www.ed.ac.uk/health/research/ethics/sponsorship-and-governance>). The principal investigator is responsible for ensuring compliance with any additional ethical requirements that might apply, and/or for compliance with any additional requirements for review by external bodies.

This research project does not require external ethics approval.

OR

If you require external approval, please state the name of the review body:

IRAS (NHS research ethics)

Local Authority

Other:

NB: If you require external approval from IRAS/NHS/Caldicott, **you must have external approval before submitting your application for School of Health in Social Science Research Ethics approval.** You can only submit your application to us once external approval has been obtained, and you must include all documentation including your application to and approval of external approval as an attachment.

If you require approval from a **local authority**, you must first receive ethics approval from the School of Health in Social Science Research Ethics Committee, before submitting your application to the local authority.

Q1. Project summary

Please provide a brief summary of your proposed study. Do not exceed 1500 words. Our interest is in areas of your methodology where ethical issues may arise so please focus your detail on areas such as recruitment, consent, describing your participants and the nature of their involvement, and data handling.

This is a secondary dataset analysis. No new data is being collected.

Introduction

The World Health Organisation (WHO) declared the virus to be a 'Public Health Emergency of International Concern' in January 2020. The first UK-wide lockdown was implemented on 23rd March 2020, which established Public Health Safety Measures (PHSM) to reduce the spread of the virus. Although the implementation of government measures prevented widespread COVID-19 related deaths, the closure/suspension of schools, clinical services and respite put significant pressures on parents of children with ID. England began coming out of Lockdown in March 2021 with Wales, Scotland and Northern Ireland following suit in April 2021. Despite the whole of the UK being out of lockdown, there still remains significant reductions in services and support for children with ID and their families.

We must identify how children with intellectual disabilities and their families are coping and understand how the easing of restrictions and return to schools is being experienced by children with ID and their families.

Morris and Ballantyne (2021) conducted a qualitative study by interviewing (n = 15) mothers of children with Intellectual Disabilities.

Ethics

Ethical approval was sought and granted for the original study from the University of West Scotland (UWS) in 2021 under the supervision of Dr Carrie Ballantyne as part of a larger collaborative project with Dr Karri Gillespie-Smith (therefore both CB and KGS own the data). Participants were sent information sheets and consent forms before the interview, as well as the interview schedule, they were sent a debrief from after the interview. All documents were sent electronically via email due to Covid-19 restrictions and participants gave their informed written consent, also via email, before interviews were carried out. The researcher did not record any personal data and names were not referred to in the write up of the project. Documents relating to the participants were destroyed once the data was analysed and the study completed. Participants were informed that they could withdraw from the study at any time and refuse to answer any questions they did not feel comfortable with, but none of the participants withdrew or refused to answer questions.

The current audio recordings and transcripts which we will use in the current study are therefore pseudo-anonymised with no identifying information will be available to the current researcher. Data will be stored on the University of Edinburgh online secure servers and will be accessed on the researcher's personal, password protected laptop.

Design

This is a secondary data set analysis. We are interested in the experiences of children with ID and their families when returning to school during Covid lockdown transition phases. A qualitative approach will be taken for this research topic. In order to carry out this research we will transcribe audio recordings of interviews and analyse semi-structured interviews with parents of children with ID.

Participants

15 mothers of children with ID were interviewed. Participant demographics are as follows:

Sex: Males x 16; Females x 10

Diagnosis: ADHD X 11, Dyslexia X 2, ASD X 8, PDA X 2, Anxiety x 1, Autism x 9, Learning disability x 2; ODD X 1 , Asperger's Syndrome x 1, Dyspraxia, Global development delay x 1

Ages of the children: 8, 9 (3) , 13 (4) , 14, 16, 19, 17, 5 (3), 12, 10, 7, 15 (3), 11 (2), 6 (2),

Mainstream school: x 23

Special needs school: 3

Settings

Due to the Covid-19 pandemic, all interviews were carried out over the telephone. Data will be analysed from the current researcher's home.

Procedure for recruitment

Participants were recruited through the original researcher, the original supervisor and ads placed on Twitter and Facebook

Procedure for interviews

As interviews had to take place remotely due to Covid-19 restrictions, signed consent was sought from participants via email. The researcher called the participants on the phone at a pre-arranged date and time and conducted the interviews on the phone over loudspeaker. The researcher recorded interviews on a Dictaphone for later transcription.

The interview questions included:

Introduction Question

1. Before we start, is there anything that is unclear about the research question, the interview, consent form or information sheets, or that you would like to ask?

Interview Questions

2. How has your experience been with home learning during the COVID-19 pandemic? Are there any specific challenges that you faced; can you give examples?

3. Could you give examples of styles of learning that you used to help home school your child?

4. Has there been any changes to your scheduling with your children returning to school post COVID-19? If so, can you tell me about it?

5. How have you coped as a parent with your child returning to school post COVID-19, have you had any anxieties or fears?

6. How has COVID-19 impacted your child's transition back to school in relation to his/her mental health and wellbeing?

7. How has your child returning at school impacted your mental health and wellbeing and other members of the family?

8. How do you think the Department of Education have supported families and children to return to school? What else could they have done better?

9. What has your child's experience/attitude been like post COVID-19 towards going to school?

10. How has your child coped with the social distancing guidelines that are in place in schools? Have they impacted your child's mental health in any way?

11. How do you think wearing masks has impacted the social connection your child has with other students and his/ her teachers?

12. Do you think wearing masks will impact your child's development in any way?

- a. If participant needs prompting could say about social/ emotional development
13. Can you tell me about the support children with ASN, and their families have been given during the COVID-19 lockdown while home schooling from other organisations?
14. Overall has COVID-19 had any kind of significance or done any long-term damage to your child's emotional wellbeing?
15. Is there anything you would do differently, and can you recommend any of the coping strategies that you used at home during lockdown that could help teachers in schools?
16. Is there anything else that you would like to say?

Analysis in the current study

We now hope to analyse data from these interviews using thematic analysis.

Q2. Will you collect or use NHS data?

- Yes No

If "yes" – what NHS data will you collect or use?

Q3. What information about participants/data subjects will you collect and/or use?

Data has already been collected regarding subjects sex, and age/age of child but this is not linked to individual participants, no further information will be collected.

Q4. What training will staff who have access to the data receive on their responsibilities for its safe handling? Have all staff and students who have access completed the mandatory data protection training on the self-enrolment page of Learn?

Mantra training, and the data protection training that is available via the university of Edinburgh Learn system has been undertaken by the Researcher and the Supervisor, and NIHR Good Clinical Practice training have been undertaken by the Researcher in addition.

Q5. Will the information include special categories of personal data (health data, data relating to race or ethnicity, to political opinions or religious beliefs, trade union membership, criminal convictions, sexual orientations, genetic data and biometric data)?

- Yes No

If “yes” – Explain what safeguards e.g. technical or organisational you have in place; including any detailed protocols if this requires special and/or external processing, storage, and analysis.

Q6. Please indicate how your research is in the public interest:

- Your research is proportionate
- Your research is subject to a governance framework
- Research Ethics Committee (REC) review (does not have to be a European REC)
- Peer review from a funder
- Confidentiality Advisory Group (CAG) recommendation for support in England and Wales or support by the Public Benefit and Privacy Panel (PBPP) for Health and Social Care in Scotland
- Other

Q7. It is essential that you identify, and list all risks to the privacy of research participants. You will then need to consider the likelihood of the risks actually manifesting and the severity of harm if the risks actually manifest.

Risk	Likelihood of risk manifesting			Severity of harm		
	Remote	Possible	Probable	Minimal	Significant	Severe
Identifiable due to data linkage	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifiable due to low participant numbers	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifiable due to geographical location	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifiable due to transfer of data	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Identifiable due to access of data	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>Insert more rows as appropriate</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please use this text box to record any other risks and the likelihood of them occurring, along with the severity of harm. Please also use this when dealing with secondary data.

To avoid losing any anonymous data no data will be stored on a computer or hard drive it will be stored on the online servers of Edinburgh university.
 We will ensure that identifying data included alongside the audio recordings. The audio recordings will be transcribed and then deleted straight away. Any identifying information provided during the interview will be removed during transcription to ensure that no participant is made identifiable.

Please identify measures you could take to reduce or eliminate risks identified as possible/significant or probable/severe.

See above

Q8. Will information containing personal, identifiable data be transferred to, shared with, supported by, or otherwise available to third parties outside the University?

Yes No

If “yes” - Please explain why this necessary and how the transfer of the information will be made secure. If the third party is based outside the European Economic Area please obtain guidance from the Data Protection Officer.

Q9. Other than the use by third parties, will the data be used, accessed or stored away from University premises?

Yes No

If “yes” - Describe the arrangements you have put in place to safeguard the data from accidental or deliberate access, amendment or deletion when it is not on University premises, including when it is in transit, and (where applicable) it is transferred outside the EEA.

Data will be accessed on the researcher’s password protected laptop. Data will be stored on password protected and encrypted online servers hosted by the University of Edinburgh.

Q10. Will feedback of findings be given to your research project participants or data subjects?

Yes No

If “yes” - How and when will this feedback be provided?

If “no” - Please provide rationale for this.

The data will be taken from anonymized transcripts. We will not have access to the participants.

Q11. How do you intend to use/disseminate the results of your research project?

The current study will be written as an article for submission to a peer reviewed journal and may also be disseminated via an academic blog, policy brief and/or presented at a conference.

Section 2: Security-sensitive material

The Terrorism Act (2006) outlaws the dissemination of records, statements and other documents that can be interpreted as promoting or endorsing terrorist acts.

Q12. Does your research involve the storage on a computer of any such records, statements or other documents?

- Yes No (if you answered no to this question please jump to section 3)

If “yes” - Please type 'Yes' to indicate that you agree to store all documents on that file store

Q13. Might your research involve the electronic transmission (for example, as an email attachment) of such records or statements?

- Yes No

If “yes” - Please type ‘Yes’ to indicate that you agree not to transmit electronically to any third party documents stored in the file store

Q14. Will your research involve visits to websites that might be associated with extremist, or terrorist, organisations?

- Yes No

If “no”, please proceed to Question 15.

If “yes” - You are advised that such sites may be subject to surveillance by the police. Accessing those sites from University IP addresses might lead to police enquiries. Please type ‘Yes’ to acknowledge that you understand this risk

By submitting to the ethics process, you accept that your School Research Ethics Officer and the convener of the University’s Compliance Group will have access to a list of titles of documents (but not the contents of documents) in your document store. *Please type ‘Yes’ to acknowledge that you accept this.*

Please confirm that you have contacted your School Research Ethics Officer to discuss security-sensitive material by ticking 'Yes'

- Yes, I have contacted my School's Research Ethics Officer
- No, I have not contacted my School's Research Ethics Officer

Section 3: Copyright

Q15. Does your project require use of copyrighted material?

Yes

No

If "yes" please give further details

Section 4: Good conduct in collaborative research

Q16. Does your project involve working collaboratively with other academic partners?

- Yes No (if you answered no to this question please jump to section 5)

If “yes” - Is there a formal agreement in place regarding a collaborative relationship with the academic partner(s)?

There is a formal agreement in place between Dr Karri Gillespie-Smith and Dr Carrie Ballantyne to share this data since it is related to a larger collaborative project (that began in 2021 that KGS and CB are both involved with). Therefore the data is owned by both KGS and CB and they have agreed to allow Emy Nimbley to transcribe and analyse the data.

If “no” - Please explain why there is no formal agreement in place

Q17. Does your project involve working collaboratively with other non-academic partners?

- Yes No

If “yes” - Is there a formal agreement in place regarding a collaborative relationship with the non-academic partner(s)?

If “no” - Please explain why there is no formal agreement in place.

Q18. Does your project involve employing local field assistants (including guides/translators)?

- Yes No

If “yes” - Is there a formal agreement in place regarding the employment of local field assistants (including guides and translators)?

If "no" - Please explain why there is no formal agreement in place

Q19. Will care be taken to ensure that all individuals involved in implementing the research adhere to the ethical and research integrity standards set by the University of Edinburgh?

Yes No

If "no" - Please explain why care will not be taken

Q20. Have you reached agreement relating to intellectual property?

Yes No

If "no" - Please explain why you have not reached agreement

Section 5: Good conduct in publication practice

In publication and authorship, as in all other aspects of research, researchers are expected to follow the University's guidance on [integrity](https://www.ed.ac.uk/governance-strategic-planning/content-to-be-removed/research-integrity). <https://www.ed.ac.uk/governance-strategic-planning/content-to-be-removed/research-integrity>. By ticking yes, you confirm that full consideration of the items described in this Section will be addressed as applicable

Yes

No

If you intend to collect new data, please continue completing the Level 2 application in the next page.

If you are NOT collecting any new data, you have now completed the Level 4 application. Please submit this document alongside all

Appendix D: Interview Schedule

Interview Schedule

Introduction Question

1. Before we start, is there anything that is unclear about the research question, the interview, consent form or information sheets, or that you would like to ask?

Interview Questions

2. How has your experience been with home learning during the COVID-19 pandemic? Are there any specific challenges that you faced; can you give examples?
3. Could you give examples of styles of learning that you used to help home school your child?
4. Has there been any changes to your scheduling with your children returning to school post COVID-19? If so, can you tell me about it?
5. How have you coped as a parent with your child returning to school post COVID-19, have you had any anxieties or fears?
6. How has COVID-19 impacted your child's transition back to school in relation to his/her mental health and wellbeing?
7. How has your child returning at school impacted your mental health and wellbeing and other members of the family?
8. How do you think the Department of Education have supported families and children to return to school? What else could they have done better?
9. What has your child's experience/attitude been like post COVID-19 towards going to school?
10. How has your child coped with the social distancing guidelines that are in place in schools? Have they impacted your child's mental health in any way?
11. How do you think wearing masks has impacted the social connection your child has with other students and his/ her teachers?
12. Do you think wearing masks will impact your child's development in any way?
 - a. If participant needs prompting could say about social/ emotional development
13. Can you tell me about the support children with ASN, and their families have been given during the COVID-19 lockdown while home schooling from other organisations?

14. Overall has COVID-19 had any kind of significance or done any long-term damage to your child's emotional wellbeing?
15. Is there anything you would do differently, and can you recommend any of the coping strategies that you used at home during lockdown that could help teachers in schools?
16. Is there anything else that you would like to say?

Appendix E: Examples of Coding

CB: So how did you cope when the children return to school after the pandemic? Did you have any anxieties and fears about them going back to school?

transition has been really difficult

C: I did ^{cope} ~~come~~. I wasn't at first, but then after a while when we had to have like one of my younger ones, he had to come in because he had to self isolate. So he's got dyslexia. So he was just starting to learn to read properly. I am and then I cannot has education started feeling it started going behind him so he had to stay up for two weeks. Then he went back for a couple weeks then had to stay off again. Then the other daughter. She had to self isolate as well. So that was taking time away from she had just got used to come back. And then get into the routine and then she had to come back out for two weeks. So she ended up sleeping all day and staying awake all night. They were having to take out the cams because of her mental health was deteriorating and so it was. It was. I was panicking about having to send them back to school because then they might be getting sent back again as well and whether they were passing COVID on and and throughout the school and come back and sometimes I just thought themselves, would it be better if they were just staying at home again then actually going into school?

couldn't afford to parent and think for daughter

CB: So those are my next question. Is COVID-19 ^{impact} ~~emphire~~ the transition back to school impacted your child's mental health and well being will? Clearly?

C: Yes yes. 'cause Rebecca she's had to have had him. Can I appointments on screen worth the cams now she's a man. It was just a pleasure because mental health. I've never seen it like that before but she just stared at a wall for hours and hours on end and then I would try and ask her what was wrong. She couldn't explain it to me but then she was just crying. So eventually I said look, we can't have this. We need you. She stopped eating stopped drinking and after two days of me trying to just get her to set water was running. I was like we're gonna have to take their GP but don't know what's wrong and there was nothing medical but we could find. So we knew that it was their mental health was deteriorating and so the nurses can. I spoke to her about trying to get sleep patterns and trying to get regular walks and exercise. So even after school is interrupted or the transition back into school and that she's doing some kind of routine at

loss of function

routine not structured helpful

Difficult decision/ dilemma to send back to school.

feels like whiplash

Return to school bumpy -> stop start of isolation

the in and out had impact on son's academic performance

Deterioration of MH

led to the other

Daughter's schedule flipped Day to night

Fear of social - "panic" making the wrong decision Dilemma -> send them or not

Described deep deeper deeply impacted -> lack of routine and routine constantly changing

loss of function sleep/ - Compromised - newly started school need to get help.

Describes the importance of routine and meaningful activity

2

routine of structure helpful as long as it is consistent

need to work for support + transition

These fears especially without extremes

No support from gov + transition

home. And stayed to try and support after it up, but we found that in like when she's gone back to school, but we're hoping that came after someone hold these. She would maybe get to speak to them before going in and things like that. So they've said they might know he teams meeting. A day before, just to see if they can, ~~XXXXXXXXXXXX~~ How about you and getting our back end? And if if she can't get in in that first week, she can go in the following week so that she can get like maybe it's talking to some of our teachers online and then going back in but it's it's a big struggle for her to get back end and that's home. Now she's going into fifth year.

CB: Has has the has the children going back to school impacted your mental health or other members of the family?

C: And well, I wouldn't say so. I think that going back to school, UM, does petal better of extra stress on me because even though I'm working from home I still get a phone call from school saying like your child to get a cough. Can you come and get them or your child got a runny nose? Can you come get them and I'm like thanks so they haven't distort my work today and go and get them//That's very stressful//It's very stressful as Yep. And then my panic is is that I'm seeing them enter school. We are those people you can hear stories that people are seeing over that. That whole classroom gets sent home. Well, this whole classroom get sent home. Then I'm thinking, what if they get covered what they pass it on to their grandparents off the pass it on to me. Obviously you're hoping that they would be OK, but then you're just you're panicking about all of that. So as I would say, it's really stressful, actually.

CB: Do you think the Department of Education is supported? Children and families with the return back to school and and uh, or do you think there's something they could have done better?

C: And no, I don't think we've done that at all. I don't think UM. Supporting them, coming back to school, and things like that. I mean, there is no nobody really checked in on what I would see the Baker at all and and there is no actual support and transition in heart back, but that's about that extra needs that she needed. But also with my other children. There is no kinda UM support film. They were quite distressed about going back 'cause one of them. He's kinda worried about germs and things, so he was kind of

Trying to make a plan w/ school

- Asking for support w/ another transition back to school ease in w/ the plan + structure

- Talking is the plan but talking is difficult for her

- emphasis on importance of need become point? Success impacted for this family?

Frustrated at the transition transition not complete -> lots of backwards/forwards

Panic / distress / anxiety even though clinical support.

You're - talking about self in 3rd person -> observing herself to panic
Panic about what last time
Panic about daughter
Panic about Covid
High stress.

No support during transition -> D of E hasn't provided any support.

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