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What are the effects of the COVID-19 pandemic on the development of children with special educational needs and disabilities from parents' experiences? An integrative review

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ABSTRACT

The COVID-19 pandemic led the United Kingdom (UK) into a national lockdown in March 2020. The UK government has acknowledged that children and young people (CYP) with Special Educational Needs and Disabilities (SEND) were left behind during the pandemic. This integrative literature review aims to investigate the effects of the COVID-19 pandemic on the development of CYP with SEND from parents' experiences. The review included 14 papers: quantitative, qualitative and mixed methods. Parents' experience of the COVID-19 pandemic was mostly negative; CYP were left behind, experienced reduced or suspended services, and loss of social interactions and support networks. However, a few parents reported some positive effects; families could spend more time together, and children experienced reduced anxiety as strict routines were relaxed. Most papers identified were completed during or just after the first lockdown. Therefore, none of the papers included whether CYP's development has been affected in the longer term.

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Special education needs and disabilities (SEND); COVID-19 pandemic; parents; experience; effects

Introduction

In the United Kingdom (UK), approximately 1.4 million children and young people (CYP) are living with special educational needs and disabilities (SEND) (Office for Standards in Education, Children Services and Skills [OFSTED], 2022). Within the 1.4 million CYP, 9% have a diagnosis of a physical disability (Department of Work of Pensions 2021). A CYP with SEND is defined as being aged 0–25 years and having a learning difficulty or disability which requires special educational assistance (SEND Code of Practice 2015, 15).

The recent SEND Green report discussed current issues with SEND provisions in the UK, summarising that CYP with SEND *'too often the experiences and outcomes of children and young people are poor'*, concerning education and health care provisions (Zahawi and Javid 2022, 9). In addition, SEND provisions are not financially stable, and the systems do not consistently meet the needs of CYP with SEND. While the SEND Green Report (Zahawi and Javid 2022) highlights areas of concern, it does not address the effect of the COVID-19 pandemic; other than identifying

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that 'during the pandemic, 68% of parents reported that their child's needs were "not met at all" or only "somewhat met" in accordance with their EHCP, during the pandemic' (Zahawi and Javid 2022, 8). An initial literature search and the SEND Green paper identified a potential gap in the research on this topic, and therefore, an integrative literature review was conducted.

Background

In March 2020, like other countries, the UK entered a national lockdown due to the global COVID-19 pandemic, leading to the closure of schools and many other services (Department of Health [DH], 2021). The UK government identified that CYPs with SEND and had complex needs were at a greater risk of contracting the COVID-19 virus, as they were more vulnerable due to existing health conditions such as respiratory difficulties, and their outcomes from having the virus would be more severe (Department of Health 2022). Therefore, many CYPs with SEND were shielding (Department of Health 2022). Shielding in the UK was advised for individuals vulnerable due to illness, disability or caring duties; they were advised to stay home and have limited contact with individuals other than their households (Department of Health 2022).

Schools reopened to CYP with SEND earlier if they held an Educational Health Care Plan (EHCP) (Theis et al. 2021). An EHCP is provided to a CYP with SEND, where they require additional support and meet the required threshold (SEND, GOV.UK, 2022). However, many CYPs with SEND who hold an EHCP did not take up the option of returning to school during the lockdown, as parents felt they were at greater risk and their health could be impacted, so they remained at home with their parents (Conti 2020; Theis et al. 2021b; Zahawi and Javid 2022). Unfortunately, it was reported that CYPs with SEND were left behind during the COVID-19 pandemic and did not meet their medical, physical, intellectual, social and emotional needs (Ofsted and Care Quality Commission [CQC] 2021). In addition, CYPs with SEND and who have complex needs were reported to be affected, as their services were reduced or dissolved, including respite, therapies, hospital appointments, medical procedures, loss of carers, loss of social worker intervention and loss of physical activity (Conti 2020; Couper-Kenney and Riddell 2021; Ofsted 2021, Bellomo et al. 2020; Theis et al. 2021).

Historically, services for CYP with SEND in the UK have been required to change to enable access to social care, education, and health services exclusively (Department of Health 2022; Ofsted 2021). However, the joint report from OFSTED and the CQC (2021) clearly outlines increased concerns about meeting the needs of CYP with SEND during and since the COVID-19 pandemic. It appears that limited thought has been given to the development of CYP with SEND and the long-term effects of the COVID-19 pandemic (Bailey, Hastings, and Totsika 2021). This literature review explores parents' experiences of the effects of the COVID-19 pandemic on the development of CYP with SEND. The rationale for focusing on parents' experiences rather than CYP-reported experiences is due to the complex needs that are often not explored due to limited abilities to communicate their feelings and experiences. Therefore, parents are often the research participants.

Methods

An integrative literature review was conducted to allow different types of studies to be included, such as quantitative, qualitative and mixed methods (Bowden and Purper 2022; Whitemore and Knafel 2005). Integrative literature reviews are argued to produce new knowledge for critical review, produce a data synthesis, and produce new frameworks and perspectives on the research question/topic (R. Torraco 2005; 2016; Yorks 2008). In addition, integrative literature reviews allow for fresh new perspectives to be generated; they are suitable for new emerging topics and better suited when there have not been extensive or comprehensive literature reviews on the subject previously (Cronin and George 2023; R. J. Torraco 2016). Elsbach and Knippenberg (2020, 1277) suggest integrative literature reviews are *'the most useful vehicles for advancing knowledge and furthering research in a topic domain'*. There are several stages to an integrative literature review, which are the problem identification, the literature search, the data evaluation, the data analysis, the data reductions, the data display, the data comparison, and finally the conclusion drawing and verification (Whitemore and Knafel 2005).

Search approach

The search engine Discovery Host was used, and journal articles from various sources were combined (Arts & Humanities Citation Index, LSBU Research Open, PsycARTICLES, Education Research Complete, ASCE Library, Medical Online PsycINFO, Social Sciences Citation Index, BASE, SAGESocINDEX, MEDLINE, Science Citation Index, Taylor & Francis, British Education Index, ERIC, British Library ETHOS, CINAHL Complete, Education Index British Standards Online, Child Development & Adolescent Studies Scopus®, Educational Administration). Bettany-Saltikov's (2012) Population, Exposure, and Outcome approach formed the search terminology (Table 1).

The literature search comprised of the following words using 'and' or 'not' and were included in the abstract: *'AB (children or adolescent* or youth or child or teenager*) AND AB (special education or special needs or disabilities or SEND) AND AB (covid-19 or coronavirus or 2019-ncov or sars-cov-2 or cov-19) AND (experiences or perception or perceptions or experiences) NOT (vaccination or vaccine)*. Filters were used to identify the literature that met the inclusion and exclusion criteria, and the Abstract was selected for key search terms. When inputting words such as 'child', this would generate similar words from the search engine used in articles such as youth, children, young people/person, etc. All words generated as similar, meaning the same, were used for each selected word 'Child, COVID-19, SEND and experience'.

Table 1. Population, exposure and outcome.

Population	Exposure	Outcome
Parents of CYP with SEND	CYP with SEND experiences of the COVID-19 pandemic.	The experience of the effects of the COVID-19 pandemic on the development of CYP from the parent's perspective.

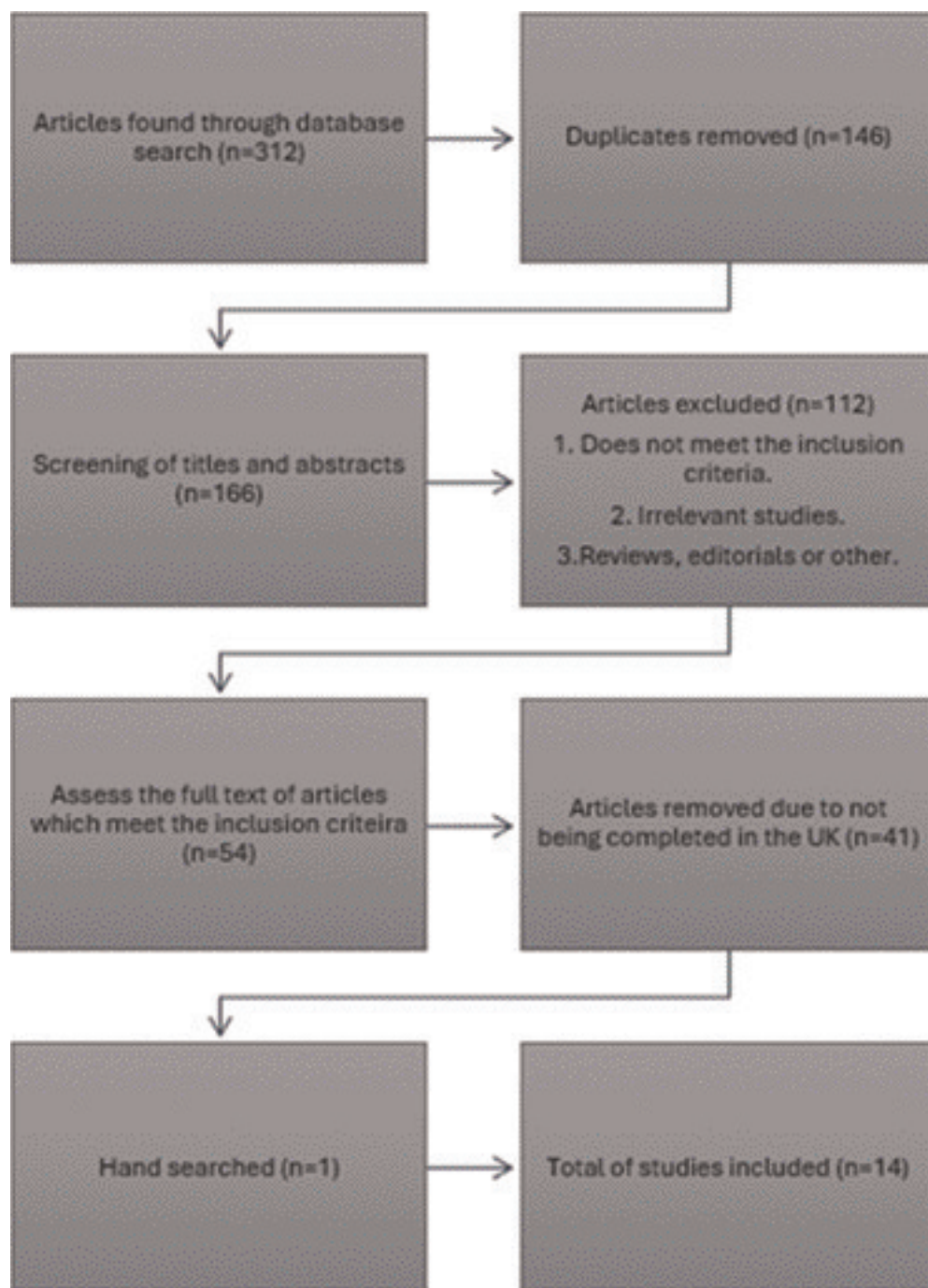


Figure 1. Sifting process.

Inclusion and exclusion criteria

Inclusion and exclusion criteria was devised before conducting the search and these were intricately connected with the PEO table (Table 1). The inclusion criteria were parents of CYP with SEND, aged 0–25 years old, male and female; studies were carried out in the UK, were written in English, dated from 2020 to July 2023 and peer-reviewed to ensure quality. Exclusions included telehealth-only studies, typically developing children, adults, and non-UK studies; Figure 1 shows the sifting process and results.

Data evaluation and analysis

The mixed methods appraisal tool (MMAT) (Hong et al. 2018) allows for one template for all the different design methods. The initial search identified that the studies included in this literature review used various design methods, and therefore, using one template minimises the potential for errors. When using the MMAT, the article must meet two initial criteria within the template to be included: 'S1. Are there clear research questions? And S2. Do the collected data allow to address the research questions?' (Hong et al. 2018, 2). Following on from the initial two questions, which were met for each included study, each article has five questions that need to be analysed and scored. This is completed by applying a percentage met for each of the questions. Of the 14 studies included, eight were quantitative, four were qualitative, and two were mixed methods. Overall, the appraising score was good quality; nine studies scored 100%, and five scored 80%. Two of the papers were one study reporting results in separate papers (Asbury and Toseeb 2022; Asbury et al. 2021). Table 2 provides a summary of the study and the critical appraising score.

Data reduction

Data reduction begins with the reviewer reducing the primary papers by identifying the main concepts of the study, such as the study, design, methods and appraisal (Table 2). Following the initial process, the researcher continues with the next stage, which is to select the information from the primary papers, which are put into subcategories. An example would be papers discussing psychological difficulties; another could be behavioural problems; these would form subcategories for the review question. Manual coding was then conducted with each paper, where the researcher read through the paper results or findings and extracts selected abstracts relevant to the research questions and marked these on the side of the paper (Whittemore and Knafel 2005). An example of codes was feeling sad, anxious and acting out. These abstracts are the codes, and then the researcher inserts these codes into an Excel sheet, where additional comparison and data display occur.

Table 2. Summary of the 14 included studies.

Study	Research Design and Methods	Participants	Appraisal score
	Quantitative		
1. Bailey et al. (2021)	Naturalistic exposure design Quantitative online survey Longitudinal data collection	397 parents with a CYP with intellectual disabilities, aged 5–16.	100%
2. Greenway and Eaton-Thomas (2020)	Quantitative Online survey	238 parents of CYP with SEND,	80%
3. O'Connor et al. (2021)	Quantitative survey Online survey	239 parents of CYP with SEND	80%
4. Pavlopoulou et al. (2020)	Quantitative Online Survey	449 parents of CYP with Autism.	100%
5. Sideropoulos et al. (2022a)	Quantitative Online Survey Cross-sectional design	402 parents of CYP with SEND. 186 CYP with SEND.	100%
6. Sideropoulos et al. (2022b)	Quantitative Online survey Cross-sectional design	48 CYP with Downs Syndrome 56 typical developing children.	100%
7. Theis et al. (2021)	Quantitative Online survey Cross-sectional design	125 parents of CYP with SEND	80%
8. Toseeb and Asbury (2022)	Quantitative Online survey Longitudinal study	527 parents/carers of CYP with autism.	100%
Study	Qualitative Research Design and Methods	Participants and setting	Appraisal Rate
9. Asbury et al. (2021)	Qualitative study: online semi-structured interviews and questionnaire.	241 parents/carers of CYP with SEND aged 5–18.	100%
10. Asbury and Toseeb (2022)	Qualitative- using a free text question in a questionnaire online.	517 parents of CYP with Autism.	100%
11. Canning and Robinson (2021) UK	Qualitative design Ethnographic narrative design using telephone interviews and online video conferences.	8 families Children diagnosed with SEND/ Autism 5–11 years old.	100%
12. Rogers et al. (2021)	Qualitative Interviews online or telephone.	8 mothers of CYP with SEND.	100%
Study	Mixed Methods Research Design and Methods	Participants and setting	Appraisal Rate
13. Gillespie-Smith et al. (2021)	Quantitative Online survey with closed and free text questions online	67 typical developing children. 43 CYP with SEND.	80%
14. Wolstencroft et al. (2021)	Mixed method Online Survey Semi-structured telephone interviews.	23 mothers of children with intellectual disabilities aged 5–15 years old.	100%

Data display and comparison

After completing the coding for each paper, the codes are then displayed and compared. This is where the codes are brought together as a group of similar codes, known as clusters. These clusters are put together based on patterns that are forming. From these patterns, the cluster of codes, themes and subthemes for the literature review are developed using thematic analysis (Coughlan and Cronin (2021)). Thematic Analysis is a data analysis process that allows the reviewer to summarise and synthesise the results and address the aims of the literature review (Coughlan and Cronin 2021). An example of codes that were clustered together was

Table 3. Overarching themes and subthemes.

Overarching Theme	Subtheme
Theme 1 Psychological effects on children, young people and parents.	a) Psychological distress of parents and child. b) Challenging behaviour or behaviours of concern. c) Experiences of loss.
Theme 2 Effects on services for CYP with SEND.	a) Professional services b) The government guidance and approach. c) Education.
Theme 3 Positive outcomes and future implications.	a) Positives reported. b) Concerns for the future.

acting out, biting, and hitting, which were clustered to form a theme of behaviour concerns.

Presentation of results

The findings from completing the thematic analysis are in [Table 3](#), which shows the overarching themes and the subthemes developed from the codes in the thematic analysis.

Theme 1 Psychological effects on children, young people and parents

There were three subthemes: psychological distress of parents and child, challenging behaviours or behaviours of concern, and experiences of loss.

Psychological distress of parents and child

Psychological distress can be understood as the condition of someone's mental health and well-being. Ohayashi (2012, 2) suggests that '*psychological distress is a term used to describe the general psychopathology of an individual with a combination of depressive symptoms, anxiety and perceived stress*'. Therefore, the codes identified for psychological distress were worry, depressed, sad, stress, overwhelmed, fear, anxiety, mood, despair, crying, acting out and exhaustion. Psychological distress was reported in all the studies across all of the different research designs for both parents and CYP with SEND. This subtheme is considered in two parts: parents' psychological distress and child's psychological distress.

For parents with psychological distress, studies reported that they experienced difficulties, often related to the CYP's education (Sideropoulos et al. 2022a). Another worry parents reported was becoming ill and/or dying and not being able to look after their CYP and who would take care of them if they were unable to (Pavlopoulou, Wood, and Papadopoulos 2020). Parents also reported in both quantitative and qualitative studies that they felt stressed, anxious, distressed, and overwhelmed with meeting their child's needs and or educational requirements and coping with additional responsibilities (Asbury and Toseeb 2021; Bailey, Hastings, and Totsika 2021; Canning and Robinson 2021; Rogers et al. 2021; Toseeb and Asbury 2022; Wolstencroft et al. 2021). Another psychologically distressing factor parents experienced in quantitative studies was fear,

which was linked with the child's educational needs, feeling tired and exhausted from home-schooling, and meeting their child's needs (Greenway and Eaton-Thomas 2020; Pavlopoulou, Wood, and Papadopoulos 2020). In their qualitative study, Rogers et al. (2021) found that parents reported feeling guilty for not being a good mother/parent, or when offered support from family and friends to go food shopping, they declined as they saw this as not fulfilling their parental responsibilities. Parents also reported in both quantitative and qualitative studies an increased strain on them, whether it was taking care of their child's needs or trying to balance working and home life, which led to feeling burnt out (O'Connor et al. 2021; Rogers et al. 2021; Wolstencroft et al. 2021).

In all the studies, CYP reported at least one psychologically distressing factor (Table 3). The CYP with SEND was reported in two quantitative studies as fearing people dying, e.g. their family and friends (Greenway and Eaton-Thomas 2020; Pavlopoulou, Wood, and Papadopoulos 2020). Parents in quantitative, qualitative and mixed-method studies reported their child was often overwhelmed, had low mood, was sad, stressed, worried or fearful, and showed signs of withdrawal or depression (Asbury and Toseeb 2022; Asbury et al. 2021; Bailey, Hastings, and Totsika 2021, Canning and Robinson 2021; Gillespie-Smith et al. 2021; O'Connor et al. 2021; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Sideropoulos, Dukes, et al. 2022a; Theis et al. 2021; Toseeb and Asbury 2022). Parents considered the cause to be being at home all the time and missing their peers, friends, social networks and support (Rogers et al. 2021). Other factors were the confusing guidance by the government for the child with SEND and becoming obsessive over the COVID-19 restrictions (Gillespie-Smith et al. 2021), and finally, the expectations of schoolwork (Canning and Robinson 2021; Greenway and Eaton-Thomas 2020; O'Connor et al. 2021).

Challenging behaviour or behaviours of concern

It is not uncommon for CYP with SEND to display challenging behaviour (O'Connor et al. 2021). However, many parents reported in qualitative, quantitative and mixed method studies an increase in challenging behaviour or behaviours of concern (Asbury et al. 2021; Asbury and Toseeb 2022; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Theis et al. 2021b; Wolstencroft et al. 2021). These behaviours included acting out, meltdowns, self-harming, finger and hand biting, outbursts, lashing out, aggression, shouting and isolation (Asbury et al. 2021; Asbury and Toseeb 2022; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Theis et al. 2021; Wolstencroft et al. 2021).

Experiences of loss

Whilst the loss of some of the services for CYP with SEND is discussed in theme 2, under the subtheme of 'Professional Services', there are other aspects of loss for CYP with SEND due to the COVID-19 pandemic. Parents of CYP with SEND reported in quantitative, qualitative and mixed-methods studies a significant loss of structure and routine in the CYP's daily life (Asbury et al. 2021; Asbury and Toseeb 2022; Gillespie-Smith et al. 2021, Greenway and Eaton-Thomas 2020; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Toseeb and Asbury 2022; Wolstencroft et al. 2021). The loss of routine and

structure would significantly affect the CYP with SEND as many find such changes difficult (Theis et al. 2021).

Along with the loss of routine and structure, parents also reported other losses such as loss of respite, freedom, access to facilities and resources, support from family and friends, carers, activities to stimulate the child, finances, specialist input, different support networks and structures, loved ones who died due to the virus and child's social skills (Asbury et al. 2021; Asbury and Toseeb 2022; Gillespie-Smith et al. 2021, Greenway and Eaton-Thomas 2020; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Toseeb and Asbury 2022; Wolstencroft et al. 2021).

In the mixed-methods studies, parents of CYPs with SEND reported that they and their children became more isolated than they already were (Gillespie-Smith et al. 2021; Wolstencroft et al. 2021). Rogers *et al.* (2021) discussed how parents sacrificed their paid work to meet their children's daily needs, impacting their income. As Asbury et al. (2021) report in their qualitative study, parents recognised that a CYP with SEND and meeting their needs is a much greater task than for typical developing children.

Theme 2 Effects on services for CYP with SEND

This theme had three sub-themes: professional services, the government's guidance and approach and education.

Professional services

In March 2020, the first lockdown demonstrated the difficulties families faced with CYP with SEND and receiving access and support from professional services (Asbury and Toseeb 2022; Canning and Robinson 2021, Greenway and Eaton-Thomas 2020; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Theis et al. 2021; Wolstencroft et al. 2021). Social care support was reported by parents to be either withdrawn or working with skeleton staff, and families felt unsupported by the service (Canning and Robinson 2021; Gillespie-Smith et al. 2021; Rogers et al. 2021; Wolstencroft et al. 2021). Gillespie-Smith et al. (2021) found in their mixed-methods study that 81% of participants had no contact with their Local Authority during the lockdown.

Theis *et al.* (2021) reported in their qualitative study that parents felt there was a perceived idea of social care and medical support, which was not actually the case. In contrast, quantitative research by Pavlopoulou *et al.* (2020) found that 58% reported still having access to at least one support from services, even though this was described as not being timely or sufficient. Rogers et al. (2021) argued that parents of CYP with SEND felt they were abandoned by professional services, including social care and medical professionals. Greenway and Eaton-Thomas (2020) reported in their quantitative study that out of all their 238 participants, 34 reached out to their Local Authorities for social care, but only 16 received any form of resources and or support.

Gillespie-Smith et al. (2021) also argued in their mixed-method study that parents did not receive any form of check-ins or contact from Local Authorities and that families were left to cope independently. Wolstencroft et al. (2021) reported that parents only felt

supported when they had contact with social care and other professionals and if they checked in on the families to see how they were doing. Many of the quantitative and mixed-method studies found that the most significant impact of COVID-19 was the loss of respite, which was usually provided by social care (Asbury et al. 2021; Asbury and Toseeb 2022; Gillespie-Smith et al. 2021; Wolstencroft et al. 2021). The studies reported that respite was withdrawn, including carers attending the family's home and supporting the CYP with SEND (Asbury and Toseeb 2022; Wolstencroft et al. 2021).

This review excluded studies that focused solely on telehealth experiences, which is any health appointment carried out using communication technologies to provide distance when meetings, such as telephone calls, video conferences and other media (Barenboim et al. 2023; World Health Organisation 1997). However, the two mixed-method studies reported on experiences with professional services such as therapists, medical appointments, doctors, and hospitals, with some referring to telehealth (Gillespie-Smith et al. 2021; Wolstencroft et al. 2021). Wolstencroft et al. (2021) discussed that parents encountered difficulties in supporting and managing their CYP's medical needs, finding that 91% of parents said they had cancelled or rescheduled medical and social care appointments. There was a critical emphasis that telehealth (appointments using phone, zoom, and Facetime) appointments did not replace face-to-face appointments when managing CYP's needs with SEND (Wolstencroft et al. 2021). In addition, parents did not always hear from the medical settings or social care regarding their appointments unless they made the initial contact first (Wolstencroft et al. 2021). Therefore, from the analysis of these studies, it is evident that families did not feel supported by professional services, which usually provide considerable support.

The Government's guidance and approach

The UK government's guidance and approach to managing the COVID-19 pandemic continuously changed for everyone. This was a particular challenge for CYPs with SEND, often confusing parents and the CYP with SEND (Gillespie-Smith et al. 2021). It was also reported that CYPs with SEND did not always understand the rules and restrictions and found them hard to follow (Gillespie-Smith et al. 2021; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Wolstencroft et al. 2021).

The government's approach to CYP with SEND in several studies has been reported as overlooked, left behind, not addressed, unsupported and forgotten (Gillespie-Smith et al. 2021; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Wolstencroft et al. 2021). Pavlopoulou *et al.* (2020) found in their quantitative study that 86% of parents reported that they felt that children with autism and other SEND needs did not have their needs addressed by the government adequately.

Education

During the national lockdown in the UK, schools were initially closed to all children and replaced with online learning, completed at home (Department of Education 2022). Six of the fourteen studies (qualitative and mixed-methods) found that children with SEND, and their parents experienced difficulties with the education set-up during this period (Asbury et al. 2021; Asbury and Toseeb 2022; Gillespie-Smith et al. 2021, Greenway and Eaton-Thomas 2020; O'Connor et al. 2021; Wolstencroft et al. 2021). Asbury et al. (2021) and

Gillespie-Smith et al. (2021) reported that parents did not feel their children were sufficiently educationally supported during the lockdown. Asbury et al. (2021) also found that parents felt their child's needs were not met by the education system.

Several studies found conflicting views regarding whether parents felt their CYP with SEND was educationally supported during the COVID-19 lockdown. Whilst some parents felt their CYP was supported, others reported their CYP was supported very little (Gillespie-Smith et al. 2021; O'Connor et al. 2021; Wolstencroft et al. 2021). Again, whilst some parents reported they had good contact with their children's schools, other parents reported having poor contact (Greenway and Eaton-Thomas 2020; Gillespie-Smith et al. 2021; O'Connor et al. 2021; Wolstencroft et al. 2021). Greenway and Eaton-Thomas (2020) found in their quantitative study that 62% of parents felt they received good contact from schools; however, in contrast, they also found that 72% of participants reported they did not receive enough educational support.

The resources sent from schools to children with SEND were emphasised in several studies (Greenway and Eaton-Thomas 2020; Gillespie-Smith et al. 2021; O'Connor et al. 2021; Wolstencroft et al. 2021). Whilst it was reported in both quantitative and mixed-methods that some schools offered resources, others did not (Greenway and Eaton-Thomas 2020; Gillespie-Smith et al. 2021; O'Connor et al. 2021; Wolstencroft et al. 2021). In several studies, parents argued that the resources for their children with SEND were either not received, not suitable, not accessible or not challenging enough (Greenway and Eaton-Thomas 2020; Gillespie-Smith et al. 2021; O'Connor et al. 2021; Wolstencroft et al. 2021). Greenway and Eaton-Thomas (2020) found that 50% of parents reported that the resources received were not suitable for their child's needs or age. In addition, Wolstencroft et al. (2021) raised that for children with SEND to complete schoolwork, they needed to be continuously supported to do so.

Asbury and Toseeb (2022) and Greenway and Eaton-Thomas (2020) found that parents could not home-school their children. Asbury and Toseeb (2022) found that to reduce the stress and anxiety of their children, parents withdrew from home-schooling. Greenway and Eaton Thomas (2020) reported that 42% of parents could not home-school for various reasons. Both Asbury et al. (2021) and O'Connor et al. (2021) found that parents really felt the importance of their children attending school and having contact with familiar faces so that their children would do well when schools were closed.

Theme 3 Positive outcomes and future implications

There are two sub-themes in this theme: positive outcomes reported and concerns for the future.

Positive outcomes reported

A small number of participants in several studies found some positive effects of the lockdown during the COVID-19 pandemic (Asbury et al. 2021; Asbury and Toseeb 2022, Greenway and Eaton-Smith 2020; O'Connor et al. 2021; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Theis et al. 2021, Toseeb and Asbury 2022;

Wolstencroft et al. 2021). Families in five studies found that they enjoyed spending time together, which was a positive outcome (Greenway and Eaton-Smith 2020; O'Connor et al. 2021; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Wolstencroft et al. 2021).

Another positive outcome found was that some parents found that being able to relax routines, such as daily routines and getting children ready for school, had a positive effect on children with SEND; this was due to parents reporting that their children find it stressful getting ready for school (Asbury et al. 2021; Asbury and Toseeb 2022; Gillespie-Smith et al. 2021; Pavlopoulou, Wood, and Papadopoulos 2020; Rogers et al. 2021; Toseeb and Asbury 2022; Wolstencroft et al. 2021). In addition to reducing stress levels, in some studies, a small number of parents reported that CYP were happier and calmer being at home (Asbury et al. 2021; Asbury and Toseeb 2022; Gillespie-Smith et al. 2021; Wolstencroft et al. 2021).

In addition to feeling happier and calmer and having relaxed routines, Rogers et al. (2021) reported in their qualitative study that some CYPs in their study slept better, had increased mood, fewer seizures and reduced obsessive and compulsory routines. In addition, Wolstencroft et al. (2021) found in their mixed-method study that some parents felt their CYP's mental health improved during the lockdown. Finally, Rogers et al. (2021) reported that a few parents suggested their CYP's behaviour improved, and they had a reduction in challenging behaviour. As well as the child's behaviour improving, parents felt they would now be more resilient when coping with school holidays, compared to before COVID-19 (Rogers et al. 2021).

Concerns for the future

Whilst little was reported in the studies about the long-term effects of the COVID-19 pandemic, some studies reported parents' concerns for the future, although as many of the studies were completed in 2020 and 2021, they have not addressed this research question in detail (Asbury et al. 2021; Pavlopoulou, Wood, and Papadopoulos 2020). Theis *et al.* (2021) reported that parents were worried that children's behaviour, learning and fitness would deteriorate, which was a long-term concern. Asbury et al. (2021) found in their qualitative study that parents were worried that children who experience SEND will fall further behind than they already are. However, Pavlopoulou *et al.* (2020) found that in their quantitative study, parents reported that they did not want to return to the situation pre-COVID-19, but this feedback was not discussed in detail.

Discussion

This integrative literature review aimed to explore parents' experiences of the effects of the COVID-19 pandemic on the development of CYP. The integrative literature review has identified that during the COVID-19 pandemic, CYP has been affected for several reasons. The main reasons identified were the psychological distress of parents and CYP, the challenging behaviour or behaviours of concern of the CYP, the changes experienced with professional services, the changing and confusing government guidance, and being left behind or forgotten about by the government. In addition, parents and CYP experienced a lack of support and access to education services, felt lost and had concerns about

the future. However, a few studies identified some positive effects, such as spending more time together and being less constrained by routines, positively impacting their CYP's behaviour. It could be argued that the reason parents reported negative experiences was due to the natural negative associations of the COVID-19 pandemic. For example, the government took measures such as lockdowns and distancing from one another. All of this lends research to focus on the negative attributes of the COVID-19 pandemic rather than positive research questions on the effects on CYP with SEND.

While many studies reported the adverse effects that the COVID-19 pandemic had on their children, there were also some positive effects (Rogers et al. 2021). There are two reasons that a positive outcome may have occurred. Firstly, some studies were conducted during the first lockdown, and this may have impacted the responses as it was earlier on in the COVID-19 pandemic (Asbury and Toseeb 2022; Bailey, Hastings, and Totsika 2021; Gillespie-Smith et al. 2021). Bailey *et al.* (2021) suggested that if they had collected their data later into the pandemic, for example, after the lockdown periods, their results might have differed, as parents may have found being at home different. Secondly, some of the studies were completed with mainly affluent parents, which may have influenced the positive outcomes they were experiencing due to income and access to resources already obtained (Rogers et al. 2021). Greenway and Eaton Thomas (2020) argue that parents on a lower income may not have internet access and be computer literate. Therefore, these parents may be the ones who were struggling the most, and their data were not included (Greenway and Eaton-Thomas 2020).

A further reason may have been that in some of the studies, parents who were more under pressure, struggling to manage the needs of their CYP, may not have had time and resources to respond and complete the research, especially lone parents (Toseeb and Asbury 2022). Sideropoulous et al. (2022a) argued that parents who had high levels of anxiety and other disorders may not have been able to report either, again reducing the data reliability; therefore, the only parents who were able to report would have been those with less challenging CYP, more access to funds and resources and of two-parent families.

Another limitation identified was that some parents had pre-existing psychological distress, which may have affected the data collected (Asbury et al. 2021; Bailey, Hastings, and Totsika 2021; Canning and Robinson 2021; Rogers et al. 2021; Toseeb and Asbury 2022; Wolstencroft et al. 2021). Gillespie-Smith et al. (2021) discussed that whilst most parents can answer robustly and honestly, there is a possibility for biased responses. Greenway and Eaton-Smith (2020) also said parents may have self-reported what was socially acceptable. In contrast, Theis et al. (2021) asked parents to score their own confidence levels in relation to their answers about their CYP; these scores were high in measuring their confidence in the accuracy and reliability of their answers.

A final limitation is that two studies reported having low participant numbers, leading to reduced generalisability to the SEND population, limited to areas within the UK and particular SEND needs (Rogers et al. 2021; Wolstencroft et al. 2021). Asbury et al. (2021) argue that the UK will not be able to address the problems which have occurred since the COVID-19 pandemic and the effects on CYP with SEND, but instead, a personal approach is needed when services and provisions open. This review has identified one crucial factor for parents' experiences of

having a CYP with SEND and the effects of the COVID-19 pandemic: the essential role of having the appropriate support for their CYP in education, health and social care.

Conclusion drawing and verification

The integrative literature review identified that, during the first two lockdowns, UK parents reported that their CYP with SEND were affected by the COVID-19 pandemic, with psychological distress and challenging behaviour, poor access to professional services, including education, and concerns about the future. Some positive effects were also identified in a few studies. However, further research about parents' experiences of the long-term effects of the COVID-19 pandemic on CYP with SEND is needed, as in all the studies included in this literature review, the data was collected in the first year of the outbreak of the COVID-19 pandemic. Although this study was conducted in the UK, the findings could benefit international audiences since this was a global pandemic, and countries may have responded similarly to the UK. In addition, very little is included about the effects of the COVID-19 pandemic on the development of CYP with SEND long-term (post-March 2021). Therefore, further research is required to investigate these aspects.

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References

- Asbury, K., L. Fox, E. Deniz, A. Code, and U. Toseeb. 2021. "How Is COVID-19 Affecting the Mental Health of Children with Special Educational Needs and Disabilities and Their Families?" *Journal of Autism & Developmental Disorders* 51 (5): 1772–1780. <https://doi.org/10.1007/s10803-020-04577-2>.
- Asbury, K., and U. Toseeb. 2022. "A Longitudinal Study of the Mental Health of Autistic Children and Adolescents and Their Parents During COVID-19: Part 2, Qualitative Findings." *Autism: The International Journal of Research & Practice* 27 (1): 105–106. <https://doi.org/10.1177/13623613221086997>.
- Bailey, T., R. P. Hastings, and V. Totsika. 2021. "COVID-19 Impact on Psychological Outcomes of Parents, Siblings and Children with Intellectual Disability: Longitudinal Before and During Lockdown Design." *Journal of Intellectual Disability Research* 65 (5): 397–404. <https://doi.org/10.1111/jir.12818>.

- Barenboim, H., B. Damitz, L. Brusky, and Z. Franco. 2023. "How Telehealth Can Work Best for Our Patients." *The Journal of Family Practice* 72 (5): 210–214. viewed 4 July 2023. <https://doi.org/10.12788/jfp.0603>.
- Bellomo, T. R., S. Prasad, T. Munzer, N. Laventhal, M. McLaughlin, and C. Vercler. 2020. "The impact of the COVID-19 pandemic on children with autism spectrum disorders." *PRM* 13 (3): 349–354. <https://doi.org/10.3233/PRM-200740>.
- Bettany-Saltikov, J. 2012. *How to Do a Systematic Literature Review in Nursing*. Maidenhead: Open University Press.
- Bowden, V. R., and C. Purper. 2022. "Types of Reviews—Part 3: Literature Review, Integrative Review, Scoping Review." *Pediatric Nursing* 48 (2): 97–100.
- Canning, N., and B. Robinson. 2021. "Blurring Boundaries: The Invasion of Home As a Safe Space for Families and Children with SEND During COVID-19 Lockdown in England." *European Journal of Special Needs Education* 36 (1): 65–79. <https://doi.org/10.1080/08856257.2021.1872846>.
- Canning, N., and B. Robinson. 2021. "Blurring boundaries: the invasion of home as a safe space for families and children with SEND during COVID-19 lockdown in England." *European Journal of Special Needs Education* 36 (1): 65–79. <https://doi.org/10.1080/08856257.2021.1872846>.
- Conti, G. 2020. "Supporting Parents and Children's Early Years During and After COVID-19 Crisis." Accessed July 22, 2021. <https://voxeu.org/article/supporting-parents-and-children-early-years-during-and-after-Covid-19-crisis>.
- Coughlan, M., and P. Cronin. 2021. *Doing a Literature Review in Nursing, Health and Social Care*. 3rd ed. Thousand Oaks: Sage.
- Couper-Kenney, F., and S. Riddell. 2021. "The Impact of COVID-19 on Children with Additional Support Needs and Disabilities in Scotland." *European Journal of Special Needs Education* 36 (1): 20–34. <https://doi.org/10.1080/08856257.2021.1872844>.
- Cronin, M. A., and E. George. 2023. "The Why and How of the Integrative Review." *Organizational Research Methods*. [Online] 26 (1): 168–192. <https://doi.org/10.1177/1094428120935507>.
- Department of Education. 2022. *Summary of the SEND Review: Right Support, Right Place, Right Time*. Accessed November 29, 2022. <https://www.gov.uk/government/publications/send-and-ap-green-paper-responding-to-the-consultation/summary-of-the-send-review-right-support-right-place-right-time>.
- Department of Health. 2022. "Coronavirus 19 in the UK." Accessed June 15, 2022. <https://coronavirus.data.gov.uk>.
- Department of Work of Pensions. 2021. *National Statistics Family Resources Survey: Financial Year 2020 to 2021*. Accessed June 17, 2022. <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021/family-resources-survey-financial-year-2020-to-2021>.
- Elsbach, K. D., and D. Knippenberg. 2020. "Creating High-Impact Literature Reviews: An Argument for 'Integrative Reviews'." *Journal of Management Studies*. [Online] 57 (6): 1277–1289. <https://doi.org/10.1111/joms.12581>.
- Gillespie-Smith, K., D. McConachie, C. Ballantyne, B. Auyeung, and K. Goodall. 2021. "The Impact of COVID-19 Restrictions on Psychological Distress in Family Caregivers of Children with Neurodevelopmental Disability in the UK." *Journal of Autism & Developmental Disorders* 53 (4): 1–15. <https://doi.org/10.1007/s10803-021-05132-3>.
- Greenway, C. W., and K. Eaton-Thomas. 2020. "Parent Experiences of Home-Schooling Children with Special Educational Needs or Disabilities During the Coronavirus Pandemic." *British Journal of Special Education* 47 (4): 510–535. <https://doi.org/10.1111/1467-8578.12341>.
- Hong, Q. N., P. Pluye, S. Fàbregues, G. Bartlett, F. Boardman, M. Cargo, P. Dagenais, et al. 2018. "Mixed Methods Appraisal Tool (MMAT), Canadian." *Intellectual Property Office* 34 (4): 1–10. <https://doi.org/10.3233/EFI-180221>.
- O'Connor, U., J. Bates, J. Finlay, and A. Campbell. 2021. "Parental Involvement During COVID-19: Experiences from the Special School." *European Journal of Special Needs Education* 37 (6): 936–949. <https://doi.org/10.1080/08856257.2021.1967297>.
- Ofsted. 2021. "Improving Outcomes for Children and Young People with SEND." <https://www.gov.uk/government/news/improving-outcomes-for-children-and-young-people-with-send>.

- Ohayashi, H. 2012. *Psychological Distress: Symptoms, Causes and Coping*. New York: Nova.
- Pavlopoulou, G., R. Wood, and C. Papadopoulos. 2020. *Impact of COVID-19 on the Experiences of Parents and Family Carers of Autistic Children and Young People in the UK*. United Kingdom, Europe: UCL Institute of Education.
- Rogers, G., G. Perez-Olivas, B. Stenfort Kroese, V. Patel, G. Murphy, J. Rose, V. Cooper, et al. 2021. "The Experiences of Mothers of Children and Young People with Intellectual Disabilities During the First COVID-19 Lockdown Period." *Journal of Applied Research in Intellectual Disabilities: JARID* 34 (6): 1421–1430. <https://doi.org/10.1111/jar.12884>.
- SEND Code of Practice. 2015. "SEND Code of practice 0-25 years: Statutory guidance for organisations which work with and support children and young people who have special educational needs and disabilities." Accessed June 16, 2023. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf.
- Sideropoulos, V., D. Dukes, M. Hanley, O. Palikara, S. Rhodes, D. M. Riby, A. C. Samson, and J. Van Herwegen. 2022a. "The Impact of COVID-19 on Anxiety and Worries for Families of Individuals with Special Education Needs and Disabilities in the UK." *Journal of Autism & Developmental Disorders* 52 (6): 2656–2669. <https://doi.org/10.1007/s10803-021-05168-5>.
- Sideropoulos, V., H. Kye, D. Dukes, A. C. Samson, O. Palikara, and J. Van Herwegen. 2022b. "Anxiety and Worries of Individuals with Down Syndrome During the COVID-19 Pandemic: A Comparative Study in the UK." *Journal of Autism & Developmental Disorders* 53 (5): 2021–2036. <https://doi.org/10.1007/s10803-022-05450-0>.
- Theis, N., N. Campbell, J. De Leeuw, M. Owen, and K. C. Schenke. 2021. "The Effects of COVID-19 Restrictions on Physical Activity and Mental Health of Children and Young Adults with Physical And/Or Intellectual Disabilities." *Disability and Health Journal* 14 (3): 101064–101064. <https://doi.org/10.1016/j.dhjo.2021.101064>.
- Theis, N., N. Campbell, J. De Leeuw, M. Owen, and K. C. Schenke. 2021b. "The Effects of COVID-19 Restrictions on Physical Activity and Mental Health of Children and Young Adults with Physical And/Or Intellectual Disabilities." *Disability and Health Journal* 14 (3): 101064. <https://doi.org/10.1016/j.dhjo.2021.101064>.
- Torraco, R. 2005. "Writing Integrative Literature Reviews: Guidelines and Examples." *Human Resource Development Review* 4 (3): 356–367. <https://doi.org/10.1177/1534484305278283>.
- Torraco, R. J. 2016. "Writing Integrative Literature Reviews: Using the Past and Present to Explore the Future." *Human Resource Development Review*. [Online] 15 (4): 404–428. 4 (3). <https://doi.org/10.1177/1534484316671606>.
- Toseeb, U., and K. Asbury. 2022. "A Longitudinal Study of the Mental Health of Autistic Children and Adolescents and Their Parents During COVID-19: Part 1, Quantitative Findings." *Autism: The International Journal of Research & Practice* 27 (1): 13623613221082715. <https://doi.org/10.1177/13623613221082715>.
- Whittemore, R., and K. Knafl. 2005. "The Integrative Review: Updated Methodology." *Journal of Advanced Nursing* 52 (5): 546–553. <https://doi.org/10.1111/j.1365-2648.2005.03621.x>.
- Wolstencroft, J., L. Hull, L. Warner, T. N. Akhtar, W. Mandy, and D. Skuse. 2021. "'We Have Been in Lockdown Since He Was born': A Mixed Methods Exploration of the Experiences of Families Caring for Children with Intellectual Disability During the COVID-19 Pandemic in the UK." *British Medical Journal Open* 11 (9): e049386. <https://doi.org/10.1136/bmjopen-2021-049386>.
- World Health Organisation. 1997. A Health Telematics Policy in Support of WHO's Health-for-All Strategy For Global Health Development. Accessed 19 June, 2023. https://iris.who.int/bitstream/handle/10665/63857/WHO_DGO_98.1.pdf?sequence=1&isAllowed=y.
- Yorks L. 2008. "What We Know,What We Don't Know,What We Need to Know—Integrative Literature Reviews Are Research." *Human Resource Development Review* 7 (2): 139–141. <https://doi.org/10.1177/1534484308316395>.
- Zahawi, N., and S. Javid. 2022. "The Green Paper." Accessed June 10, 2022. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1063620/SEND_review_right_support_right_place_right_time_accessible.pdf.