National Institute for Health Research Policy Research Programme Project: A Rapid cross-sectional mixed methods study to scope, understand and co-develop the policy priorities for reducing inequalities and mitigating the long-term impacts of COVID-19 for children and young people with SEND

NIHR202718

26/10/2022

Authors:

Dr Emma Ashworth, Liverpool John Moores University

Prof. Lucy Bray, Edge Hill University

Prof. Amel Alghrani, University of Liverpool

Dr Joanna Kirkby, Liverpool John Moores University

This research is funded by the National Institute for Health Research (NIHR) Policy Research Programme (project reference NIHR202718). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Index of Content

Keywords

Children and young people; special educational needs and disabilities; COVID-19; pandemic; children's rights; inequalities; education; health and social care.

Lay Summary

Aims

This study aimed to understand the impact of the COVID-19 pandemic and associated lockdowns on children with special educational needs and disabilities (SEND). The focus was on finding out the lessons learned throughout the pandemic and to identify priorities for education, health, and social care practice and policy.

Approach

The study used mixed-methods across three phases. Phase 1 involved a rapid review of the evidence about the impact of the pandemic on children with SEND. Phase 2 used online surveys and interviews, to gather information about the impact of the pandemic and the lessons learnt from the perspective of children with SEND, parents/carers, education, health and social care professionals, and Local Authority staff. Phase 3 involved face-to-face and online workshops to co-develop priorities for policy and practice ‘going forward’ to promote recovery.

Findings

The pandemic had a negative impact on children with SEND, and their needs and rights were reported as not being adequately met. Their education, health, and social care provision was adversely affected, with online appointments and remote learning often not meeting their needs. Children with SEND’s social, emotional, and physical development were also negatively impacted.

Key Conclusions and Recommendations

To recover, children with SEND’s rights should be prioritised in policy and funding. The co-developed priorities for policy and practice focused on five key rights of children, in regard to recovery from the COVID-19 pandemic and in the case of any future infectious illness outbreaks:

1. My right to play, socialise, have fun and be part of my community.
2. My right to support for my social, emotional well-being and mental health.
3. My right to flexibility, choice and support so I can feel safe, belong and learn in school.
4. My right to health and social care services and therapies in order for me to stay healthy.
5. My right to support for my parents/carers and my family.

Executive Summary

Study Aims

The aim of the research was to examine the perceptions, experiences, lessons learnt and priorities of children and young people (CYP) with special educational needs and disabilities (SEND), their parents/carers, and professionals, to reduce the inequalities and mitigate the long-term impacts of COVID-19 for CYP with SEND. We had five objectives to achieve this:

- To examine the evidence and policy.
- To capture the impact and lessons learnt from various perspectives.
- To explore the experiences of CYP with SEND, parents/caregivers and professionals.
- To understand potential impacts of the COVID-19 pandemic on the long-term development and wellbeing of this generation.
- To work collaboratively with CYP, parents/carers, and professionals to identify priorities for 'going forward' through lockdowns and restarts to promote recovery.

Background

Before the COVID-19 pandemic, there were already stark inequalities and weaknesses in the provision of services for children with SEND (CQC & Ofsted, 2020; Harris & Davidge, 2019: Byrne et al., 2020; National Autistic Society, 2020; Alghrani & Byrne, 2020). COVID-19 has exacerbated all these realities. In May 2020, children with Education, Health and Care (EHC) Plans had their legal rights formally downgraded (Byrne, 2020; Children's Commissioner, 2020) by the Coronavirus Act 2020. Local Authorities and health commissioning bodies were only required to use 'reasonable endeavours' to discharge their legal duty under section 42 of the Children and Families Act 2014. Essential services (outlined in EHC Plans) such as 1-to-1 educational support, mental health support, and physiotherapy were often discontinued (Alghrani & Byrne, 2020).

This research aimed to address a clear gap in how service provision can be improved and how any inequalities exacerbated by COVID-19 can be mitigated and overcome. Given the negative impact which COVID-19 has had on service provision for CYP with SEND (Alghrani & Byrne, 2020; House of Commons Education Committee, 2020), the need to establish best practice for future provision represents a critical policy priority.

Methods

We used a Rapid Assessment and Response (RAR) approach (Manderson & Aaby, 1992; WHO 2002; Kamineni et al., 2011) to learn from and work with stakeholders to investigate, understand, analyse, and prioritise constraints and opportunities, and make informed and timely decisions regarding policy (WHO 2004; Murphy et al., 2018). Specifically, we used a mixed-methods cross-sectional approach to collect data across three phases (1 and 2 running concurrently).

Phase 1, Review of the Evidence: The study utilised established rapid review methods (Tricco et al., 2015) to locate, appraise, and map the key concepts, current evidence, and policy underpinning the SEND provision for CYP during the pandemic. 33 sources were included.

Phase 2, Sequential Mixed-Methods Data Collection: Structured online surveys and qualitative semi-structured interviews were used to gain insight into the perceived impacts, lessons learnt, experiences, and perspectives of CYP with SEND, parents/carers, and professionals. Interviews occurred via online platforms and used activity books to support children's involvement. CYP surveys were designed to foreground their abilities using 'write and draw' techniques and emojis. Data collection methods were tailored to each stakeholder group and co-developed with guidance from the steering group and public and patient involvement groups. Participants were recruited via social media, and through relevant organisations/networks. 55 children with SEND, 893 parent/carers, 163 health and social care professionals, 100 education professionals and 44 Local Authority professionals completed the survey. 4 children with SEND, 10 parent/carers, 10 health and social care professionals, 3 education professionals and 2 Local Authority professionals took part in interviews.

Phase 3, Prioritisation Exercise: The online surveys (phase 2) asked all respondents to identify key priorities to help mitigate the impact of the COVID pandemic on CYP with SEND. These priorities were themed and refined, before being further developed through seven facilitated workshops. Professionals' workshops were online, CYP workshops were face-to-face using creative methods in special schools and through SEND charities, and parent/carer workshops were conducted at local support groups. The priorities were co-developed via an iterative and flexible approach, and are framed using a rights-based approach according to the United Nations Convention on the Rights of the Child (1989).

Results

CYP with SEND described how lockdowns had negatively impacted their social, emotional and physical development and health. The lockdowns compounded existing SEND (e.g., autistic CYP struggled with the change in routine), and for many it exacerbated underlying social and communication difficulties.

The majority of parents/carers (69%; n=509) reported that the pandemic had a negative impact on their child's education and learning, with many (89%; n=655) reporting that their child was not able to access face-to-face education, and that remote learning did not effectively meet their needs (46%; n=261). CYP with SEND's access to key therapies was reported as significantly reduced (e.g., speech and language therapy - pre-COVID: 41% n=88; during lockdown: 1%; n=2). Only 6% of parents/carers felt the requirements outlined in their child's EHC Plan had been 'completely met'. Parents/carers reported that their child's social skills (71%; n=198), mental health (65%; n=179), ability to interact with others, play (86%; n=441) and make and sustain friendships (69%; n=407) had deteriorated, with many reaching crisis levels. Professionals reported high levels of concern and challenges in providing care and support to children with SEND during the pandemic, including increased numbers of safeguarding concerns (62%; n=62). Parents and professionals noted the negative impact on their own wellbeing; 67% (n=582) of parents said their mental health 'got worse', and 77% (n=125) of health and social care professionals felt that the quality of their service provision was negatively affected.

Key Findings

Priorities for policy and practice (both in case of future lockdowns, and recovery moving forward) were co-developed with children, parents and professionals, and positioned within five themes:

1. My right to play, socialise, have fun and be part of my community.
2. My right to support for my social, emotional well-being and mental health.
3. My right to flexibility, choice and support so I can feel safe, belong and learn in school.
4. My right to health and social care services and therapies in order for me to stay healthy.
5. My right to support for my parents/carers and my family.

Our priorities indicated that CYP with SEND need to be explicitly considered in any future legislative changes or restrictions, and any changes should be underpinned by a Children's Rights Impact Assessment (CRIA). Moving forwards, health and social care services for CYP with SEND (e.g., CAMHS, physiotherapy, respite, social services) should be readily available without long waiting lists, continue uninterrupted, and should be tailored to CYP's individual needs (e.g., online or face-to-face, alternative therapies offered). Flexibility should be offered in school (in both curriculum and delivery), and all professionals working with CYP should have a SEND-specific component to their training. In the event of another lockdown, CYP with SEND need to be offered a place in school, any additional support should continue, and work should be appropriately differentiated. Clear and timely guidance on restrictions should be provided to any services/organisations who support CYP with SEND; information should also be communicated with parents/carers (to outline how their child's provision will be affected) and CYP with SEND in an appropriate format (e.g. social stories).

Conclusions and Recommendations for Further Research

The needs and rights of CYP with SEND were not given due consideration during the pandemic. Legislative restrictions meant that health and social care services were prevented from running face-to-face, and most CYP with SEND could not go to school. Online appointments and remote learning were not deemed to be a sufficient alternative for most. CYP with SEND's mental health declined, and their social, emotional and physical development was negatively impacted. Parents/carers of children with SEND received little respite or support and consequently their mental health also declined. Professionals encountered many more families of children with SEND in crisis and had increased safeguarding concerns. There has been an increase in demand for services, longer waiting lists, staff shortages, and burnout among staff who support CYP with SEND. Further research is needed to ensure children with SEND's voices continue to be heard and their needs met moving forwards. We have already begun work exploring this – we have shared our priorities with our steering group for review, to identify priorities for future research and to continue our collaborative working.

Dissemination Plans

We have published multiple evidence briefings and plain language summaries, which have been shared widely with key stakeholders through social media and the project webpage. We also held a publicly available webinar to launch the findings. We are working on peer-reviewed papers and bespoke evidence briefings for key parliamentary groups and policymakers.

Expected Impact

We anticipate that the findings will influence policy and practice in the SEND field. Our priorities align with various Government departments, including the Department for Education and the Department for Health and Social Care. Our findings have been submitted to the steering group of the Government's current SEND review, have been presented to the DfE at a research seminar, and have been provided to the All Party Parliamentary Group for SEND. Study findings were cited in the COVID-related discussions of the SEND Review Green Paper, and a written response to the public consultation of the review has been submitted by the study team.

Description of the Research

Objectives and Approach

Research Question

What are the perceptions, experiences, lessons learnt, and priorities of CYP with SEND, their parents/carers and stakeholders for reducing inequalities and mitigating the long-term impacts of COVID-19 for CYP with SEND?

Research Aim

To examine the perceptions, experiences, lessons learnt, and priorities of CYP with SEND, their parents/carers, and stakeholders to reduce the inequalities and mitigate the long-term impacts of COVID-19 for CYP with SEND.

Research Objectives

1. To examine the evidence and policy impacting on SEND provision for CYP during the COVID pandemic (phase 1 scoping review).
2. To capture the impact and lessons learnt over the pandemic from the perspectives of CYP with SEND, parents/carers, and stakeholders (phase 2 survey).
3. To explore the experiences of CYP with SEND, parents/caregivers, and stakeholders of SEND provision during the pandemic (phase 2 interviews).
4. To understand potential impacts of the COVID-19 pandemic on the long-term development and wellbeing of CYP with SEND (phase 2 surveys and interviews).
5. To work collaboratively with CYP, parents/carers, and stakeholders to identify priorities for 'going forward' through lockdown, restarts, and to promote recovery (phase 3 prioritisation exercise).

Resources

The project team consisted of Dr Emma Ashworth (Liverpool John Moores University; principal investigator), Prof Amel Alghrani (University of Liverpool; co-investigator), and Prof Lucy Bray (Edge Hill University; co-investigator). Dr Ashworth is a Chartered Psychologist and Lecturer in Psychology, with expertise in children's mental health and educational psychology. Prof Alghrani is a (non-practicing) Barrister and Professor of Law, with expertise in SEND and medical law. Prof Bray is a registered Children's Nurse and Professor of Children's Health Literacy. Dr Joanna Kirkby was recruited as the research assistant for the project due to her experience with qualitative research methods and work with children with SEND.

The project was supported by Dr Carianne Hunt through the Liverpool Health Partners' 'Starting Well' theme, which is focused on maternal and child health and actively links together organisations and professionals in this field. The project was also informed by a multi-disciplinary steering group of professionals who work with CYP with SEND. This included paediatricians, teachers, lawyers, nurses, allied health professionals, and policy officers. The steering group met four times over the course of the project and advised on key milestones such as the development of the data collection tools, refinement of the results, and the dissemination of the findings. The project was also supported by Public and Patient Involvement (PPI) advisors; more detail on this is provided in a separate section below.

The majority of the resources used for this project were already available via our institutions, such as Qualtrics to collect survey data, and Microsoft Teams to conduct online interviews. However, we purchased a licence for Survey Monkey for data collection with CYP, due to its feature allowing participants to upload attachments. We also developed some resources for our workshops with CYP; details of these are in the results section below.

Design

We used a Rapid Assessment and Response (RAR) approach (Manderson & Aaby 1992, WHO 2002, Kamineni et al 2011) to enable the team to learn from and work with stakeholders to investigate, understand, analyse, and prioritise constraints and opportunities (WHO 2004, Murphy et al 2018).

A RAR approach is underpinned by 5 key principles (WHO 2004);

- rapidity – to produce data and an action plan quickly;
- resource effectiveness – cost effective in terms of human and time resources;
- multiple methods – using multiple methods in combination with multiple data sources;
- practical adequacy – pragmatic collection and use of data;
- action oriented – priority given to the development and enhancement of practical responses.

This mixed-methods cross-sectional study collected data across three phases (1 and 2 running concurrently) to enable rapid insights to be gained and priorities identified. The study was completed within 9 months between May 2021 and January 2022.

Methods

Phase 1 (Rapid Scoping Review)

The rapid scoping review of the literature aimed to identify the reported impacts of the COVID-19 pandemic on the education, health, and social care of children with SEND. This review, conducted in June 2021, aimed to identify the emerging evidence at this time and feed into the priority development work. Given the timely nature of the topic, a rapid scoping review (Tricco et al., 2017) approach was utilised. This approach fits within the family of rapid reviews, which are a form of knowledge synthesis that aim to produce evidence in an efficient manner, accelerating the process of a traditional systematic review through the streamlining or omitting of a variety of methods (Hamel et al., 2021). The rapid scoping review approach we adopted ‘intended to respect the key principles of knowledge synthesis' (Tricco et al 2017, p5) and included a 'clear review aim, statement of review objectives, predefinition of eligibility criteria and the systematic presentation and synthesis of results' (Tricco et al 2017, p5). In line with Arksey & O'Malley's (2005) scoping review framework we did not appraise the evidence for quality or assess the evidence for validity (Joanna Briggs Institute 2015; Tricco et al., 2017).

The rapid scoping review focussed on studies that involved children with SEND, including children with needs in the following areas: communication and interaction; cognition and learning; social, emotional, and mental health difficulties; and sensory and/or physical needs. Children with SEND included in the review were aged 5-15, as this age range is typically when most children are in formal and compulsory education. However, we recognise there is research which focuses on older young people with SEND (aged 16-25; e.g., ALLFIE, 2021; O'Brien & Dadswell, 2021).

The review focussed on research studies and reports involving children with SEND from within the UK. Children with SEND in different countries may have varying experiences of the pandemic due to different Government policies and guidelines. We recognise there are many studies on how COVID-19 has impacted children with SEND from outside the United Kingdom (e.g. Neece et al., 2020; Petretto, Masala & Masala, 2020; Nusser, 2021; Marachetti et al., 2020; Fontanessi et al., 2020). All types of empirical evidence (qualitative, mixed methods, quantitative) were included in the rapid scoping review.

The evidence was located by searching databases (CINAHL, MEDLINE, PSYCinfo) using comprehensive search terms, Boolean operators, and wildcard term endings, and we made a call for evidence to key organisations (e.g., Council for Disabled Children, ADHD Foundation, Autism UK, WellChild) on social media to identify any grey literature or reports that have not been published. We also searched Google and Google Scholar. The searches were conducted in June 2021. The searches, selection and review of evidence were discussed within the team to check publications against the inclusion criteria and review aim. Whilst the review process did not include a quality appraisal stage, as a team we checked the methods and nature of the evidence for each paper to ensure ethical conduct.

We identified 68 papers and reports. The abstract and title screening excluded 35 papers and reports. In total, we reviewed and synthesised evidence from 11 papers and 22 reports. We extracted the data from the included studies and reports into a simple table designed for this review. The extraction focussed on mapping the different aspects (education and learning, health and social care) of children's lives which were reported as being impacted by the pandemic. We also remained open to inductively identify any other key aspects the evidence identified.

Phase 2 (Sequential Mixed-Methods Data Collection)

The mixed-methods cross-sectional design used an explanatory Quant→Qual (Cresswell et al., 2003) sequential design, utilising mainly quantitative surveys followed by qualitative interviews. Phase 2 enabled us to gain insight into the perceived impacts, lessons learnt, experiences, perspectives, and priorities of CYP with SEND and key stakeholders in their lives. The use of multiple methods to gain breadth and depth of data from multiple sources is a key element of a RAR approach. The methods were agile and enabled engagement during coronavirus restrictions and facilitated the involvement of those who have language, communication needs, developmental disabilities, or those who may have been shielding due to long term health conditions or disabilities.

Online Surveys

Participants were recruited to take part in the online survey using social media and through the distribution of study information via key organisations working with children with SEND between June and August 2021. In total, 55 children with SEND, 893 parent/carers, 163 health and social care professionals, 100 education professionals and 44 local authority professionals completed the online survey. Respondents were distributed across the UK (although the vast majority, 95.7%, were in England), children had a broad range of SEND, and a range of multi-disciplinary health and social care, Local Authority and education professionals took part.

Separate online anonymous surveys for each stakeholder group were designed with patient and public involvement (PPI) from CYP with SEND, parents of children with SEND, health and social care professionals, education professionals, and Local Authority staff. The data collected came from a range of question formats, including multiple choice questions, yes/no responses, and open text responses. Initial questions pertained to general demographic information, and subsequent questions were then organised into several themed sections, including recreation and play, health and social care, and education and learning. Examples of questions aimed at professionals included: '*overall, during the last year (back to March 2020) has there been an increase or a decrease in reported safeguarding concerns for children with SEND?'* (choice of answers: *a large increase; a small increase; no change; a small decrease; and a large decrease*). An example of a question for parent/carers is: '*overall, as a parent/guardian of a child with special educational needs and disabilities, over the COVID-19 pandemic (back to March 2020), my general wellbeing has…*' (choice of answers: *got better; got worse; stayed the same; not sure; and prefer not to say)*. Examples of open text questions included*: if there was another school closure, what would you like to see done differently?*' and *'the difficult things about coming out of lockdown, things opening up and everyone being back in school for me were…*'.

The CYP survey was produced in consultation with PPI groups and was designed to foreground children's abilities. Children could choose how they wanted to respond to the questions, including selecting emojis, writing text, or drawing and uploading pictures. The child survey was accessed via the parent/carer survey; this allowed any demographic details to be completed by their parent and also facilitated parental consent prior to a child or young person accessing their survey.

Each survey ended by asking participants to identify their top priorities for policy and funding to support CYP with SEND in recovering from the pandemic. CYP were asked '*if you were in charge of the country, what would you do to help children with special educational needs and disabilities over the next year?'*

Descriptive statistical analyses in SPSS were used to examine the data for key findings. Qualitative data from the open text response boxes were collated into a single document for each participant group. The qualitative responses in many cases, particularly those from parents, were detailed and lengthy. Thematic analysis was used to analyse the data in NVivo. Data were analysed inductively to allow for unanticipated findings to be identified. The data were coded per participant group by a member of the team and were then grouped into themes and sub-themes. Much of the data across all participant groups aligned with the main areas of SEND provision e.g. education, health and social care whilst other key areas around play and family support were identified within the survey responses. The themes and sub-themes were then checked, reviewed, and discussed with members of the team and shared and discussed with the parent PPI advisors.

Qualitative Online Interviews

At the end of the online survey, parents/carers and professionals were asked if they (or their child) would like to participate in a follow-up online interview by leaving their details in a linked separate survey. Participants who registered an interest were contacted via an email with an invitation to participate (for parents/carers this was both for themselves and/or their children), and were provided with participant information sheets. If potential participants responded, written opt-in consent was then sought from parents/carers and professionals, and opt-in assent for children. If children wanted to participate, they were offered a ‘hello’ meeting via the online platform to talk about the study, meet the researcher, and ask any questions they may have. This ‘hello’ meeting helped to build rapport and allowed the researcher to ascertain each child’s individual communication needs and preferences. Each child was sent an activity pack to help prepare for their interview, which included details about the types of questions they may be asked, and space to note down their thoughts.

Interview schedules were designed with PPI from CYP with SEND, parents/carers of children with SEND, and steering group guidance. Separate interview schedules were designed for CYP, parents/carers, education professionals, health and social care professionals, and Local Authority staff. The interview schedule followed a semi-structured format, to ensure that certain topics highlighted by the survey were covered, but that participants had the flexibility to lead the interview direction and talk about issues of importance to them. Questions were open-ended, and prompts were used to elicit more detailed responses. Questions for parents/carers, CYP, and professionals covered topics such as the positive and negative impacts of the COVID-19 pandemic on CYP with SEND, experiences of education, health and social care provision during the pandemic, and the priorities for moving forward out of the pandemic. Questions were centred around key findings from the online surveys.

Qualitative data were collected between August and September 2021. 4 children aged 8-14 with SEND, 10 parent/carers, 10 health and social care professionals, 3 education professionals, and 2 Local Authority professionals took part in the interviews. Respondents were distributed across the UK, CYP had a broad range of SEND, and a variety of multi-disciplinary health and social care and educational professionals took part. ‘Quotable quotes’ (Hunter, 2010) were identified to note key sections and content from the interviews. This approach saved the costs and time associated with transcription and aligned with the RAR (WHO, 2002) approach. The ‘quotable quotes’ were then analysed by the research assistant for each participant group using Braun and Clarke’s (2006) reflexive thematic analysis. Data were analysed inductively to allow for unanticipated findings to be identified. Data were coded in NVivo by the research assistant, before being collated into potential themes. These themes were then reviewed with the rest of the team for feedback, and further refined and defined. Final themes were then checked again by the research team.

Phase 3 (Prioritisation Workshops)

This phase of the study used an adapted Policy-Delphi approach (Turoff 1970), which rapidly mapped overlapping priorities from different perspectives and identified mutual priorities across stakeholder groups. We began by taking the priority data identified from the surveys and interviews in phase 2 for each participant group. For parents/carers, this was their top priority for their child over the next year. For professionals, this was their top three priorities for funding and top three priorities for policy over the next year. For CYP with SEND, this involved taking their answers to the question ‘*if you were in charge of the country, what would you do to help children with special educational needs and disabilities over the next year?*’. We reviewed the priorities for each participant group separately and used a tally system to analyse the frequency of different priorities within each group. We then grouped similar priorities together. Then through further analysis we refined priorities to create the top priorities for each participant group (between 4 and 21 top priorities).

The top priorities identified within each participant group were presented at two steering group meetings. The discussion with steering group members identified the need to develop a more integrated set of priorities to prevent ‘silo working practices’. The priorities were also discussed as needing to more clearly reflect the challenges that CYP with SEND, parents, and professionals faced as a result of the pandemic, against the backdrop of the pre-existing challenges faced by this group of children. The steering group meetings also identified that the funding and policy priorities overlapped and were repetitious, and it was decided to merge these priorities to create a single comprehensive list. When merged, the priorities were grouped under 5 key themes/areas.

These five key priority areas were then taken to several stakeholder workshops and were presented to participants (CYP with SEND, parents/carers, and professionals) to obtain their thoughts. CYP were recruited to take part through local special schools and a national charity’s family support group. Parents/carers were recruited through a national SEND charity, and a local parent support group. Professionals were recruited via social media.

At the workshops, participants were presented with the key findings from Phases 1 and 2 and were invited to discuss the identified areas/themes. They were asked to help identify actionable and targeted priorities that would best address or mitigate the impact of the pandemic, and what would need to change in order for this to happen. The workshops with CYP with SEND and parents/carers occurred face-to-face, using creative methods and mapping activities that were developed through consultation with our CYP and parent PPI groups. The activities included:

- Large sheets of paper placed on the wall or floor to present the key themes and evidence which had been drawn from the survey data and interviews. Workshop participants were encouraged to draw, write, stick post-it notes, or dictate their views of the key areas of priorities.
- Thumbs up and thumbs down templates to examine what the key challenges had been during the pandemic and what things had worked well.
- A post box and postcards to encourage participants to write or dictate a key message to the Prime Minister about the 'most important' thing which needed to be done for children and young people with SEND now to help recovery from the pandemic.

The workshops held with professionals took place via online platforms. At the professional workshops, we presented evidence from phase 1 (scoping review), phase 2 (surveys and interviews), and the 5 developed themes. We presented each of the key themes one by one and allowed professionals to give their thoughts on each theme, what each theme might look like in practice, and to discuss anything they thought was missing. We recorded each workshop.

Findings

Due to the time-sensitive nature of the project and to ensure maximum reach and dissemination, evidence briefings were made available online throughout the project once data were collected and analysed. Thus, in order to avoid unnecessary duplication, we only present a summary of the findings here, and refer the reader to our dedicated study webpage for a detailed overview of the project findings from each phase and element of the study:

https://www.ljmu.ac.uk/research/centres-and-institutes/research-centre-in-brain-and-behaviour/expertise/forensic-and-social-research/suicide-and-self-harm-research/looking-back-to-move-forward.

Phase 1: Rapid Review of the Literature

The evidence in the rapid review of the literature was drawn from 34 sources: published papers and published and unpublished research reports. The majority of the evidence was drawn from parent reports gathered using online surveys (n=20); the views and experiences of CYP with SEND were directly sought in six studies. Five studies gathered information from professionals. Most studies used a mixed-methods (n=23) or qualitative (n=4) approach to gain insight into the impact of the pandemic on CYP with SEND and their parents/carers and services in the UK.

Evidence from the literature suggested that the COVID-19 pandemic has disproportionately impacted children with SEND, exposing and exacerbating already stark inequalities and weaknesses in SEND provision (e.g., CQC & Ofsted, 2021; Harris & Davidge, 2019: Byrne et al., 2020; National Autistic Society, 2020; Alghrani & Byrne, 2020; Skipp et al., 2020). The evidence indicated that children with SEND's education had been adversely affected during the pandemic. Although children with an EHC Plan should have been able to attend school, the majority did not, and many were not offered a place in school (Alghrani & Byrne 2020). Online learning was not an adequate substitute for children with SEND as it was inaccessible, and work was not differentiated and individually tailored to their needs (e.g., Alghrani & Byrne, 2020; Council for Disabled Children, 2021; Canning & Robinson, 2021; Greenway & Eaton-Thomas, 2021). Furthermore, in many cases, health and social care provision completely stopped, or moved online, with a negative impact on children's physical health (e.g., National Autistic Society, 2020; Couglan, 2020; Ashbury et al., 2020; Family Fund, 2021). Many children with SEND struggled with deteriorating emotional wellbeing and mental health, for which there was little or no support (e.g., Family Fund, 2021; Disabled Children's Partnership, 2021a, 2021b; Council for Disabled Children, 2021). With very little respite care available, families of children with SEND have been left exhausted and sometimes in despair (CQC & Ofsted, 2021). Recommendations from the evidence were orientated around the need for CYP with SEND to be prioritised in recovery plans moving forward after the pandemic.

Phase 2: Quantitative Survey Findings

Perceptions of Children with SEND

55 children with SEND shared their views in the online survey. Children were located across the UK and had a broad range of SEND. Out of 53 children, 89% (n=47) had a formal/official SEND diagnosis and 11% (n=6) did not. Of those with a diagnosis, 60% (n=32) had a communication and interaction diagnosis (e.g. autistic spectrum conditions), 57% (n=30) had a cognition and learning diagnosis (e.g. learning disabilities), 42% (n=22) had social, emotional and mental health difficulties (e.g. anxiety disorder) and 23% (n=12) had sensory and/or physical needs (e.g. cystic fibrosis).

When sharing their views of the pandemic and lockdowns, children with SEND shared mixed views:

😐 35% (n=17) of children chose this emoji.

😠 23% (n=11) of children chose this emoji.

😢 13% (n=6) of children chose this emoji.

Children with SEND were asked what they felt about coming out of lockdown, things opening up, and everyone being back in school:

😐 28% (n=12) of children chose this emoji.

🙂 23% (n=10) of children chose this emoji.

😁 19% (n=8) of children chose this emoji.

Children with SEND were asked what they felt about the year ahead:

😁 36% (n=14) of children chose this emoji.

😐 28% (n=11) of children chose this emoji.

🙂 23% (n=9) chose this emoji.

In terms of open text responses from CYP, they reported that some good things about life during the COVID-19 pandemic were not having to go to school, and being at home with their families. Specifically, children enjoyed being in the garden and having more time for activities such as walking, playing, baking, watching movies, talking to friends online, and playing games online. Children who continued to go to school liked that school was quieter and class sizes were smaller. In terms of online learning, children enjoyed being able to take more breaks, and one child said that they found home learning easier than learning in school. Several children said that good things about lockdown were that there was '*no forced socialising*'. For example, *'I get to be antisocial with no repercussions'* and '*being able to be me'*.

Conversely, children reported that difficult things about the pandemic included not going to school, not seeing family and friends, and not being able to do activities and sports such as swimming and dance. Several children told us how *'scary'* the pandemic was, and one child was '*worried thinking a family member will catch covid and die'*. Some children did not like wearing masks, and some told us that they found online learning difficult without learning support or a teacher at home to help them.

Children told us that the good things about coming out of lockdown were seeing friends and family, going out to different places, and going back to clubs and activities such as cubs, swimming and horse riding. In terms of education and learning, children enjoyed being back in *'proper'* lessons and being able to *'learn properly'* again.

Children told us that the difficult things about coming out of lockdown were being confused and scared by the new and changing rules, wearing masks, being away from their parents, and places being busy and noisy again. Some children were scared about catching COVID-19 and about going into lockdown again. One child told us they were scared to leave the house because everything had changed. In terms of education and learning, some children did not like going back to school, found school too noisy and busy, and did not like being in bigger classes again.

Children reported that over the next they are most looking forward to getting back to ‘normal’ again, going out and having fun, seeing their family, making friends, and going on holiday.

Perceptions of Parents/Carers of Children with SEND

893 parents of children with SEND shared their views in the online survey. Parents were located across the UK. 91% (n=767) of parent/carers reported that their child did have a formal/official diagnosis of a SEND, 9% (n=73) reported that their child did not have a SEND diagnosis, and 1% (n=7) did not know. For those who did have a SEND diagnosis, 67% (n=600) had communication and interaction needs, 52% (n=465) had cognition and learning needs, 42% (n=379) had social, emotional and mental health difficulties, and 34% (n=306) had sensory and/or physical needs. Parents could tick as many boxes as applied.

A main challenge reported by parents of children with SEND was that many (89%; n=655) of their children were not able to access face-to-face education throughout the pandemic, and many parents (46%; n=261) reported that remote learning was not at all effective in meeting their child’s needs. When comparing responses by school type, 9% of children who attended mainstream education continued to attend face-to-face schooling during the first lockdown, compared to 3% of children who attended special education provision. This difference was statistically significant (x^2 (2, 704) = 9.37, p = .009). However, there was no statistically significant difference by school type in parents’ ratings of the effectiveness of remote learning for their children. When comparing parents’ responses for children with and without EHC Plans, there were no statistically significant differences in the proportion of children who attended face-to-face schooling (6.6% with EHC vs 7.2% without attended school), or in parents’ ratings of the effectiveness of remote learning (48% with EHC vs 44% without reported remote learning perceived it to be ineffective).

For those children who were learning from home, 89% (n=397) were not given the SEND-specific technology they needed to engage in their learning during the first national lockdown. These challenges resulted in 69% (n=509) of parents reporting that the national lockdowns had either an ‘extremely’ or ‘somewhat’ negative impact on their child’s education and learning. There was no statistically significant difference in perceptions of impact between parents whose children attended mainstream and those who attended special provision, or between parents whose children had an EHC Plan and those who did not.

Children with SEND’s access to key therapies in school, such as speech and language therapy (40%; n=86) and physiotherapy (30%; n=63) were reduced. Parents reported that as a result of the pandemic and lockdowns, their child's social skills (71%; n=198), mental health (65%; n=179) ability to interact with others, play (86%; n=441), and make and sustain friendships (69%; n=407) had deteriorated. When the national lockdowns ended, many parents/carers reported their children as struggling to transition back to education (52%; n=192), with minimal transition support provided (37%; n=199), and some (21%; n=121) children stayed at home.

The majority of the parents (67%; n=582) who responded to the survey identified that their mental health had 'got worse' over the pandemic.

In their open text responses, parents/carers told us about a multitude of challenges they and their children faced during the pandemic. For example, many children with SEND struggled with anxiety, isolation, loneliness, and found it hard to leave the house. Children were especially impacted by *'constantly changing routine',* which in some cases *'caused large meltdowns'.* Parents/carers found it challenging '*dealing with spiralling mental health issues'* of their children and would now like there to be more mental health support readily available.

Parents/carers commonly told us about *'juggling'* a multitude of responsibilities such as trying to provide 1-2-1 learning support to their child with SEND, whilst working full time either from home or as a keyworker. Parents/carers told us how difficult it was to do this without a break or respite. On top of this, parents/carers commonly highlighted that no health care support was available for their child during the pandemic. Parents told us that it was hard to get in touch with services. When parents/carers did make contact, they were often told that the service was closed or that appointments were delayed due to the pandemic. Some parents managed to get telephone consultations or virtual appointments which they said were beneficial, quick and easy.

In terms of education and learning, many parents told us that their child was not offered a school place during the lockdowns even though they had an EHCP. One reason parents/carers gave as to why their children could not go to school was that they were not keyworkers; however, even some children whose parents were keyworkers were not offered a place at school. Parents/carers told us that many children found online learning hard, but one good thing about it was that it enabled children to work at their own pace. Many parents mentioned their children found the return to school tough due to anxiety and sensory overload in noisy, busy classrooms, and some children have not been able to return to school at all.

Concerning social needs, friendships, play and recreation, parents told us that the pandemic consisted of isolation, lost friendships, and a loss of social skills for many children with SEND. Although parents reported that many children with SEND found online interaction easier than face-to-face interaction, online interaction was not without its issues—for example, inappropriate friendships, safeguarding issues, and excessive screen time. Many parents reported how difficult it was for children's playgrounds, activities, and clubs to be closed. Especially problematic was the loss of sports clubs and structured opportunities for exercise.

Parents/carers told us that the things that helped them the most during the pandemic were online support groups, other parents/carers of children with SEND, and support 'bubbles' with close friends or family. Parents/carers commented that the things that helped their children the most were support from their parents/carers, having family time, video calls with friends and family, and internet gaming.

Looking forwards, parents would like to be listened to, and have access to more timely support without having to fight for it. Additionally, parents/carers would like more respite, more clubs and activities for their child with SEND, and support to help their child to readjust back into the community.

Perceptions of Education Professionals

100 education professionals shared their views in the online survey. Respondents were located across the UK and had a wide variety of job roles. 28% (n=28) were teachers, 22% (n=22) were teaching assistants, 28% (n=28) were part of their school's senior leadership team, 44% (n=44) were SEND co-ordinators (SENDCos), 3% (n=3) were pastoral support, and 6% (n=6) described their job role as 'other'. (N.B. participants could choose all that applied in relation to their job role). Education professionals worked across both primary and secondary education, and in both mainstream schools and specialist/alternative provision.

During the first national lockdown (March 2020-July 2020), when schools were closed for most pupils, educational professionals' role and ability to offer support to children with SEND was impacted. During the initial stages of the pandemic, 58% (n=57) of education professionals had a change in job role and 32% (n=24) of those thought that this role change had a negative impact on their ability to deliver education for pupils with SEND. This change in role and the change to the provision of teaching and learning meant that 40% (n=38) of education professionals reported that they were not able to provide the alternative/specialist resources needed for children with SEND.

58% (n=58) of education professionals reported that they felt that pupils with SEND had been more negatively affected by the pandemic than pupils without SEND, and 58% (n=58) reported that in the last year they had seen an increase in the number of children with SEND needing mental health/wellbeing support. The challenges throughout the pandemic had resulted in professionals reporting an increased number of requests for SEND support/assessments (77%; n=77), and an increased number of safeguarding concerns for children with SEND (62%; n=62).

Six themes were identified from the education professionals' open text responses. The first theme focussed on the benefits for those children who attended school during lockdown. The second theme highlighted the different support available for children with SEND during the pandemic, with many professionals reporting a lack of resources and training meaning that many children with SEND had difficulties learning effectively from home. The third theme linked to concerns for children's mental health and wellbeing, with health and social care services for children with SEND being reported as reduced and children with SEND's mental health and wellbeing deteriorating. The fourth theme focussed on the support available for parents/carers of children with SEND during the pandemic, and accounts of how difficult the situation was for many parents.

The fifth theme linked to the support available for schools and school staff during the pandemic, with many professionals reported going above and beyond during the pandemic to support children with SEND's learning, as well as both the child's and their parents' physical and mental health. However, the sixth theme relates to the extra burden placed on school staff. Combined with increased staff shortages, and the provision of unclear, delayed, and rapidly changing guidance from the Government, this had a detrimental impact on their own wellbeing. Education professionals were left feeling burnt out, stressed, and expressing concerns for their own health and wellbeing.

Perceptions of Health & Social Care Professionals

163 health and social care professionals completed the online surveys. Respondents were located across the UK and had a wide variety of job roles such as speech and language therapist, disability nurse, occupational therapist, autism practitioner, health visitor, social worker, and Educational Psychologist. 15% (n=24) of respondents worked in social care, 14% (n=23) worked in SEND specific social care, 33% (n=53) worked in community primary care, 20% (n=33) worked in SEND specific primary care in the community, 3% (n=5) worked in a hospital-based care setting, 2% (n=3) worked in a SEND specific hospital-based care setting, 3% (n=5) worked as a school nurse, 3% (n=4) worked as a SEND specific school nurse, 3% (n=5) worked as a social worker, and 5% (n=8) responded as working in an 'other' service area.

During the initial stages of the pandemic (March 2020-July 2020), most health and social care professionals (77%; n=125) reported that the quality of their service provision was 'much worse' or 'slightly worse' than before the COVID pandemic, and 72% (n=117) reported that there had been 'many more' or 'slightly more' requests for support, resources, and provision from their service. Furthermore, 47% (n=50) reported that waiting lists were 'significantly longer' or 'slightly longer'.

Nine themes were identified from the open text responses: perceived positive impacts of the pandemic (including the way that online platforms enabled multi-disciplinary meetings to be better attended and more efficient), perceived negative impacts of the pandemic, changes to services as a result of the pandemic, what has worked well during the pandemic, what has not worked well during the pandemic, the main barriers to the provision of services for children with SEND, new practice, the perceived biggest challenges going forward, and what health and what social care professionals would like to see done differently in the event of another lockdown.

In conclusion, health and social care professionals identified that children with SEND had faced huge disadvantages as a result of COVID-19. Professionals used words like 'disgusting', 'abandoned' and 'serious harm' to describe how the pandemic and associated lockdowns had impacted on health and social care service provision. Waiting lists were reported as increasing, and children were delayed in accessing the services they needed. In addition, health and social care professionals identified that respite provision and community activities completely stopped during the first lockdowns, negatively impacting many families. Particularly disadvantaged through prolonged exclusion from services and the need to shield were children who required aerosol generating procedures, children with neurodisabilities, enterally fed children, and children who were not able to follow COVID-19 rules in schools. Health and social care professionals also reported how younger children and those with complex disabilities were disadvantaged, as they were less able to engage in a meaningful way with online appointments and sessions.

During the pandemic, a significant challenge for health and social care professionals was staff shortages due to the redeployment of staff to cover COVID-19 wards, staff leaving their posts, and staff sickness due to COVID-19. There were reports that staff shortages contributed to an almost unmanageable workload for some staff, which impacted some staff's mental health and increased the risk of burnout. Health and social care professionals also reported that inconsistent advice and guidance was problematic as it meant that they struggled to know 'what they were allowed to do and what they were not allowed to do'.

Perceptions of Local Authority Professionals

44 Local Authority professionals completed the online survey. Respondents were located across the UK and had a variety of job roles. 14% (n=9) of participants were Directors of Children’s Services, 5% (n=2) were Associate Directors of Children’s Services, 7% (n=3) were SEND case workers, 25% (n=11) were a Head of SEND services, and 50% (n=22) were ‘other’ such as Assistant Director for Education, Assistant Director of SEND Strategic Improvement, and Head of Education Inclusion Service.

The majority of Local Authority professionals (89%; n=39) reported including all children with EHCPs in their definition of ‘vulnerable’ during the first national lockdown, meaning they were allowed to continue attending school. 68% (n=30) of those Local Authority staff who responded to the survey reported that an individual risk assessment had been used to help determine if a child was ‘vulnerable’. 23% (n=9) of Local Authority staff reported that schools were allowed to decide which children were deemed ‘vulnerable’ and 14% (n=6) stated the Local Authority decided.

The pandemic has impacted on requests and completions of EHCPs for children with SEND. 65% (n=22) of Local Authority staff reported an increase in requests to their Local Authority for EHCP assessments since March 2020, and 40% (n=14) reported that fewer EHCP assessments were completed in the statutory time frame since March 2020, in comparison to the previous year. Whilst many professionals reported that EHCP reviews moved online (49%; n=19), compared to pre-pandemic, there was a reported delay in annual reviews of EHCPs being conducted (28%; n=11).

Local Authority professionals also reported an increase in requests for the provision of services for SEND children and their families since March 2020, including an increase in requests for educational support (59%; n=19), respite and short breaks (49%; n=16), health care support (40%; n=13), social care support (47%; n=15) and play and recreation (22%; n=7).

The open text responses from Local Authority staff highlighted that Government guidance on which children were ‘vulnerable’, and thus could access onsite education, was unclear and changed during the course of the pandemic, leaving them unable to discern which children fell within the definition. Furthermore, interpretations of ‘vulnerable’ did not always mean that a child could access a school place in lockdown. There was variation in who made that decision – the Government guidance regarding the initial school closures received a mainly critical response from Local Authority professionals with descriptions of the guidance including: ‘*ambiguous’, ‘hit and miss’, ‘haphazard’, ‘chaotic’, ‘contradictory’, ‘terrible’, ‘poor’, ‘ill informed’, unhelpful’* and *‘not thought through’*. Legislative changes and the pandemic were reported to affect service delivery in education, healthcare, social care, and play and recreation.

Many professionals who responded welcomed the ‘reasonable endeavours’ legal modification. Safeguarding concerns were reported as increasing during the pandemic due to additional pressures on families, with more cases concerning children with complex needs, domestic abuse cases, and those related to emotional harm and neglect. Local Authorities varied in how they monitored what was happening with SEND provision for children during the pandemic; many liaised frequently with schools and used risk assessments to do this, but a few also contacted parents of CYP with SEND directly. In terms of what worked well in the year preceding the survey, respondents mainly cited multi-disciplinary working and the success of conducting virtual teaching, training, meetings, and work experience for CYP with SEND. Online platforms were also reported as enabling EHCP assessments and Annual Reviews to continue virtually. There were varied responses regarding what in the last year did not work so well, and many cited the disruption to social and healthcare services, and communication between Local Authorities and parents.

Local Authority professionals reported many obstacles to provision for children with SEND. The obstacles to education provision centred around “*school closures*”, and a lack of “*access to regular schooling*”, which led to “*disrupted learning experiences*”. In terms of healthcare, Local Authority professionals noted that there was a lack of access to health services for children with SEND. Regarding social care provision, Local Authority professionals mentioned a lack of short breaks and respite as major obstacles to supporting families of CYP with SEND. In terms of play and recreation, Local Authority professionals reported that provision (such as soft play, parks and out of school activities) completely stopped, which impacted children with SEND’s ability to interact with peers and gain exercise. In future lockdowns, Local Authority professionals would like to see schools remaining open for all CYP with SEND. Coming out of the pandemic, they would like to see more funding for Local Authorities, services, schools, short breaks and specialist provision so that children with SEND “*can access the services they need without resourcing being the main consideration”.*

Phase 2: Qualitative Interview Findings

Four children aged 8-14 with SEND, ten parent/carers, ten health and social care professionals, three education professionals, and two Local Authority professionals took part in the interviews. Interviews were conducted between August and September 2021. Participants were distributed across the UK, and a range of multi-disciplinary health and social care, educational, and Local Authority professionals took part. The key findings are presented according to participant type.

CYP with SEND's Perceptions

The main themes identified in the data included:

1. Lockdown was "lonely" and "boring"; and it stopped me going out;
2. "I could not use zoom like other children": Lack of opportunity to socialise;
3. "I don't think I learnt much": Remote learning;
4. "It was better when we went back to school": Coming out of lockdown and going back to school

Children with SEND told us they could not go out of the house as often and lacked the opportunity to socialise. Children took part in activities and played games inside the home, and they did not like remote learning. Children also preferred going back to school after lockdowns had ended. We recognise that some of the themes are not necessarily SEND specific, however, the lockdown compounded existing SEND (e.g., children with Attention Deficit Hyperactivity Disorder [ADHD] were unable to do the activities that allowed them to expend their energy, children with Autism Spectrum Condition (ASC) struggled in particular with the change in routine and friendships), and for many it exacerbated underlying social and communication difficulties.

Parents/Carers of Children with SEND's Perceptions

The themes identified were organised into five overarching categories: 1) the pre-existing lack of support for children with SEND, 2) health and social care, 3) education, 4) children's activities and social interaction over the pandemic, and 5) parent support. Themes for each category are listed below:

1. Pre-existing lack of support for children with SEND which was exacerbated over the pandemic.
2. Health and social care: health appointments and therapies being cancelled, delayed or moved online; the impact of the pandemic on children with SEND's mental health.
3. Education and learning: challenges in school places for children with SEND during the first lockdown; lack of support and communication from school during remote learning; remote learning for children with SEND; inaccessible technology; no differentiated work; the transition back to school; attending school; the Government guidelines did not work for children with SEND.
4. Friendships, activities, and social interaction: friendships and social interaction; the cessation of activities and clubs for children with SEND.
5. Parent support: lack of respite; mental health of parents of children with SEND during the pandemic.

Parents/carers told us that there was already a pre-existing lack of support for their children with SEND, and this was exacerbated during the pandemic. Health care, health appointments and therapies were cancelled, delayed or moved online. Parents/carers reported that the pandemic negatively impacted their child with SEND's mental health.

School places for children with SEND were reported as not being available during the first lockdown and there was a lack of support and communication from school during periods of online learning. Remote learning for children with SEND was extremely challenging, if not impossible, as it was inaccessible and schoolwork was not differentiated for their child's needs. Parents also told us that their child had little support with transitioning back to school after national lockdowns. Parents described how the requirements outlined in their child's EHC Plan were not met. The pandemic was reported as also impacting on their child's friendships and social interaction, as activities and clubs for children with SEND completely stopped. Parents also spoke about a lack of respite and short-breaks and how this impacted on a decline of their own mental health.

Professionals' Perceptions

There was consistency across the professionals of key themes. The themes identified were organised into three overarching categories: 1) the recognition of children with SEND during the pandemic, 2) health and social care, and 3) education and learning. Themes for each category are listed below:

1. Recognition of children with SEND during the pandemic
2. Health and social care: Services were prevented from running; unclear, inconsistent and rapidly changing guidelines; supporting and reassuring parents during the pandemic; concerns over not being able to 'see' children; safeguarding and social care provision; accessibility of remote support, collaborative online working; demand and waiting lists; workload; burnout and staff turnover.
3. Education and learning: School places, remote learning; parents understanding their child's needs

Professionals told us that children with SEND were not taken into consideration during the pandemic. Those interviewed reported that the services that support children with SEND were prevented from operating and that guidelines were unclear, inconsistent, and rapidly changing. Professionals identified challenges in not being able to work directly with children, and concerns this raised about safeguarding and social care provision. Professionals told us about increased demand for services, increased waiting lists, staff shortages, and increased workload and burnout. Despite many challenges, professionals described supporting and reassuring parents during the pandemic and trying to maintain support for families in crisis. Professionals also commented on the accessibility of remote support and how online working had facilitated improved inter-agency collaboration.

Places for children to attend school were reported as being not available for CYP with SEND, as well as the many challenges encountered in engaging children in remote learning. For those children who had been able to access in-person schooling, small classes were reported as working better for children with SEND. Professionals reported that over lockdown, some parents had gained a greater understanding of their child's needs.

Phase 3: Workshops and Priority Setting

20 children with a range of SEND, 11 parent/carers, and 38 professionals participated across 8 workshops. Findings from phase 2 (surveys and interviews) regarding priorities for policy and funding were presented in the workshops, and participants were asked to indicate what would need to change in order for those priorities to be actioned effectively.

CYP Workshop Findings

Many of the children with SEND identified the need to prioritise children’s declining mental health over the lockdown, and the need for increased support for children's mental health. Children identified the importance of the school environment in making them feel safe and making them want to attend. The children in the workshops who had continued to access face-to-face school over lockdowns told us that school was better during these times as it was quieter and there was more 1-2-1 support to do schoolwork. CYP identified that priorities for recovery should focus on lessons being more varied and fun, for example, being able to do more P.E. lessons, go swimming, and play more games. Outside of school, children would have liked to have a place to go to participate in activities without judgement and exclusion, play with their friends, and make new friends.

Parents/Carers Workshop Findings

Parents/carers described how exhausting it was to fight continually for support, and the difficulties and challenges encountered in navigating the SEND system. All parents felt that the evidence and their experiences indicated that an advocate to help guide parents through the process of obtaining support and access to services was important. Having safe places for children with SEND to go and be part of the community, socialise, and have fun without judgement were described as a 'lifeline' for CYP and their parents/carers. Parents/carers told us that groups and activities should be local and community-based, as often long distances needed to be travelled to access appropriate SEND specific services and activities.

Parents/carers agreed with the evidence from the study that children with SEND's anxiety increased over the pandemic and that access to services was challenging. As such, there needs to be increased early intervention and SEND-specific mental health provision for CYP with SEND, to prevent them reaching crisis point. For services to provide more effective care, parents/carers suggested that mental health professionals need to understand SEND and offer types of therapy other than counselling. In terms of education and learning, parents/carers endorsed children’s accounts and discussed how many children with SEND found the transition back to school overwhelming. Parents/carers felt giving children with SEND time and space to maintain and catch up on social interaction should have been prioritised. Furthermore, parents/carers drew on their own experiences and the evidence to discuss how CYP should be provided with more opportunities to pursue special interests, increase their independence, and develop life skills, rather than solely focusing on the curriculum. Parents/carers mentioned that they would like mainstream schools to be more inclusive and have more SEND trained staff.

Parents/carers noted that some professionals provided excellent care during the pandemic, going 'above and beyond'. However, most parents/carers told us that the majority of health and social care provision for children with SEND and respite completely stopped. A regular 'check in' phone call from professionals would have been appreciated by parents/carers during this time. Parents/carers indicated that online meetings and phone consultations worked well for some children with SEND but not others. As such, parents/carers suggested that their children with SEND could be given the option of a face-to-face or online appointment in the future. Parents/carers advised that the wait is too long to get a diagnosis and see a specialist, and they would like to see additional clinics for easier access to specialists.

Professionals' Workshop Findings

In response to the identified need for improved mental health support for children with SEND, professionals stated there was a need for a graduated response towards mental health support, from lower-level wellbeing support in school to specialists who can support a child in crisis. Additionally, professionals said that the whole children's workforce (education, health, social care and Local Authority) needs to be better trained around mental health issues and disability, and the education system needs to be more nurturing of children's mental health. Professionals commented that following the pandemic, schools should focus on the wellbeing of children rather than 'catching up' on the academic curriculum. The evidence and the workshops highlighted that remote learning had worked well for some children with SEND and therefore should be kept as an option for these children. Professionals spoke about the value of inclusion and that, currently, mainstream schools are often not inclusive enough for children with SEND. Professionals mentioned that in their experience, community inclusion is also essential for CYP with SEND and activities should be written into EHC Plans.

Professionals noted that parents/carers were exhausted during the pandemic as social care resources "dried up". Professionals reported that they had seen an enormous increase in demand for SEND support, which services were reported as not able to meet. As such, professionals suggested that services need to have more funding and resources. Professionals remarked that workforce challenges have been exacerbated during the pandemic, with many staff burning out or leaving their positions. Services are struggling to recruit new staff as there is shortage of suitably trained staff within the system. As such, professionals advised that there is a need to provide more opportunities to train more health care workers.

Priorities for Policy and Practice

The workshops led to the development of tightly focused priorities for policy and practice for CYP with SEND linked to the COVID-19 pandemic (outlined below). These priorities were informed by the research evidence from Phases 1, 2 and 3, and were developed through consultation with CYP with SEND, parents and carers, and professionals who work with CYP with SEND. These priorities for policy and practice apply to all CYP with SEND aged 5-15 years, both with and without an EHCP, unless explicitly stated. The priorities for policy and practice are informed by a rights-based approach to child-centred recovery and renewal, as recognised by the United Nations Convention on the Rights of the Child (Cohen, 1989). Children's rights should be centrally considered in any pandemic management.

One of the earliest legislative changes enacted under the Coronavirus Act 2020 was to reduce the legal duty contained in section 42 of the Children and Families Act 2014, which places an 'absolute duty' on Local Authorities to meet the needs of CYP with SEND. This was replaced with a 'reasonable endeavours' duty. However, this was enacted without the benefit of either a children's rights impact assessment (CRIA) or an equality rights impact assessment (ERIA). The evidence from this research highlights the adverse impact which COVID-19 had on CYP with SEND. To prevent against any future legal downgrading of the rights of CYP with SEND, central government in conjunction with Local Authorities, should engage in a review to ensure sufficient staffing, resources (financial, human, technical, informational and otherwise) and facilities are available to meet the needs of CYP with SEND.

In order for these priorities to be implemented and addressed there needs to be:

- Recognition that many aspects of the SEND system were already underfunded and often ill-equipped to meet the needs of CYP with SEND. There needs to be increased and sustained investment from the government across all sectors to meet the rights of CYP with SEND.
- Recognition that many professionals and organisations went 'over and above' and navigated round restrictions and challenging circumstances to care for and provide support to CYP with SEND and their families during the pandemic.
- Proper implementation of the existing SEND legal framework across the country to ensure the rights of CYP with SEND are upheld.
- Increased integrated working between all services and professionals who care for CYP with SEND alongside increased accountability and clear lines of responsibility to ensure children and young peoples' needs and rights are met.
- Accountability for services providing care and support to CYP with SEND in ensuring that their commissioned activity is inclusive.
- Equitable provision across all regions of the UK and an end to the postcode lottery of provision.
- Equitable provision to address social deprivation and inequalities faced by CYP with SEND.
- Meaningful inclusion of CYP with SEND and their parents/carers in service development and any decision-making.

Children's rights as identified in the UN Convention on the Rights of the Child (Cohen, 1989) which apply to all the priorities for policy and practice are as follows:

- Article 1 - Everyone under the age of 18 has all the rights in the Convention.

- Article 2 - The Convention applies to every child without discrimination, whatever their ethnicity, sex, religion, language, abilities or any other status, whatever they think or say, whatever their family background.
- Article 3 - The best interests of the child must be a top priority in all decisions and actions that affect children.
- Article 4 - State parties shall take all appropriate legislative, administrative, and other measures for the implementation of the rights recognised in the present Convention.
- Article 6 - Every child has the right to life. Governments must do all they can to ensure that children survive and develop to their full potential.
- Article 12 - Every child has the right to express their views, feelings and wishes in all matters affecting them, and to have their views considered and taken seriously.
- Article 23 - A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families.
- Article 39 (recovery from trauma and reintegration) Children who have experienced neglect, abuse, exploitation, torture or who are victims of war must receive special support to help them recover their health, dignity, self-respect and social life

Whilst these priorities for policy and practice have been framed by the rights of the child as recognised within the UNCRC (Cohen, 1989), those working with CYP with SEND need to also recognise children's rights as identified in the Equality Act 2010 and the Children and Families Act 2014. These priorities are based on key issues that parents, children, and professionals have directly highlighted as significant barriers to the effective provision of fundamental education, health, and social care. Thus, while these priorities may appear ambitious, they represent changes within the SEND provision that are needed in order to ensure children with SEND's rights and needs are met.

My Right to Play, Socialise, Have Fun, and be Part of my Community

Article 31 Every child has the right to relax, play and take part in a wide range of cultural and artistic activities.

Article 15 - Every child has the right to meet with other children and to join groups and organisations, as long as this does not stop other people from enjoying their rights.

Article 23 - A child with a disability has the right to live a full and decent life with dignity and, as far as possible, independence and to play an active part in the community. Governments must do all they can to support disabled children and their families.

Evidence from our study	Policy and practice priorities specific to pandemic management	Policy and practice priorities linked to recovery and renewal
• A lack of access to opportunities for children and young people to fulfil sensory (vestibular) needs for movement during the pandemic • A lack of accessible, adaptable and available specialist play services (disabled playgrounds were locked and specialist play providers closed) • A lack of access to accessible and adaptable opportunities to be active and join in activities • Lost friendships and social connections as a result of the pandemic, especially for children and young people with autistic spectrum condition (ASC) • A lack of access to reasonably adjusted opportunities to socialise, resulting in decreased social skills and increased isolation and loneliness • Fewer opportunities for social engagement leading to slower speech and language development.	• Children and young people with SEND should retain existing opportunities for play and physical activity, particularly where lack of it may compound and exacerbate existing SEND (e.g. the need for children with ADHD/ADD to move, sensory circuits for those with Sensory Processing Difficulties, or maintaining a routine for children with ASC). • Play and activity sessions during lockdown should be facilitated by credible and appropriately SEND trained professionals who can provide 1-2-1 support. • Outdoor playgrounds and sensory rooms should remain open for children and young people with SEND and there should be greater coordination between Local Authorities and Central Government regarding funding issues to ensure playgrounds are accessible, adaptable and available.	• Local Authorities should ensure statutory provision of SEND-accessible play and recreation services. • Local Authorities, Integrated Care Services, and Third Sector Organisations should design and deliver play and recreation activities in collaboration with children and young people with SEND and their families. • Any new centrally-funded recovery programmes and initiatives (e.g. holiday activities and food programmes) need to include activities that are accessible and adaptable to children and young people with SEND.

- A lack of opportunities to build important life skills and independence within the community that were tailored to children and young people's needs. - Some charitable services which are important for children and young people with SEND were at a real risk of closing down e.g. horse riding and sensory rooms	- Areas for play and recreation should be provided within schools that in previous lockdowns were closed (e.g hydrotherapy pools and sensory rooms should be maintained and kept open as essential for children and young people with SEND). - Government guidelines should allow children and young people with SEND to play in close pairs or social bubbles and engage in repeated mixing, and Local Authorities should facilitate activities outside. - Older children and young people with SEND should have independence and life skills built into their curriculum and this should remain accessible/ongoing if there are any further lockdowns. - Vocational skills (e.g. work experience) should continue where possible.	- Local Authorities need to provide SEND-specific play and recreation activities and groups, which are accessible, adaptable and available and designed to meet the needs of children and young people with all types of SEND. - Local Authorities and central Government should ensure non-SEND specific play and recreational activities are inclusive and accessible for children and young people with SEND. - Local Authorities and central Government should ensure that activities should be regular and ongoing (not long waiting lists, not limited to 6 sessions). - Local Authorities and central Government should ensure that activities are facilitated by credible staff who have been provided with SEND-specific training and who can provide 1-2-1 support. - Local Authorities need to work with schools to promote and deliver accessible and adaptable play and recreational activities. - As part of EHCP assessments/annual reviews, Local Authorities should specifically consider the need to make individual play and recreational social communication interventions available for children and young people with SEND.

My Right to Support for my Social and Emotional Wellbeing (SEW) and Mental Health

Article 6 - Every child has the right to life, survival and development. Governments must do all they can to ensure that children survive and develop to their full potential.
Article 24 - Every child has the right to the best possible health. Governments must provide good quality health care, clean water, nutritious food, and a clean environment and education on health and well-being so that children can stay healthy.

Evidence from our study	Policy and practice priorities specific to pandemic management	Policy and practice priorities linked to recovery and renewal
• Children and young people with SEND experienced deteriorating mental health and social-emotional wellbeing (SEW) over lockdown. • Children and young people with ASC struggled with a change to routine (anxiety, uncertainty, behaviours that challenge). • Children and young people with ADHD/ADD struggled with distress and demonstrated increased behaviours that challenge due to limitations to exercise and activity. • Education professionals reported seeing increased levels of self-harm in pupils with SEND. • Children and young people with SEND experienced worsening mental health and anxiety over leaving the house.	• Children with SEND should be offered the option of face-to-face in-person learning in school throughout any future lockdowns. • NHS England and Local Authorities should provide tailored information and interventions to provide public health information to children and young people with SEND (e.g. social stories to explain change and COVID-19 restrictions). • Children with SEND should always have their right to play and engage in leisure activities upheld in future lockdowns. • If there is another lockdown, there needs to be clear legislative guidance for Local Authorities, schools, and parents from the outset, provided in a timely manner, which explicitly considers children with SEND. This needs to be clearly communicated to children to decrease uncertainty and allow for preparation for new change (e.g. via social stories etc.).	• Health Education England should ensure that GPs and primary care services should receive training in appropriate services for diagnosis and support for children with SEND experiencing mental health difficulties. • Department for Education, Department of Health and Social Care and Health Education England should ensure Investment in training positions to increase the workforce within SEW and mental health, both in and outside of school (e.g. CYP Psychological Wellbeing Practitioner, Education Mental Health Practitioner). Training in these positions should include a SEND-specific component. • Local Authorities should ensure there is a comprehensive and up-to-date access point as part of the Local Offer about the statutory and voluntary services for SEW and mental health which are available for children with SEND. • In line with the NHS long-term plan, all children with SEND should be triaged and begin receiving support for mental health difficulties within 4 weeks of

● There were delays in children and young people with SEND accessing appropriate early interventions for their SEW and mental health. ● Mental health practitioners do not have adequate knowledge of SEND specific mental health needs (e.g. ASC). ● The delivery of SEW and mental health services were not tailored to meet the SEND specific needs of these children and young people. ● Government guidance was inconsistent and rapidly changing on how mental health service provision should be delivered. ● Mental health services for children and young people with SEND have longer waiting lists and are harder to access.	● On the return from any further restrictions which impact children with SEND, or any school closures/long term absences, there needs to be an individually tailored transition plan for children with SEND from being at home to going to school/clubs/being outside with other people, to ensure a smooth transition (this could include a revisiting of an EHCP for those children who have one). ● School staff should check in with parents/carers/children regularly (e.g. minimum once per week) to identify any developing SEW or mental health issues, and then offer appropriate support. ● SEW and mental health services should continue to offer the option of face-to-face appointments, with necessary Personal Protective Equipment (PPE), for those children and young people with SEND who struggle to communicate via video/telephone. ● Any Government or Local Authority responses to the pandemic, including future restrictions or lockdowns, need to consider evidence which demonstrates how lockdowns impact on the mental health of children with SEND, and ensure provision is put in place to mitigate these. This should be underpinned by a Children’s Rights Impact assessment (CRIA). ● Mental health services need to maintain the same, or increased, level of service for children with SEND if lockdown restrictions come back into force	referral, based on their individual specific needs. ● Department of Health and Social Care/The Health and Care Professionals Council should provide/require specific SEND training (both core training and post-qualification) for all mental health professionals working with children and young people (e.g. clinical psychologists, psychological wellbeing practitioners, school counsellors). ● Department for Education/Local Authorities should provide all professionals (school nurses, teachers, teaching assistants) who have contact with children and young people with SEND with specific SEND training. ● Department of Health and Social Care and Integrated Care Systems should ensure alternative, SEND-appropriate, therapeutic options are readily available and offered to children and young people with SEND (e.g. music therapy)

My right to flexibility, choice, and support so I can feel safe, belong, and learn in school

Article 28 (right to education) - Every child has the right to an education. Primary education must be free and different forms of secondary education must be available to every child. Discipline in schools must respect children’s dignity and their rights.
Article 29 (goals of education) - Education must develop every child’s personality, talents and abilities to the full. It must encourage the child’s respect for human rights, as well as respect for their parents, their own and other cultures, and the environment

Evidence from our study	Policy and practice priorities specific to pandemic management	Policy and practice priorities linked to recovery and renewal
● Not all children and young people with SEND (including some with EHCPs) were offered access to in person education. ● Not all EHCP assessments and reviews were conducted on time. ● Many children and young people with SEND’s needs according to their EHCP were not met over the pandemic. ● Government advice and guidance for education settings was unclear and delivered too late to operationalise safely. ● Education staff were re-deployed away from being able to deliver SEND support.	● Department for Education/Local Authorities should ensure all children with SEND (whether they have an EHCP or not) are offered the opportunity to attend in person education provision full time where possible. ● Where children with SEND must learn remotely, schools (with support from the Local Authority/Department for Education) should ensure online learning is inclusive and appropriately differentiated. ● Government guidance for COVID-related restrictions should include a specific focus on and prioritised delivery of education and learning for children with SEND. ● Local Authorities should ensure EHCP assessments and annual reviews continue to be completed within the statutory deadlines, with the option of face to face or online meetings offered to families.	● Department for Education should require all mainstream schools to embed inclusive teaching practises in the classroom (e.g. active listening, visual aids and auditory memory techniques explicitly taught and built into daily classroom life). ● Department for Education should allow schools the option of a flexible curriculum (e.g. subjects) and delivery (e.g. outdoor learning) that supports children with SEND (e.g. opportunities for blended learning online and in school), and they should provide schools with the resources and training to do this. ● Local Authorities should ensure EHCPs are specified and quantifiable as per the Children and Families Act 2014. ● Department for Education should provide schools with the opportunity to promote wider skills for children with SEND (e.g. life skills, transitions to

• Many education staff who provide SEND support have left their posts during the pandemic. • Children and young people with autistic spectrum condition (ASC) experienced anxiety and stress as a result of the uncertainty and lack of routine around education and learning. • There was a lack of support for children and young people with SEND to reintegrate back into school, and a lack of support for key educational transitions caused high levels of anxiety and disengagement from the learning environment. • Children and young people with SEND experienced lost learning and increased disengagement over the pandemic, resulting in a decreased ability to reach their academic potential. • Many parents struggled to support their child's additional learning needs during homeschooling. • There was reduced communication between parents and education providers and the Local Authority about their child's learning needs and wellbeing. • Families had a lack of access to appropriate learning equipment or technology to meet their child's needs. • Online learning systems used over the pandemic were not designed for and did not meet the additional learning needs of pupils with SEND.	• Schools (with support from the Local Authority/Department for Education) should ensure a child's educational provision detailed within their EHCP/Individual Education Plan/Early Help Assessment Tool is still delivered, even during periods of lockdown or pandemic restrictions. • Clear and timely guidance and information from the Government needs to be provided to Local Authorities and schools regarding shielding and restrictions, to allow enough time for professionals to plan appropriate support and access for children with SEND. • Department for Education, NHS England and Public Health England should provide children with SEND with clear and accessible tailored information on any updated COVID guidance to help reduce anxiety. • Schools (with support from the Local Authority/Department for Education) need to offer children and young people with SEND an individually tailored transition programme, co-produced with children and parents, to facilitate their return back to school after any lockdown/periods of time in home-schooling (e.g. virtual transition meetings, social communication sessions and social stories to support transitions). • Local Authorities should ensure children and young people with SEND moving educational institutions (e.g, starting school, year 6 pupils or year 11 pupils) are offered the opportunity to visit new schools/education providers prior to moving and continue with transition plans despite COVID restrictions. They should support schools to facilitate this.	adulthood, work experience). • Department for Education should increase the links for education staff between special schools and mainstream schools (e.g. school buddy system), to provide opportunities for shared learning, training, and the sharing of resources. • Department for Education should ensure all school staff receive SEND-specific training (both core training and post-qualification), to effectively support children and young people with SEND. • Ofsted criteria should incorporate the extent to which schools are inclusive and children with SEND feel psychologically and physically safe, supported, and included. • Department for Education should invest in recruitment, training, and retention of SEND-related education posts (e.g. Learning Support Assistants, SENCO's and SEND support staff), e.g. offering bursaries to enter the profession, increasing remuneration in recognition of the skills and challenges such positions may entail. • Local Authorities should ensure that schools nationally implement individual transitioning plans to support all children with SEND (not just those with EHCPs) who are moving schools, and enable a visit to a new school. • Department for Education should avoid pressure on academic 'catch-up'. The Government guidelines should include recommendations for supporting children with SEND during this time. • Schools should restore or establish means of day-to-day communication with parents/carers to pre-pandemic methods, to facilitate communication

- Some children and young people with SEND flourished with an increased flexibility to learning and children and families expressed a wish for this flexibility to be maintained.	- Department for Education should provide education staff with training on how to provide and adapt online learning for children with SEND, to help deliver effective education in future lockdowns or periods of time when children with SEND need to isolate. - Schools (with support from the Local Authority/Department for Education) should ensure the focus of any recovery curriculum is on mental health and wellbeing, in addition to making up for missed education components. - Schools (with support from the Local Authority/Department for Education) should limit the amount of new pandemic-related responsibility placed on staff, provide guidance on ensuring their safety in school, and offer effective wellbeing support.	and ensure that a child's daily needs are known by educational professionals. - Department for Education should offer flexibility for compulsory assessments (e.g. GCSEs) for children and young people with SEND to be assessed in a way that best suits their needs (e.g. exams or coursework).

My Right to Health and Social Care Services and Therapies in Order for me to Stay Healthy

Article 24 - Every child has the right to the best possible health. Governments must provide good quality health care, clean water, nutritious food, and a clean environment and education on health and well-being so that children can stay healthy.

Evidence from our study	Policy and practice priorities specific to pandemic management	Policy and practice priorities linked to recovery and renewal
● Skilled SEND staff in health and social care left posts after redeployment and work pressures (burnout and fatigue). ● Waiting lists and referrals for access to health care services and therapies increased for children and young people with SEND. ● There was a lack of access to NHS services or therapies for children and young people with SEND during the pandemic - many services 'just stopped'. ● Access to NHS services or therapies was only available by video or phone which was not suitable to many children and young peoples' needs. ● Some phone and/or online appointments and multi-disciplinary team meetings have helped parents and children access some health and social care services. ● A lack of access to equipment for therapies was experienced by many children and young people	● Integrated Care Services for health and social care should ensure uninterrupted regular and ongoing access to therapies (especially in school) for children and young people with SEND, even during lockdowns and restrictions. ● NHS England should ensure families are offered face-to-face access to therapies and health services for children and young people with SEND. ● Local Authorities should ensure sensory circuits/movement plans put in place by Occupational Therapists are maintained in school settings and where not possible, shared with parents/carers for a child to do at home. ● Clear and timely guidance and information from the government is needed regarding shielding and restrictions, to enable professionals adequate time to plan appropriate support and access to children with SEND.	● Investment and resources (workforce, funding, equipment, facilities) are needed from Department of Health and Social Care/NHS England to reduce waiting lists for therapies/treatment and health assessments. This would be evidenced by quarterly updates. ● Local Authorities should ensure that EHCP assessments and annual reviews are completed within the statutory deadlines, with families being offered face-to-face or online meeting options. ● NHS England/Integrated Care Services should provide options for face-to-face or online therapies and assessments based on families' preferences. ● NHS England/Integrated Care Services should streamline the administration process for accessing health and social care services and therapies, reducing the volume and length of forms and phone calls needed.

with SEND (delays to access and difficulty installing equipment at home). • Children and young peoples' speech and language development deteriorated over lockdown. • Many children and young people with SEND have physically deconditioned. • The increased use of online platforms has led to the increased ability of multi-disciplinary team members to meet and integrate working practises. • There was a reported increase in safeguarding concerns for children and young people with SEND.	• Local Authorities should ensure that EHCP assessments and annual reviews are completed within the statutory deadlines with families being offered face-to-face or online meeting options, regardless of COVID restrictions or future lockdown. • Integrated Care Services should provide tailored physical activities for children with SEND to improve and maintain their physical health, regardless of future COVID restrictions or lockdowns (e.g. hydrotherapy, occupational therapy). • Where there are safeguarding concerns, Local Authorities should ensure health and social care professionals can always see children considered to be at risk face-to-face throughout lockdowns with suitable PPE.	• Department of Health and Social Care (Health Education England) should ensure all professionals working in health and social care are trained (both core training and post-qualification) in and are knowledgeable on SEND-specific conditions and the physical and mental health implications of these. • NHS England/Integrated Care Services should ensure that first assessment occurs within 3 months and the pathway for ASC and ADHD/ADD to diagnosis should be no longer than 12 months.

My Right to Support for my Parents/Carers and my Family

- Article 18 - Both parents share responsibility for bringing up their child and should always consider what is best for the child. Governments must support parents by creating support services for children and giving parents the help they need to raise their children.
- Article 27 - Every child has the right to a standard of living that is good enough to meet their physical and social needs and support their development. Governments must help families who cannot afford to provide this
- Article 42 (knowledge of rights) Governments must actively work to make sure children and adults know about the Convention.

Evidence from our study	Policy and practice priorities specific to pandemic management	Policy and practice priorities linked to recovery and renewal
● Increased poverty and deprivation over the pandemic has disproportionately impacted families of children and young people with SEND. ● Increased isolation of families, and families being 'left to get on with it'. ● Deteriorating mental health and general wellbeing of parents of children and young people with SEND over the pandemic. ● Increased parental stress and burnout due to no access to carers, short breaks, or respite. ● The increased use of online platforms has led to the increased ability of multi-disciplinary team members to meet and integrate working practises. ● There was a reported increase in safeguarding concerns for children and young people with SEND.	● All children and young people with SEND (not just those with EHCPs) need to be offered a place in school to enable working parents to continue working, should there be further lockdown restrictions. ● Government restrictions should always allow any 1-to-1 carers to attend to children and young people with SEND in their home and in school, with appropriate PPE. ● Schools should ensure that children and young people with SEND in receipt of free school meals have money vouchers sent home if further lockdown measures mean they are not in school.	● Local Authorities should increase the provision of parent support groups and schools should provide opportunities for parents to connect (this may be particularly important for parents of children in specialist provision). ● Department of Health and Social Care should increase resources and enhance support for statutory, charitable and centrally-funded organisations to provide support and advocacy services for parents/carers and siblings of children with SEND. ● Local Authorities and schools should acknowledge parent/carers' expertise and include them meaningfully in meetings, EHCP assessments and Annual Review meetings. ● Local Authorities should update the Local Offer to include clear and accessible information for parents about their child's legal entitlements. ● Local Authorities should update the Local Offer to

• Parents found access to SEND provision over lockdown reduced and difficult to navigate.	• Department for Education should ensure necessary ring-fenced funding is put in place for schools to be able to provide equipment needed for children and young people with SEND to facilitate their ability to study remotely. This should go beyond the provision of laptops/tablets (e.g. ear defenders, weighted items, fidget items, theraputty, adaptive pens, seating adaptations, overlays etc.). • Government guidance should ensure that respite and short break provision for children and young people with SEND can be maintained in any future lockdowns. • Local Authorities should update the Local Offer to include information about changes to service access and provision during lockdowns and restrictions. • Local Authorities should inform parents/carers of children and young people with an EHCP of any change in laws/regulations/restrictions and explain specifically how it will impact the provision offered to their child, and what support remains available to them during any restrictions. They should also facilitate navigation of SEND support and provision available.	include clear and accessible information for parents about available services for their child with SEND. • Integrated Care Services should streamline the processes for applying to Disability Living Allowance, schools and other services, so the same forms do not need to be completed multiple times. • Department of Health and Social Care should provide parents/carers with access to training from statutory, charitable, and centrally-funded organisations to improve their SEND health literacy and knowledge of children’s rights.

Public and Patient Involvement (PPI)

3 parent advisors provided guidance throughout the study. The parents all had children with SEND and helped guide the initial project design and research objectives, the recruitment methods, and materials used for Phase 2 and Phase 3. The parent advisors also helped draft and review the lay summaries of the study and advised on the language and format used in all the materials. The parent advisors provided feedback and guidance via phone calls, face-to-face meetings, video calls, and emails, as this allowed flexibility of engagement alongside other commitments. Written materials were provided to parents before planned meetings/feedback. The guidance from parents ensured that the recruitment materials for Phase 2 were appealing, avoided jargon, and highlighted the key parts of participation – we believe this helped recruitment at a time when families were managing high levels of stress. The parent advisors also provided key links to organisations supporting families with SEND, which helped the reach of the survey and the dissemination of materials.

We used a flexible approach to consult with CYP. An initial meeting with young people who were part of an established forum helped to endorse the planned approach and focus of the research, whilst challenging the team to create engaging surveys for children. We were limited in our initial consultation activities with children as at the time England was still following strict social distancing rules and our access to in-person youth forums was restricted. The questions within the survey and information sheets were reviewed by two young people with SEND and amendments were made to sections of text and the language used.

We held a face-to-face meeting with 8 CYP with SEND at a local youth centre. This was very valuable and shaped the priority setting workshops, by ensuring our methods were flexible and creative to meet a range of needs and preferences for participation, as well as facilitating children to move around within a space whilst participating. The methods had to be simple and not require lengthy explanations from the research team and we had to go ‘where children were already’ and not be an ‘extra thing to go to’.

The PPI consultation within the steering group, with parent advisors and with CYP was invaluable to guiding the process; we learnt to work flexibly throughout the course of the study to ensure engagement was according to the preferences of those involved.

Equality and Diversity

Our research study focused on the experiences of CYP with SEND. All CYP aged 5-15 with any type of SEND were invited to participate. CYP with SEND, particularly those of younger ages, with complex needs or who are attending special schools, are often ‘seldom heard’ and under-represented in research, as are participants from minority ethnic groups and lower socio-economic groups. The team worked hard to ensure that CYP with a broad range of needs and ages could participate in the study. We developed data collection techniques in collaboration with our CYP PPI group to ensure they were accessible and engaging. We offered a range of response formats for the surveys (e.g., selecting emojis, drawing pictures) and developed activity booklets for CYP for the interviews. We also used creative methods for the CYP workshops, offering participants a range of activities to share their experiences (e.g., writing postcards, drawing pictures). We also acknowledged that many additional needs can be generational and so any materials for parents were written in simple language.

In terms of other 'seldom heard' communities who are under-represented in research, we were supported by members of our steering group (active citizens and community workers - Dianne Garrison, Saba Ahmed, Rahima Farah) to ensure we recruited parents/carers and CYP from Black and Ethnic Minority (BAME) backgrounds. We also worked with regional charities and support groups to recruit parents/carers who did not speak English as a first language.

The work to reach lesser heard participants resulted in 35% of CYP participants attending special schools or alternative provision, and 67% having an EHCP. 59% were of primary school age, and there was a roughly even gender balance. Approximately 10% of parents/carers were unemployed, and 10% identified as belonging to a minority ethnic group (which is in line with the national average for the UK).

Finally, in Phase 3, we chose to frame the policy priorities using a rights-based, child-centred approach. Through this, we aimed to foreground the needs and rights of CYP with SEND as opposed to relying on the proxy reports of CYP's experiences.

Outputs

Published Reports

- Ashworth E., Kirkby, J., Bray, L. & Alghrani, A. (2022). The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND): The Ask, Listen, Act Plain Language Summary.
  https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/ask-listen-act-study-summary-for-parents.pdf?la=en
- Ashworth E., Kirkby, J., Bray, L. & Alghrani, A. (2022). The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND): The Ask, Listen, Act Study Executive Summary.
  https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/ask-listen-act-study-summary-final.pdf?la=en
  Ashworth E., Kirkby, J., Bray, L. & Alghrani, A. (2022). Ask, Listen, Act - Working together to get through it together; a child-centred rights-based approach to recovery and renewal for children and young people with Special Education Needs and Disabilities (SEND) linked to the COVID-19 pandemic. *Priorities for Policy and Practice for Children and Young People with SEND.*
  https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/priorities.pdf?la=en

- Ashworth E., Kirkby, J., Bray, L. & Alghrani, A. (2022). The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND): The Ask, Listen, Act Study. *Evidence briefing 8: Children with SEND, parent/carers and professionals priority development stakeholder workshops.* https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/workshop-evidence-briefing-and-priorities-final-(1).pdf?la=en
  Ashworth E., Kirkby, J., Bray, L. & Alghrani, A. (2022). The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND): The Ask, Listen, Act Study. *Evidence briefing 3: Education professionals' perceptions of the impact of the COVID-19 pandemic on children with SEND. Qualitative survey data.* https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/education-open-text--qualitative-evidence-briefing.pdf?la=en
  Ashworth E., Kirkby, J., Bray, L. & Alghrani, A. (2021). The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND): The Ask, Listen, Act Study. *Evidence briefing 2: Children with SEND, parent/carers and professionals' perceptions of impact. Qualitative interview data.* https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/qualitative-evidence-briefing.pdf?la=en
  Ashworth E., Kirkby, J., Bray, L. & Alghrani, A. (2021). The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND): The Ask, Listen, Act Study. *Evidence briefing 1: Children with SEND, parent/carers and professionals' perceptions of impact. Quantitative survey data.* https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/quantitative-evidence-briefing.pdf?la=en
    Short summary for parents/carers: https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/a-short-summary-of-the-quantitative-findings-for-parents.pdf?la=en.
    Short summary for children: https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/a-short-summary-of-the-quantitative-findings-for-children.pdf?la=en
- Kirkby, J., Ashworth E., Bray, L. & Alghrani, A. (2021). A Rapid Scoping Review - The Impact of the COVID-19 Pandemic on the Education, Health and Social Care Provision for Children with Special Educational Needs and Disabilities (SEND). https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/literature-review-cyp-send-covid-final.pdf?la=en

In Press/Planned Publications

- Evidence briefing 4: Health and social care professionals' perceptions of the impact of the COVID-19 pandemic on children with SEND. Qualitative survey data. (in preparation)

- Evidence briefing 5: Local Authority professionals' perceptions of the impact of the COVID-19 pandemic on children with SEND. Qualitative survey data. (in preparation)
- Evidence briefing 6: Parents and carers perceptions of the impact of the COVID-19 pandemic on children with SEND. Qualitative survey data. (planned)
- Evidence briefing 7: Children's perceptions of the impact of the COVID-19 pandemic on children with SEND. Qualitative survey data. (planned)
- Journal article - Legal paper - The impact of the The Coronavirus Act 2020 on children and young people with SEND (in preparation)
- Journal article - Ask Listen Act: Using creative methodologies to co-develop priorities for policy and practice for supporting children with SEND after the COVID-19 pandemic (planned)
- Journal article - The impact of the COVID-19 pandemic and restrictions on children's with SEND's education: Perspectives from parents, children, and education professionals (planned)
- Journal article - The impact of the COVID-19 pandemic and restrictions on children's with SEND's health, social care, and wellbeing: Perspectives from parents, children, and health and social care professionals (planned)

Press Releases/Media Coverage

- Vertigo Ventures: Track Impact 2022 Project Competition Winners' Showcase (22/09/2022). International People's Choice for Most Engaging Project. https://www.vertigoventures.com/resources/trackimpact-project-competition-winners-showcase/
- Liverpool Health Partners, press release (25/01/2022). Ask Listen Act - How Did COVID Lockdowns Impact Children and Young People With SEND? https://liverpoolhealthpartners.org.uk/ask-listen-act-how-did-covid-lockdowns-affect-children-and-young-people-with-send/
- The i Newspaper (29/01/2022). Children with special educational needs adversely affected by lockdown: 'I couldn't use Zoom like others'. https://inews.co.uk/news/children-send-special-education-needs-disability-covid-lockdowns-1431218
- Liverpool Echo Newspaper (31/01/2022). Children with special needs and disabilities 'isolated' due to covid and lockdowns. https://www.liverpoolecho.co.uk/news/liverpool-news/children-special-needs-disabilities-isolated-22926048
- The Financial Newspaper (04/02/2022). Children and young people with special educational needs and disabilities adversely affected by COVID-19 lockdowns. https://finchannel.com/children-and-young-people-with-special-educational-needs-and-disabilities-adversely-affected-by-covid-19-lockdowns/
- BBC Radio Merseyside 'Drive Time' invited guests (02/2022)

Other

- Ask, Listen, Act Webinar - working together to inform the provision of Special Educational Needs and Disability (SEND) support for children after the COVID-19 pandemic.
  PowerPoint slides:
  https://www.ljmu.ac.uk/~/media/files/ljmu/research/centres-and-institutes/rcbb/study-launch-event.pdf?la=en
  Webinar recording:
  https://www.dropbox.com/s/d5y0sfelwd63quu/SEND%20Recording%20v2.mp4?dl=0

Policy Relevance

Evidence from our research highlights the adverse impact COVID-19 and associated restrictions have had on CYP with SEND, and that they need to be explicitly considered in any future legislative changes or restrictions linked to pandemic management. One of the earliest legislative changes enacted under the Coronavirus Act 2020 was to reduce the legal duty contained in section 42 of the Children and Families Act 2014, which places an 'absolute duty' on Local Authorities to meet the needs of CYP with SEND with EHCPs, to one of a 'reasonable endeavours' duty. However, this was enacted without the benefit of either a children's rights impact assessment (CRIA) or an equality rights impact assessment (ERIA).

A key aim of this study was to co-develop focused and actionable priorities for policy and practice, which would support central Government in ensuring CYP with SEND's needs and rights continue to be met, both in the event of a future lockdown and moving forward out of current restrictions. These priorities were informed by a rights-based approach to child-centred recovery and renewal and fell under five themes, outlined below:

1. My right to play, socialise, have fun and be part of my community.
2. My right to support for my social, emotional well-being and mental health.
3. My right to flexibility, choice and support so I can feel safe, belong and learn in school.
4. My right to health and social care services and therapies in order for me to stay healthy.
5. My right to support for my parents/carers and my family.

These themes align with the remit of several Government departments, including the Department for Education (DfE) and Department of Health and Social Care (DHSC), whilst recognising the need and development of co-ordinated and integrated care services (ICS). It is hoped that alignment in this way helps to make the priorities actionable by these relevant departments as well as other key organisations (e.g., charities) with responsibility for children with SEND.

The priorities are outlined in full in the results section above. However, to summarise, our priorities indicated that CYP with SEND need to be explicitly considered in any future legislative changes or restrictions linked to pandemic management, and any changes should be underpinned by a CRIA. To prevent against any further impact as a result of the COVID-19 pandemic, central Government, in conjunction with Local Authorities, should engage in a review to ensure sufficient staffing, resources (financial, human, technical, informational, and otherwise), and facilities are available to meet the needs of CYP with SEND.

The findings of the study have particular relevance in the current policy context given the recent release of the SEND review. The SEND Review is a cross Government Review launched in 2019 and was originally intended to evaluate implementation of the Children and Families Act 2014. The Children and Families Minister, Will Quince MP, indicated that the DfE would publish the SEND Review in the first quarter of 2022, together with new policy and implementation proposals set out in a Green Paper. We shared our recommendations with the SEND Review and SEND sector of the DfE so that our findings and recommendations could feed into this review. Our findings were indeed cited in the COVID-related discussions of the SEND Review Green Paper, and we have submitted a written response to the public consultation of the review, based on our study's findings.

Amongst the recommendations we have made are that moving forwards, health and social care services for CYP with SEND (e.g., CAMHS, physiotherapy, respite, social services) should be readily available without long waiting lists, continue uninterrupted, and should be tailored to CYP's individual needs (e.g., online or face-to-face, alternative therapies offered). Flexibility should be offered in school (in both curriculum and delivery), and all professionals working with CYP should have a SEND-specific component to their training. In the event of another lockdown, CYP with SEND need to be offered a place in school, any additional support should continue, and work should be appropriately differentiated. Clear and timely guidance on restrictions should be provided to any services/organisations who support CYP with SEND; information should also be communicated with parents/carers (to outline how their child's provision will be affected) and CYP with SEND in an appropriate format (e.g., social stories).

While some of these priorities are specific to recovery and renewal from COVID-19, there are also some that are relevant more widely outside of the pandemic. For instance, findings suggested that professionals working with CYP with SEND (e.g., clinical psychologists, GPs, teachers), were not always appropriately trained and did not have a good understanding of how to meet these children's needs. This meant that education, health, and social care services and therapies that were offered were not always inclusive of CYP with SEND, rendering them ineffective or unsuitable. Waiting lists were long, meaning CYP were not getting the support they needed, and the support that was available was not equitable across different regions of the UK. Thus, moving forward in policy and practice, there needs to be:

- Recognition that many aspects of the SEND system were already underfunded and often ill-equipped to meet the needs of CYP with SEND.
- Increased and sustained investment from the Government across all sectors to meet the rights of CYP with SEND.
- Proper implementation of the existing SEND legal framework across the country to ensure the rights of children with SEND are upheld.
- Increased integrated working between all services and professionals who care for CYP with SEND alongside increased accountability and clear lines of responsibility.

- Accountability for services providing care and support to CYP with SEND in ensuring that their commissioned activity is inclusive (and relevant training provided for this).
- Equitable provision across all regions of the UK and an end to the postcode lottery of provision.
- Equitable provision to address social deprivation and inequalities faced by CYP with SEND.
- Meaningful inclusion of children and young people with SEND and their parents/carers in service development and any decision-making.

Dissemination

Given the time-sensitive nature of the project, we published a series of publicly-available evidence briefings and plain language summaries (see 'outputs' section above) at key milestones, to enhance dissemination and ensure the rapid provision of evidence to key stakeholders. These were shared on the study webpage and dedicated Twitter handle (@AskListenAct; 539 followers to date; first evidence briefing reached over 22,000 users), and were disseminated via networks/organisations, parent/family support groups, and steering group members; plain language summaries were also directly shared with participants who had taken part in interviews and workshops.

Our study findings were picked up by major news outlets (e.g., the i newspaper, BBC Radio Merseyside) and other key organisations in the field (e.g. Special Needs Jungle [34k followers], British Academy of Childhood Disability). To ensure maximum potential for impact, we have shared our evidence briefings with relevant ministers, the Association for Directors of Children's Services, the APPG for SEND, and the steering group for the Government's SEND review (consisting of the development of a SEND Green Paper to improve outcomes for CYP with SEND and their families). We have also been awarded further internal policy support funding to ensure we can continue developing and delivering bespoke evidence briefing to relevant ministers, APPGs, and Select Committees.

We held a free webinar in January 2022 that was open to the public, where we 'launched' the project findings. Keynote speakers included Olivia Blake MP (Chair of the APPG for SEND), Prof Brian Lamb OBE (Chair of the Inquiry into Parental Confidence in SEND), and Juliette Cammaerts (Director of Policy, Planning and Delivery; Children's Commissioner's Office). 136 members of the public, and staff from NHS England and the DHSC, registered to attend via Eventbrite. We have since presented our key findings in invited seminars to the Council for Disabled Children, Department for Education SEND group, University of Oxford, University College Dublin's COVISION series, CYP Now's SEND summit, Liverpool ICS, and Liverpool's Child Friendly City event.

Once all evidence briefings are published, we plan to produce journal articles relating to each of the project's themes (education, health and social care, policy, law), along with one overall paper discussing the co-development of policy priorities. We will submit manuscripts to high impact Gold Open Access journals (e.g. Journal of Special Education, Plos-One), to ensure they are accessible to all. We will also present our work at a national conference (e.g., Royal College of Paediatrics and Child Health; British Psychological Society).

Impact

The findings and priorities have had wide reach and engagement, and have been cited in the COVID-related discussions in the ‘SEND Review: Right Support, Right Place, Right Time’ SEND and Alternative Provision Green Paper (DfE, 2022). We have also provided a written response to the public consultation for this, based on our study’s findings. Whilst most impact is currently still anticipated at this stage, we are confident this will translate into real impact. Impacts may include changes in policy (in several Government departments, e.g., DfE, DHSC) and practice, such as the implementation of new, or improvement of existing, services nationally, funding for staff training, and adjustments to support options. As almost 16% of CYP in the UK have SEND, any policy changes have the potential to impact a significant proportion of the population, improving access to effective services, and enhancing social, emotional, and physical wellbeing. The project team won Vertigo Ventures’ International People’s Choice Award for Most Engaging Impact Project and Liverpool John Moores’ University Faculty of Health award for Excellence in Response to the COVID-19 Pandemic.

Intellectual Property (IP) and Commercial Adoption

Aside from published evidence briefings and future journal articles, we do not anticipate any intellectual property or commercial adoption resulting from this study.

Added Value Examples

Please see the case study on the following page.

Example of Added Value/Impact

1. CONTACT DETAILS

Project title: National Institute for Health Research Policy Research Programme Project: A Rapid cross-sectional mixed methods study to scope, understand and co-develop the policy priorities for reducing inequalities and mitigating the long-term impacts of COVID-19 for children and young people with SEND

NIHR PRP reference number: NIHR202718

Lead Investigator: Dr Emma Ashworth

Institution: Liverpool John Moores University

Contact details of the author

Name: Dr Emma Ashworth

Role: Principal Investigator

Email: E.L.Ashworth@ljmu.ac.uk

Tel: 0151 904 1052

2. TITLE OF THE ADDED VALUE EXAMPLE

Co-developed priorities for policy and practice; influencing the provision of services and support for children with SEND.

3. DESCRIPTION OF THE ADDED VALUE EXAMPLE

The findings of the study indicate changes are required to the access and provision of services for children and young people (CYP) with special education needs and disabilities (SEND). These link specifically to COVID-19 pandemic management and the holistic provision of services and support within the wider SEND system. The aim of the study was to co-develop priorities for policy and practice, and these align to key Government departments for actioning and delivering impact as well as being highly relevant to the remit of the awaited SEND review. The key findings and priorities have been shared and presented directly with key leaders within each department, and the SEND review steering group, to ensure this work impacts directly on any policy decisions. The team have received positive feedback and engagement from the leads within these departments and key organisations, and we will continue to engage through the creation of bespoke policy briefings with actionable and clear priorities for each APPG, Select Committee and Government department.

We hope the study findings and priorities will contribute directly to policy in health and social care, as well as education and the wider engagement of children with SEND in society. The findings highlight many gaps in current provision and clear areas for improvement and investment. Our study highlighted that many professionals are working above and beyond to try and provide care and support for CYP with SEND without the proper resources and training, and we hope the priorities will provide evidence for improvements for professional practitioners. The co-developed priorities, if implemented, have potential to improve the experiences and outcomes of children with SEND by addressing and reducing mental ill-health, improving physical health, building skills for life, and overall wellbeing. Many of the key priorities link to the need for increased early intervention and engagement, to prevent costly and harmful crisis situations arising.

The strength of the study which led to the development of robust priorities was the multiple perspectives that were part of the process. Too often children with SEND are excluded, marginalised, or engaged tokenistically in policy-related work. The team positioned children as experts on their lives and their voice, and their contribution was foregrounded throughout the study. This approach has been praised at a national level and we believe that the child-centred approach will ensure that the findings and priorities will have higher impact.

4. STAGE OF MATURITY AND NEXT STEPS REQUIRED TO ACHIEVE FULL IMPACT

The findings and developed priorities from the study have had a wide reach and high levels of engagement from across the sector and so whilst much of the impact is at this point anticipated, we are confident that this will translate into actual real impact for CYP with SEND. The findings from our study provide priorities which we anticipate will impact practice, policy, and funding in several Government departments, including DfE and DHSC, as well as NHS England. Impacts may include changes in education, health and social care services nationally, such as the implementation of new, or improvement of existing services, the provision of funding for staff training and adjustments to the support options offered to CYP with SEND and their families. Our priorities also aim to be of value to charities and organisations who support children with SEND and their families, influencing how they prioritise and campaign for the provision of services and how they will offer support.

Findings have been submitted to the steering group of the Government's ongoing SEND review, who will produce a new SEND green paper; the outcome of this review is likely to influence changes in legislation regarding the service provision for CYP with SEND. Findings have also been shared with the Chair of the APPG for SEND, who attended and presented at our webinar and are active in lobbying politicians and have the potential to enact change in policy, funding, and practice.

The team have gained additional institutional funding to help develop bespoke policy briefings to target key Government departments and policy leaders to ensure the findings of the study feed directly into policy decisions.

Aside from policy and practice, our findings contribute to understanding and knowledge around the impact of the pandemic on children with SEND, and provide new accessible evidence. For instance, we are now on the steering group of another NIHR-funded study examining the impact of the pandemic on children with SEND, ensuring work is not unnecessarily duplicated, and providing guidance on data collection and dissemination.

5. CONTRIBUTION OF THE NATIONAL INSTITUTE OF HEALTH RESEARCH POLICY RESEARCH PROGRAMME (NIHR PRP), DEPARTMENT OF HEALTH AND SOCIAL CARE (DHSC) AND OTHER STAKEHOLDERS

We received support from the NIHR PRP and DHSC stakeholders at the beginning of the study. They provided advice and guidance on the types and format of questions included in the parent/carer and professionals' surveys.

References

Alghrani, A., & Byrne, S. (2020). *The impact of COVID-19 on education and children's services.* https://committees.parliament.uk/writtenevidence/5816/pdf/

ALLFIE (2021). *Our voice: A covid-19 national participation project to amplify disabled young peoples voices, and address erasure of their educational experiences.* https://www.allfie.org.uk/wp-content/uploads/2021/07/Our-Voice-v5-25-June-21.pdf

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology*, *8*, 19-32. https://doi.org/10.1186/1471-2288-13-48

Asbury, K., Fox, L., Deniz, E., Code, A., & Toseeb, U. (2021). How is COVID-19 affecting the mental health of children with special educational needs and disabilities and their families? *Journal of Autism and Developmental Disorders*, 51, 1772–1780. https://doi.org/10.1007/s10803-020-04577-2

Boesley, L., & Crane, L. (2018). 'Forget the Health and Care and just call them Education Plans': SENCO s' perspectives on Education, Health and Care plans. *Journal of Research in Special Educational Needs*, *18*, 36-47. https://doi.org/10.1111/1471-3802.12416

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, *3*(2), 77-101.

Byrne, S. (2020). *The impact of COVID-19 on children with special educational needs and disabilities.* https://www.liverpool.ac.uk/media/livacuk/law/2-research/ecru/Briefing,Paper,2,-,The,Impact,of,COVID-19,on,Children,with,SEND,-,Seamus,Byrne.pdf

Canning, N., & Robinson, B. (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

Children's Commissioner (2020). *Childhood in the time of Covid.* https://www.childrenscommissioner.gov.uk/wp-content/uploads/2020/09/cco-childhood-in-the-time-of-covid.pdf

Cohen, C. P. (1989). United Nations: Convention on the rights of the child. *International Legal Materials*, *28*(6), 1448-1476. https://doi.org/10.1017/S0020782900017228

Couglan, S. (2020). *Coronavirus: Parents of disabled children 'cut off and ignored'.* [Press release]. http://www.bbc.co.uk/news/educa tion-52806105

Council for Disabled Children (2021). *Lessons learnt from lockdown: The highs and lows of the pandemic's impact on disabled children and young people: Children and young people's summary.*

https://councilfordisabledchildren.org.uk/sites/default/files/uploads/attachments/Lessons%20Learnt%20From%20Lockdown_Children%20and%20Young%20People%27s%20Summary.pdf

CQC & Ofsted (2021). *SEND: old issues, new issues, next steps.* https://www.gov.uk/government/publications/send-old-issues-new-issues-next-steps/send-old-issues-new-issues-next-steps?s=09

Creswell, J. W., Plano Clark, V. L., Gutmann, M. L., & Hanson, W. E. (2003). Advanced mixed methods research designs. *Handbook of mixed methods in social and behavioral research*, *209*(240), 209-240.

Department for Education (2022). SEND Review: Right support, right place, right time. Government consultation on the SEND and alternative provision system in England. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1063620/SEND_review_right_support_right_place_right_time_accessible.pdf

Disabled Children's Partnership (2021a). *The longest lockdown: The experiences of disabled children and their families during lockdown 3.* https://disabledchildrenspartnership.org.uk/wp-content/uploads/2021/03/The-Longest-Lockdown.pdf

Disabled Children's Partnership (2021b). *The loneliest lockdown: The Impact of the Pandemic on the Families of Disabled Children, their Parents and Siblings.* https://disabledchildrenspartnership.org.uk/wp-content/uploads/2021/03/The-Loneliest-Lockdown.pdf

Disabled Children's Partnership (2021c). *Left Behind: The Impact of the Pandemic on Disabled Children, their Parents and Siblings*. https://disabledchildrenspartnership.org.uk/wp-content/uploads/2021/07/Left-Behind.pdf

Family Fund (2021). *The impact of Coronavirus: A year in the life of families raising disabled and seriously ill children and young people.* https://www.familyfund.org.uk/Handlers/Download.ashx?IDMF=c7e2f959-c183-49e8-bef8-1a7ae8e12e6e

Fontanesi, L., Marchetti, D., Mazza, C., Di Giandomenico, S., Roma, P., & Verrocchio, M. C. (2020). The effect of the COVID-19 lockdown on parents: A call to adopt urgent measures. *Psychological Trauma: Theory, Research, Practice, and Policy*, *12*(S1), S79. https://doi.org/10.1037/tra0000672

Greenway, C., & Eaton-Thomas, K. (2020). Parent experiences of homeschooling 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

Hamel, C., Michaud, A., Thuku, M., Skidmore, B., Stevens, A., Nussbaumer-Streit, B., & Garritty, C. (2021). Defining rapid reviews: a systematic scoping review and thematic analysis of definitions and defining characteristics of rapid reviews. *Journal of Clinical Epidemiology*, *129*, 74-85. https://doi.org/10.1016/j.jclinepi.2020.09.041

Harris, N., & Davidge, G. (2019). The rights of children and young people under special educational needs legislation in England: an inclusive agenda?. *International journal of inclusive education*, *23*(5), 491-506. https://doi.org/10.1080/13603116.2019.1580923

House of Commons Education Committee (2020). *Special educational needs and disabilities: Government response to the committee's first report of session 2019.* https://committees.parliament.uk/publications/2067/documents/19714/default/

Hunter, S. V. (2010). Analysing and representing narrative data: The long and winding road. *Current narratives*, *1*(2), 44-54. https://ro.uow.edu.au/currentnarratives/vol1/iss2/5

Ivankova, N. V., Creswell, J. W., & Stick, S. L. (2006). Using mixed-methods sequential explanatory design: From theory to practice. *Field methods*, *18*(1), 3-20. https://doi.org/10.1177/1525822X05282260

Joanna Briggs Institute (2015). *The Joanna Briggs Institute Reviewers' Manual 2015 Methodology for JBI Scoping Reviews.* https://nursing.lsuhsc.edu/JBI/docs/ReviewersManuals/Scoping-.pdf

Kamineni, V. V., Turk, T., Wilson, N., Satyanarayana, S., & Chauhan, L. S. (2011). A rapid assessment and response approach to review and enhance advocacy, communication and social mobilisation for tuberculosis control in Odisha state, India. *BMC Public Health*, *11*, 1-13. https://doi.org/10.1186/1471-2458-11-463

Manderson, L., & Aaby, P. (1992). An epidemic in the field? Rapid assessment procedures and health research. *Social science & medicine*, *35*, 839-850. https://doi.org/10.1016/0277-9536(92)90098-B

Marchetti, D., Fontanesi, L., Di Giandomenico, S., Mazza, C., Roma, P., & Verrocchio, M. C. (2020). The effect of parent psychological distress on child hyperactivity/inattention during the COVID-19 lockdown: testing the mediation of parent verbal hostility and child emotional symptoms. *Frontiers in psychology*, 11, 3417. https://doi.org/10.3389/fpsyg.2020.567052

Murphy, A., Chikovani, I., Uchaneishvili, M., Makhashvili, N. and Roberts, B., 2018. Barriers to mental health care utilization among internally displaced persons in the republic of Georgia: a rapid appraisal study. *BMC health services research*, *18*(1), pp.1-11. https://doi.org/10.1186/s12913-018-3113-y

National Autistic Society (2020). *Left stranded: The impact of coronavirus on autistic people and their families in the UK.* https://s4.chorus-mk.thirdlight.com/file/1573224908/63117952292/width=-1/height=-1/format=-1/fit=scale/t=444295/e=never/k=da5c189a/LeftStranded%20Report.pdf

Neece, C., McIntyre, L. L., & Fenning, R. (2020). Examining the impact of COVID-19 in ethnically diverse families with young children with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 64, 739– 749. https://doi.org/10.1111/jir.12769.

Nusser, L. (2021). Learning at home during COVID-19 school closures – How do German students with and without special educational needs manage? *European Journal of Special Needs Education,* 36(1), 51-64. https://doi.org/10.1080/08856257.2021.1872845

O'Brien, N., & Dadswell, A (2021). *Young people with disabilities' experiences during the Covid-19 pandemic: Full report*. http://flipbooks.gs-cdn.co.uk/aru-b/final-report/

Petretto, D., Masala, I., & Masala, C. (2020). Special educational needs, distance learning, inclusion and COVID-19. *Education Sciences,* 10(6), https://doi.org/10.3390/educsci10060154

Skipp, A. & Hopwood, V. (2020). *Special education during lockdown: Returning to schools and colleges in September,* Ask Research. https://www.nuffieldfoundation.org/wp-content/uploads/2020/09/Special-schools-during-lockdown.pdf

Tricco, A. C., Antony, J., Zarin, W., Strifler, L., Ghassemi, M., Ivory, J., Perrier, L., Hutton, B., Moher, D. & Straus, S. E. (2015). A scoping review of rapid review methods. *BMC medicine*, *13*, 1-15. https://doi.org/10.1186/s12916-015-0465-6

Tricco, A. C., Thomas, S. M., Antony, J., Rios, P., Robson, R., Pattani, R., ... & Straus, S. E. (2017). Strategies to prevent or reduce gender bias in peer review of research grants: a rapid scoping review. *PLoS One*, *12*, e0169718. https://doi.org/10.1371/journal.pone.0169718

Turoff, M. (1970). The design of a policy Delphi. *Technological forecasting and social change*, *2*(2), 149-171. https://doi.org/10.1016/0040-1625(70)90161-7

World Health Organisation Staff (2002). *SEX-RAR guide: the rapid assessment and response guide on psychoactive substance use and sexual risk behaviour*. World Health Organization.

World Health Organization, & Światowa Organizacja Zdrowia. (2004). *World report on knowledge for better health: strengthening health systems*. World Health Organization.