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Background

Before the COVID-19 pandemic, there were already stark inequalities and weaknesses in provision for children with special educational needs and disabilities (SEND) (CQC & Ofsted, 2020; Harris & Davidge, 2019; Byrne et al., 2020; National Autistic Society, 2020; Alghrani & Byrne, 2020). In March 2020, the UK prime minister implemented the first national lockdown to slow the spread of COVID-19. 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. During this period, 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, speech and language therapy, occupational therapy, respite care, differentiated learning, physiotherapy and hydrotherapy were in many cases discontinued (Alghrani & Byrne, 2020).

The Ask, Listen Act study was funded by the National Institute for Health Research in recognition of the lack of robust national research focusing on the impact of the COVID-19 pandemic on the education, health and social care provision for children with SEND.

Study Design and Participants

The research aimed to gather evidence and engage with children with SEND (aged 5-15 years) with or without an EHCP, their parents/carers, and key stakeholders across three phases. The study was designed around a Rapid Assessment and Response (RAR) approach to enable rapid insights to be gained and priorities/recommendations identified.

June 2021

**Phase 1**

Rapid review of the evidence

The rapid evidence review included 33 published empirical research reports and unpublished research made known to us through our networks.

June-October 2021

**Phase 2**

The perspectives and experiences of children and young people with SEND, parent/carers and professionals (health, social care, education and local authority) on the impact and lessons learnt, experiences and reported impacts of the COVID-19 pandemic on children and young people with SEND

Online surveys

- 55 children with SEND
- 893 parents/carers
- 100 education staffs
- 163 health and social care staff
- 44 Local Authority staff

Online interviews

- 4 children with SEND
- 10 parents/carers
- 3 education staff
- 11 health and social care professionals
- 1 Local Authority staff

November-December 2021

**Phase 3**

Co-development of priorities for 'going forward' for children and young people with SEND

Stakeholder workshops

Seven stakeholder priority setting workshops held online and in person using creative methods in schools with;

- 20 children with SEND
- 11 parents/carers
- 38 professionals

Patient and public consultations and involvement

Steering group guidance
Phase 1 Findings: Rapid Evidence Review

The 33 sources of evidence indicate that children with SEND’s education has 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. Online learning was inaccessible to many children with SEND as work was not differentiated and individually tailored to their needs. In many cases, health and social care provision completely stopped, or moved online, with a negative impact on many children’s physical health. Many children with SEND struggled with deteriorating emotional well-being and mental health, for which there was little or no support. With very little respite care available, families of children with SEND have been left exhausted and sometimes in despair. Recommendations from the evidence were orientated around the need for children with SEND to be prioritised in recovery plans moving forward after the pandemic.

Phase 2 Findings: Online Surveys and Interviews

Perceptions and Experiences of Children with SEND

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 told us that lockdowns had been “lonely” and “boring” and they lacked the opportunity to socialise. The lockdowns 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, friendships and for many it exacerbated underlying social and communication difficulties. Children and young people described how lockdowns had negatively impacted their social, emotional and physical development and health.

“’I didn’t really like trying to do the online work because that was just horrendous... I feel like it could be massively improved, you kind of have to just try and do it by yourself. That kind of put me off. It was really annoying just trying to Google it... They need to improve it massively, because it’s really inadequate” (child)

Perceptions and Experiences of Parents/Carers of Children with SEND

Parents/carers told us that there was already a pre-existing lack of support for their child/ren with SEND, and this was exacerbated during the pandemic. 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 parents (89%; n=655) reporting that their child was not able to access face-to-face education throughout the pandemic and that remote learning was not at all effective in meeting their child’s needs (46%; n=261).
For those children who were learning from home (89%; n=655), the vast majority (89%; n=583) were not given the SEND-specific technology they needed to engage in their learning during the first national lockdown. Children with SEND’s access to key therapies was reported as significantly reduced, such as speech and language therapy (pre-COVID: 41% n=88; during lockdown 1%; n=2) and physiotherapy (pre-COVID: 32%, n=66; during lockdown 2%; n=3). Only 6% of parents/carers felt the requirements outlined in their child’s EHC plan had been ‘completely met’. Parents/carers 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, with many reaching crisis levels. Many of the activities which moved online were not accessible or engaging for children with SEND. When the national lockdowns ended, many parents/carers reported their children as struggling to transition back to education (52%; n=192), with 37% (n=199) reporting no transition support provided. Some (21%; n=121) children stayed at home. However, some parents/carers reported that their child had flourished over lockdown with not having to attend school and not having to socially interact as much.

The majority of the parents (67%; n=582) who responded to the survey identified that their mental health had ‘got worse’ over the pandemic. Parents discussed a lack of respite and short-breaks and how this impacted on a decline of their own mental health.

**Perceptions and Experiences of Education Professionals**

During the first national lockdown (March 2020-July 2020), 58% (n=57) of education professionals had a change in job role and 32% (n=24) of these 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. For those children who had been able to access in-person schooling, small classes were reported as working better for children with SEND.

58% of education professionals (n=58) 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).

Many education professionals provided examples of how they had worked over and above to try and support children with SEND despite the restrictions and constraints of the pandemic.

“One autistic child with an EHCP found lockdown and the changes very difficult and this resulted in poor attendance changing to school refusal. The break in the pattern coming to school exacerbated the problem.” (education staff)

“It was very difficult, and we had some very dark times with his violent behaviour and anxiety that was mostly aimed at me when I got home... The anger and the violence escalated a lot, so I had a black eye, and we had a lot of breakages at home and things like that because I suppose he couldn’t vent his stress anywhere else because we were at home all the time” (parent)
Perceptions and Experiences of Health & Social Care Professionals

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 worse than before the COVID pandemic, and 72% (n=117) reported that there had been more requests for support, resources and provision from their service.

Professionals 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 being able to work directly with children and raised concerns 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 working creatively around restrictions to try and maintain support to families in crisis.

Some professionals also commented on the accessibility of remote support and how online working had facilitated improved inter-agency collaboration.

Perceptions and Experiences of Local Authority Professionals

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 reported that an individual risk assessment had been used to help determine if a child was 'vulnerable'. 23% (n=9) 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 timeframe, in comparison to the previous year. Whilst many professionals reported that EHCP annual reviews moved online (49%; n=19), compared to pre-pandemic, there was still 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 children with SEND 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). 47% (n=50) reported that waiting lists were ‘significantly longer’ or ‘slightly longer’.

Our referral rate has increased, on average from the year previous by 167%… There’s such long waiting lists now... It was like that before Covid, but Covid made it worse. So I’ve got families who are waiting just for an initial appointment with a paediatrician who can be waiting three, four years… and the whole process can end up taking you another two or three years on top of that” (professional)
Phase 3: Workshop Findings and Development of the Priorities

The priorities for policy and practice from this study were co-developed via an iterative and flexible approach, and through extensive engagement with children with SEND, parent/carers and professionals. The online surveys administered in phase 2 asked all respondents to identify key priorities to help mitigate the impact of the COVID pandemic on children with SEND. These priorities were then themed, refined and developed through each of the seven facilitated workshops. The priorities are framed by a rights-based approach according to the United Nations Convention on the Rights of the Child (1989) and are aligned under 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**

The detailed priorities for policy and practice within each of the five themes are outlined in a separate document.

**Conclusion**

The needs and rights of children with SEND were not given due consideration during the pandemic. The health and social care services, clubs and activities that support children with SEND were prevented from running face-to-face, and most children could not go to school during lockdown. Online appointments and remote learning were not deemed to be a sufficient alternative for most. Children with SEND were bored and lonely, their 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 concerns over safeguarding. There has been an increase in demand for services, longer waiting lists, staff shortages, and burnout among staff who support children with SEND.
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The links to the detailed evidence briefings for the different phases of the study are as follows:-

Phase 1: Rapid scoping review
Phase 2: Quantitative survey data

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• Partnering with patients, service users, carers and communities, improving the relevance, quality and impact of our research;
• Attracting, training and supporting the best researchers to tackle complex health and social care challenges;
• Collaborating with other public funders, charities and industry to help shape a cohesive and globally competitive research system;
• Funding applied global health research and training to meet the needs of the poorest people in low and middle income countries.
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