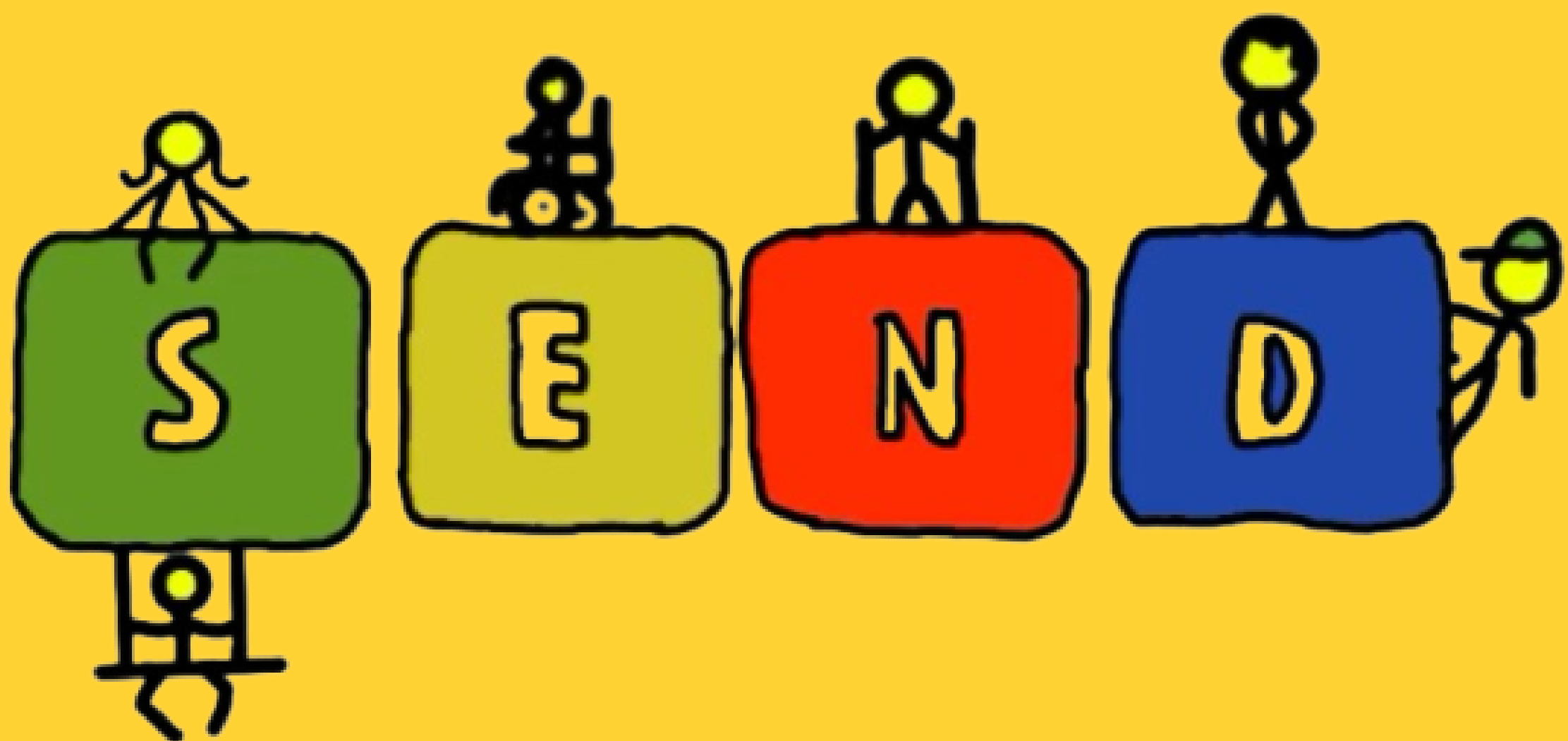


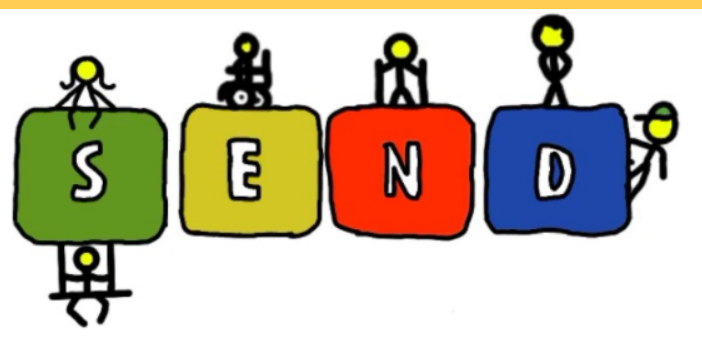
Ask, Listen, Act - working together to inform the provision of Special Educational Need and Disability (SEND) support for children after the COVID-19 pandemic.

## **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 4: Qualitative survey data; Health and social care professionals' perceptions of the impact of the COVID-19 pandemic on children with SEND**



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Ask, Listen, Act - working together to inform the provision of Special Educational Need and Disability (SEND) support for children after the COVID-19 pandemic.

## Executive Summary

### Background to the Study

This study was funded by the National Institute for Health Research's (NIHR) Policy Research Programme (Recovery, Renewal, Reset: Research to inform policy responses to COVID-19 funding stream) in May 2021. The work aimed to examine the perceptions, experiences and lessons learnt in order to scope, understand, and co-develop the policy priorities for reducing inequalities and mitigating the long-term impacts of COVID-19 for children with SEND.

In the United Kingdom (UK), the Department for Education and the Department of Health (2015) states that a child that has special educational needs and disabilities (SEND) if 'they have a learning difficulty or disability which calls for special educational provision to be made for him or her' (p. 16). They then expand on this definition by stating that a child has a learning difficulty or disability if he or she 'has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions' (p.16). To ensure that each child receives the support they need, some children with SEND have an Education, Health and Care plan (EHC Plan) drawn up by their Local Authority. An EHC Plan is a legal document that describes a child or young person's individual special education, health and social care needs and the additional support that will be given to meet those needs.


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, 2020; National Autistic Society, 2021; Alghrani & Byrne, 2020). In March 2020, the UK Prime Minister implemented the first national lockdown to slow the spread of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and COVID-19. The lockdown involved those who were not key workers staying at home, not mixing with other households, and social distancing when in public. Schools were closed except for the children of keyworkers and vulnerable children. NHS staff were redeployed to respond to COVID-19 related pressures (Special Needs Jungle, 2020), and education, mental health and social care services were rapidly withdrawn (National Autistic Society, 2020). In May 2020, children with EHC plans had their educational rights formally downgraded (Byrne, 2020; Children's Commissioner, 2020) by the Coronavirus Act.

### Study Design and Methods

The research was a rapid cross-sectional multiple phase mixed-methods study. The three phases of the study were:

- Phase 1: A rapid scoping review of the evidence related to children with SEND during the pandemic.
- Phase 2: An online survey and interviews to gain the perspectives of children with SEND, parent/carers and professionals (health, social care, education and local authority).
- Phase 3: Stakeholder workshops to co-develop priorities for 'going forward' for children with SEND, parents/carers and professionals to promote recovery and renewal.





This report focuses on the health and social care professionals qualitative online survey data from phase 2 which examined the impact of the COVID-19 pandemic on children with SEND's education, health and social care. The online survey for professionals was designed with input from the project steering group. Responses were anonymous. Ethical approval was gained through the lead researcher's institutional research ethics committee (UREC Ref: 21/PSY/020 and 21/PSY/016). Participants were recruited using social media and through the distribution of study information via key organisations working with children with SEND. The data were collected between June and August 2021. Data were analysed using thematic analysis.

## **Key Findings**

163 health and social care professionals completed the online surveys, which consisted of multiple open-text response boxes. Qualitative data from these response boxes were analysed using thematic analysis, and nine themes were identified: perceived positive impacts of the pandemic, 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 social care professionals would like to see done differently in the event of another lockdown.

## **Conclusion**

In conclusion, health and social care professionals identified that children with SEND had faced huge disadvantages as a result of COVID-19 and the associated lockdowns. 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 re-deployment of staff to cover COVID-19 wards, staff leaving their posts, and staff sickness due to COVID-19. 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'. A positive highlighted by many professionals was that online platforms enabled multi-disciplinary meetings to be better attended and more efficient.





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## Introduction


In the United Kingdom (UK), the Department for Education and the Department of Health (2015) stated that a child has special educational needs and disability (SEND) if 'they have a learning difficulty or disability which calls for special educational provision to be made for him or her' (p. 16). They then expanded on this definition by stating that a child has a learning difficulty and disability if he or she 'has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions' (p.16). To ensure that each child receives the support they need, some children with SEND have an Education, Health and Care Plan (EHC Plan) drafted by the Local Authority in consultation with the parents/carers. The purpose of an EHC Plan is 'to meet the special educational needs of the child or young person, to secure the best possible outcomes for them across education, health and social care and, as they get older, prepare them for adulthood' (DfE & DoH, 2015, p.142). This EHC Plan identifies each child's individual needs and the additional support required to meet those needs. Currently, 3.3% of children in English schools (or 294,800 children) have an EHC Plan because of their disability, while 12.1% of children (or 1,079,000 children) receive additional special educational needs (SEN) support (DfE, 2020).

Children with SEND are some of the most vulnerable children in the education system (Byrne, 2020) and are disproportionately exposed to poverty. Government statistics show that more than twice as many pupils with an EHC Plan get free school meals (35%) than pupils without SEND (around 15%) (Skipp, 2021). Children with SEND are also more likely to have a diagnosed mental health condition. For example, just over a third (36%) of children with a mental health condition also have a SEND (compared to 6% of children without a SEND), and 72% of children with a diagnosed mental health condition also have a physical health condition or a developmental disorder (NHS Digital, 2018). Furthermore, in 2018 children with SEND comprised 45% of all children who had been permanently excluded from all state-funded primary, secondary and special schools (DfE, 2019; Byrne, 2020).

Before the COVID-19 pandemic, there were already stark inequalities and weaknesses in provision for children with SEND (CQC & Ofsted, 2020; Harris & Davidge, 2019; Byrne et al., 2020; National Autistic Society, 2020; Alghrani & Byrne, 2020). Support for children with SEND was described as already diminished, threadbare, and chronically underfunded (O'Hagan & Kingdom, 2020; National Autistic Society, 2020; Boesley & Crane, 2018; Byrne, 2020), with an estimated funding shortfall of £1.5bn (Disabled Children's Partnership, 2018). In 2019 the Disabled Children's Partnership found that only 4% of parents and carers could safely care for their disabled child(ren) with the amount of support they received. On top of this, the framework for the provision of services for children with SEND is 'characterised by confusion, unlawful practices, bureaucratic nightmares, buck-passing, and a lack of accountability, inadequate resources and an overly adversarial process for parents' (Alghrani & Byrne, 2020, p. 2).

In March 2020, the UK Prime Minister implemented the first national lockdown to slow the spread of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2; COVID-19). The lockdown mandated that all except key workers stayed at home, to not mix with other households, and to socially distance when in public. Schools were closed except for the children of keyworkers and vulnerable children. NHS staff were redeployed to respond to COVID-19 related pressures (Special Needs Jungle, 2020), and education, mental health and social care services were rapidly withdrawn (National Autistic Society, 2020). In May 2020, children with EHC Plans had their educational rights formally downgraded (Byrne, 2020; Children's Commissioner, 2020) by the Coronavirus Act 2020. However, on the 28th April 2020, the Secretary of State for Education issued the relevant notification as required under paragraph 5 of Schedule 17 of the Coronavirus Act 2020 to modify section 42 CFA 2014 which meant the Local Authority only had to make 'reasonable endeavours' to provide children with EHC plans with the support they need.





Thus, from 1 May to 31 July 2020, the absolute legal duty conferred upon Local Authorities to deliver the special educational and healthcare provision set out in a child's EHC Plan under section 42 of the CFA was modified to a 'reasonable endeavours' duty to secure the provision. Whilst the relaxation was intended to balance the pressures that councils and others were under, the term 'reasonable endeavours' was vague, lacked specificity and left little room for accountability when vital services were not provided.

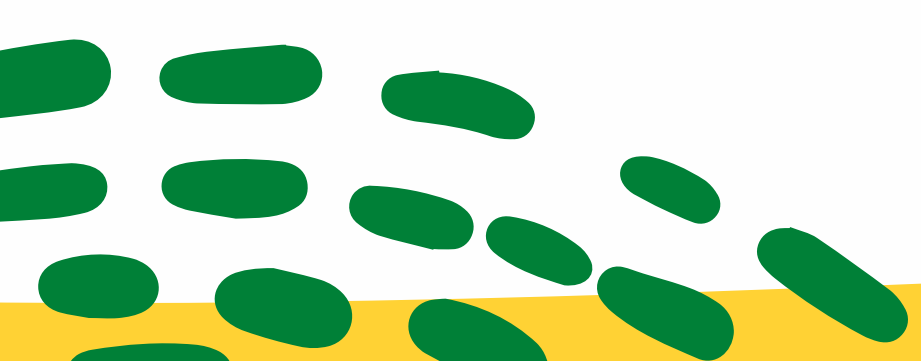
## Study Overview

Dr. Emma Ashworth (Liverpool John Moores University), Prof. Lucy Bray (Edge Hill University), and Prof. Amel Alghrani (University of Liverpool) were funded by the National Institute for Health Research's (NIHR) Policy Research Programme (Recovery, Renewal, Reset: Research to inform policy responses to COVID-19 funding stream) in May 2021. The research was 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 with SEND.

The research aimed to engage with children with SEND, their parents/carers, and key stakeholders across three phases;

1. Phase 1: A rapid scoping review of the evidence related to children with SEND during the pandemic, to examine the existing evidence and policy.
2. Phase 2: An online survey and interviews to gain the perspectives of children with SEND, parent/carers and professionals (health, social care, education and local authority) to capture the impact and lessons learnt, experiences and reported impacts of the COVID-19 pandemic on the long-term development and wellbeing of this generation.
3. Phase 3: Stakeholder workshops to co-develop priorities for 'going forward' for children with SEND, parents/carers and professionals to promote recovery and renewal.

This report focuses on the health and social care professionals qualitative online survey data from phase 2 which examines the impact of the COVID-19 pandemic on children with SEND's education, health and social care. Ethical approval was gained through the lead researcher's institutional research ethics committee (UREC Ref: 21/PSY/020 and 21/PSY/016).



## Methods

### Participants and Recruitment

Health and social care professionals 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. In total, 163 health and social care professionals completed the survey. 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.

### Data Collection

The qualitative data were collected as part of a survey collecting closed and open responses to examine the impact of the COVID-19 pandemic on children with SEND's education, health and social care. Separate online surveys were designed with patient and public involvement for children with SEND, parents of children with SEND, health and social care professionals, education professionals, and Local Authority staff. The qualitative responses from education professionals, Local Authority staff, parents, and children are presented in separate reports. The data collected for this report came from 18 optional open-text response boxes. Example questions included 'What has been the biggest challenge to your service as a result of the pandemic?' and 'Were there any particular group(s) of children with SEND who access the service you work for who were negatively impacted by the pandemic? If so, which group(s)?'. Responses were anonymous. The data were collected between June and August 2021.

### Data Analysis

Qualitative data from the 18 optional response boxes were collated into a single document. Analysis took place in NVivo. Thematic analysis was used to analyse the data. Codes were created inductively to allow for unanticipated findings to be identified, and they were then grouped into themes and sub-themes. Themes and sub-themes were then checked, reviewed and discussed with members of the team

## Findings

### Perceived Positive Impacts of the COVID-19 Pandemic

Whilst the survey responses identified the many challenges and difficulties children with SEND faced during the pandemic and lockdowns, many of the health professionals also identified some positive aspects. Health and social care professionals reported that some families found it easier to engage in online or telephone appointments as this negated the need to travel, sometimes long distances, to attend hospital appointments:

*"Transition planning clinics were held online using attend anywhere. This meant the family could keep the young person safe and shielded at home for the consultation and they didn't need pack up all their equipment to attend a hospital appointment - this was very positively received."*

There were also reported benefits aligned to multi-agency working, with professionals from the multiple services and agencies involved in a child's care being able to meet more easily:

*"I would say that CYP with considerable medical needs and continuing care eligible received a better service as we strengthened our MDT working around these CYP and Microsoft teams facilitated this"*

Health and social care professionals also identified that autistic children and young people, school refusers and those with social anxiety conditions benefited from being able to engage with services remotely:

*"Young people with an ASD generally seemed to find being at home in their own routine better, and also young people with high anxiety found not having to go out made them feel less anxious."*

*"Some children with ASD who were struggling in mainstream settings found that they coped better with the 1:1 and familiar environment and structure of home schooling."*

Some children and young people with physical health conditions were reported as also experiencing some positives of lockdown as a result of sessions and meetings being run remotely:

*"Students with debilitating health conditions that affect them being able to leave the home or cause exhaustion also found it useful to have online provision and felt they were able to access learning and begin to feel like part of a class group."*

**"These children are already vulnerable, reduced health services has impacted on some - not getting the right equipment and therapies. Some have reduced mobility and more discomfort as a result, learning has been impeded"**

**"Students with debilitating health conditions that affect them being able to leave the home or cause exhaustion also found it useful to have online provision and felt they were able to access learning and begin to feel like part of a class group"**



The ability to join online meetings and sessions and use the text or chat function to communicate had some positive associations for some children and young people with SEND:

*"Some children and young people with communication difficulties could communicate better virtually by using the 'Chat' function for example on Teams."*

As well as the benefits to some children and young people with SEND of some services being delivered remotely, some health and social care professionals identified the well-being benefits to children of being part of smaller groups in bubble systems. This was linked to less anxiety, greater ability to engage and the environment being 'more relaxed, smaller and with less work pressure', 'less busy corridors' and with 'less noise and more adult time':

*"Some of our children really responded well to the smaller groups in the bubble system, they accessed a higher level of support."*

The increased time spent with family, whilst in some cases challenging was reported as having positive associations, 'some younger children seeming to thrive spending more time with parents at home' and those who 'engaged more in walks and physical activity'.

## **Perceived Negative Impacts of the COVID-19 Pandemic**

The surveys identified high levels of challenge with children and young people facing 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. The pandemic was reported as having a large impact on the provision of services, with waiting lists increasing and children being delayed in being able to access the services they needed:

**"I think families with SEND children were forgotten. For many it was an incredibly stressful time with the withdrawal of all services, but as time went on this situation was improved but many are still having long waits for appointments and assessments"**

*"Waiting times for all children, has increased but this has had the most negative impact on the complex children with high medical needs, especially those with family members shielding."*

*"I think families with SEND children were forgotten. For many it was an incredibly stressful time with the withdrawal of all services, but as time went on this situation was improved but many are still having long waits for appointments and assessments."*

Even though many children and young people with autistic spectrum condition were reported as having some positive impact from the lockdowns, such as being less anxious at home, professionals also identified that many of these children did not engage well with remote learning, experienced heightened anxiety, struggled to understand why normal routines had been disrupted and have since struggled to re-enter educational settings. Professionals recognised that each child's circumstances were different:

**"Waiting times for all children, has increased but this has had the most negative impact on the complex children with high medical needs, especially those with family members shielding"**

*"Many who receive learning support in schools found working at home difficult. Support for learning within families was highly variable with some families being able to dedicate the time to their child's learning while others found this more difficult."*

Many children who had ASC and Social and Emotional Mental Health (SEMH) issues were not in school, this was reported as influencing their ability to access their usual therapeutic sessions, with a direct impact on their mental health.

**"Overnight short break facility was shut down, children and families did not have this support service. Other support was implemented, however the closure had a negative impact on everyone"**

In addition to a lack of access to therapies, health and social care professionals also identified that respite provision, community activities and support often just stopped during the first lockdown with a negative impact on lots of families:

*"Overnight short break facility was shut down, children and families did not have this support service. Other support was implemented, however the closure had a negative impact on everyone. It has been and continues to be very stressful for children and families."*

Professionals also reported certain groups of children who were particularly disadvantaged through prolonged exclusion from services and the need to shield, such as 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. These impacts were linked to not being able to access the therapies needed to maintain their physical health:

*"Some children who 'toe walk' seemed to deteriorate as they weren't wearing their splints/supportive footwear as often when not going to school. Children with reduced independent mobility, noticeably deconditioned with strength and endurance"*

Professionals also reported how younger children and those with complex disabilities were particularly disadvantaged as they were less able to engage in a meaningful way with online appointments and sessions:

*"Children with complex needs were unable to access assessment or video sessions, children with hearing loss also could not access video therapy."*

The wearing of masks within appointments and social settings was reported as impacting negatively on the ability of some children who had communication challenges to join in and participate:

*"The wearing of PPE, especially masks was a problem, as the children I work with need to see facial expressions to help them understand communications. As a result, communication has been much more challenging."*

There were also families who did not have access to the internet and the IT hardware such as laptops needed to engage in a meaningful way with services. Some parents were also reported as not feeling confident to use the online platforms:

**"Some children who 'toe walk' seemed to deteriorate as they weren't wearing their splints/supportive footwear as often when not going to school. Children with reduced independent mobility, noticeably deconditioned with strength and endurance"**



*"Whilst many children were in supportive homes, some children with SEND were not living 'in a household that is not emotionally or socially supportive of them"*

Children and young people with SEND were reported as not able to have important transitions supported during the pandemic, for example transitioning between paediatric and adult health services:

**"In the first lockdown we had a skeleton staff level due to re-deployment. Since we have had staffing issues as a result of staff being sick, re-deployed and leaving the service"**

*"Transitions have been far more challenging as children and young people have not had good physical introductions to new settings which has caused a lot of worry and anxiety."*

### **Changes to Health and Social Care Services as a Result of the Pandemic**

Health and social care professionals were asked what had been the biggest change to their service provision as a result of the pandemic. At the beginning of the lockdown staffing structures rapidly changed due to the redeployment of staff to cover COVID wards and care or vaccination programs.

*"Out of the four members of Speech and Language Therapy staff three of us were redeployed during the first lock down. Now that we are all back as of last week 19/7/2021 we are very far behind with our caseloads and our waiting list will now be almost a year long."*

*"In the first lockdown we had a skeleton staff level due to re-deployment. Since we have had staffing issues as a result of staff being sick, re-deployed and leaving the service."*

The frequent rule changes and practice guidance created issues with health and social care professionals knowing what they 'were allowed' to do:

*"Government guidance changing so frequently, home working, trying to get services to deliver when their own staff were in vulnerable groups etc"*

The commitment to provide services despite rapid change impacted on staff's well-being when they were facing such unprecedented challenges:

*"Staff's mental health was affected, including my own. There was also some staff who went on long term sick leave. This would then impact on our own caseloads as we needed to continually provide a statutory service."*

In many cases the biggest change reported was the use of online platforms and telephones to contact and hold consultations with children and young people with SEND and in most services the use of digital platforms to communicate with families has continued:

*"We continued to offer digital services which made our service more accessible, we are not having to travel around the country for meetings."*

**"Staff's mental health was affected, including my own. There was also some staff who went on long term sick leave. This would then impact on our own caseloads as we needed to continually provide a statutory service"**

The use of online platforms, as mentioned before was reported as improving the attendance of multi-disciplinary professionals at meetings, as well as being able to work at times more efficiently:

*"There is greater attendance and engagement at meetings on line than there was face to face. I have a role which involves many agencies and co dependencies across Health and local authority landscapes. Spending less time in my car moving from base to base to attend meetings boards and panels has helped enormously and made work more efficient."*

This level of MDT working was reported by professionals as transformational 'all teams linked to SEND worked together in the best way for the first time'. The use of digital platforms also enabled some services to engage with parents who may not have been able to attend face to face support groups:

*"We have held parent workshops online in the evening and have found that both parents have attended and lots of dad's have attended as they haven't had to organise childcare."*

Whilst online and remote engagement was reported as having many positives, the lack of ability to engage face to face with some children and young people with SEND was reported as meaning that the most vulnerable children and families in crisis had not received the care and support required:

*"Online working significantly reduced the opportunity to see young people face to face and therefore we had to rely on third hand information rather than direct assessment and observation. This affects risks assessments and the quality of support."*

This reduced ability to see children was mentioned in particular reference to safeguarding concerns:

*"From March - July 2020 I only did telephone consultations which was a very poor service as there was no ability for physical examination, and it was difficult to liaise with school staff which is vital for complex children particularly when there are also safeguarding concerns."*

**"From March - July 2020 I only did telephone consultations which was a very poor service as there was no ability for physical examination, and it was difficult to liaise with school staff which is vital for complex children particularly when there are also safeguarding concerns"**

**"We have held parent workshops online in the evening and have found that both parents have attended... as they haven't had to organise childcare"**

Professionals also faced having to 'get to grips' with online platforms whilst maintaining service provision:

*"There was a poor ITC Service, the quality of Outlook, Microsoft Teams and essential databases etc broke down daily, so prevented you from doing your work effectively."*

Some professionals identified that having to work within extremely constrained and challenging times had caused them to re-imagine and re-focus their work:

*"I genuinely think we have become better organised, more specific, better at accurate relevant signposting."*

Health and social care professionals identified that the renewed emphasis on uniforms and a more detached service provision caused some children to be upset:



*"The children are used to seeing us in our usual clothes and being able to see our faces. A lot of the children were initially very scared and didn't recognise us; we specifically don't wear uniforms normally so that they don't associate us with hospital nurses, as most of our children have to attend hospital for treatment."*

The need to wear PPE, whilst necessary, was reported as being often restrictive to staff providing a high level of care within certain services:

*"The use of PPE in therapy sessions. This is a real challenge as children cannot see your mouth or face. Particularly challenging when you are demonstrating speech sounds, or if the child has hearing impairment."*

**"There was a huge increase for referrals in the lockdowns for children with social, emotional and mental health needs, mental health has been impacted and the local CAMHS support has been depleted"**

Health and special care professions were specifically asked to report on whether their service had experienced increased or decreased requests for referrals to their service. Many services reported an increase in referrals for *'children needing increased levels of support and help due to the pandemic'*:

*"There was a huge increase for referrals in the lockdowns for children with social, emotional and mental health needs, mental health has been impacted and the local CAMHS support has been depleted. Then when children returned to school there was a heightened state of anxiety amongst children especially SEND, which led to more referrals. Many children with ASC have been unable to return to school."*

The increased level of referrals and need was often as a result of the child's needs, but also due to wider impacting factors within families:

*"Many families are finding this a struggle because the young people are finding it difficult to adjust to life after the lockdowns. I feel that there has been some family break downs and crisis as a result and increased demand for support from our service including short breaks and requests for residential provisions."*

As well as professionals reporting an increase in the number of referrals to their service, they also identified that the referrals they were receiving involved more complex cases:

*"Children who's review usually take 20-30 minutes (because they were previously receiving regular orthopaedic interventions such as botox) are now taking a hour+ to review due to requiring onward referrals to orthopaedics for more invasive surgery. Teachers have also requested more support with equipment as some of the children did not access their equipment for a significant period."*

Other services reported an initial lower level of referrals near the beginning of the pandemic as families did not want to access services due to concerns over shielding:

*"I think referrals to most SEND health services decreased in the first lockdown, and then subsequently increased, particularly referrals for Mental Health support."*

**"I feel that there has been some family break downs and crisis as a result and increased demand for support from our service including short breaks and requests for residential provisions"**

## What Worked Well During the COVID-19 Pandemic

Health and social care professionals were asked to identify what over the last year has worked well to support children with SEND and their families. Similar to the previous sections, the ability to use online platforms was seen to work really well with some groups of children with SEND and their families and enabled professionals to engage well with other multidisciplinary professionals and those less able to attend face to face sessions. Professionals reported that *'communication between teams and multi-agency working improved'*.

*"As we worked online we were able to attend more meetings as we didn't have to travel. I think parents felt that they were able to contact us easier. More parents are able to attend meetings especially if they are also working from home, it is more convenient for them."*

*"This was all due to our Information Technology Infrastructure and use of Zoom, MS Teams software. It felt like I could achieve more online than driving from appointment to appointment. Also the time spent driving I could complete my paperwork, plans and assessments."*

Professionals also reported that training, both to professional groups and parent groups could be more easily delivered online:

*"Developed online workshops and resources for families to access in their own time rather than needing to attend a face to face workshop (often poor attendance due to work/other commitments). We have seen an uptake in accessing this information since becoming virtual and easier to access."*

There were many examples provided of innovative and creative ways of using online platforms to stay in touch and provide support including 'online local farm visits', 'zoom sessions with entertainers', 'online baking clubs', virtual walks and quizzes:

**"As we worked online we were able to attend more meetings as we didn't have to travel... More parents are able to attend meetings especially if they are also working from home, it is more convenient for them"**

**"We also made wellbeing calls, provided one-to-one support over the phone and delivered food hampers to support struggling families"**

*"The partner staff toured us around the animals and gave some information about them and encouraged the children to ask questions too."*

These changes to services being delivered online and virtually was reported by professionals as being maintained by many of the services as they worked so well:

*"Virtual working has worked well with some young people. It has aided creative communication and I have enjoyed this. For example, I have played games with young people asking them to find an item that makes them happy. This has introduced different conversations and is something I am going to use moving forward."*

Services adapted and reshaped by providing 'whatever support was needed to get families through it', for example some services, whilst not their remit, helped with practical support from food banks, food parcels and support with learning by dropping off resources for home learning:

*"We were able to send sensory packs to anyone 8-25 on the Wirral who requested one. We also made wellbeing calls, provided one-to-one support over the phone and delivered food hampers to support struggling families."*



There was huge variability in professionals' reports of what had worked well, whilst some professionals described becoming *'more creative and accessible'* some professionals reflected that *despite their best efforts they felt we have really let families down*.

## What did not Work Well During the COVID-19 Pandemic

**"Felt we have really let families down"**

Health and social care professionals reported that inconsistent advice and guidance meant that they struggled to know *'what they were allowed to do and what they were not allowed to do'*, as the information they were provided with was not clear.

This left professionals often feeling that *'things were out of their control'* and they received *'conflicting and changing information between health and LA around PPE, shielding and bubbles'*.

Whilst *'moving online'* had some reported benefits, professionals identified many issues with this new way of working, specifically for some children with SEND:

*"Children who had more profound needs or behavioural difficulties were identified as particularly disadvantaged with communication and services being online."*

In addition to challenges with children with SEND engaging with remote services, health and social care professionals reported that some parents also struggled with the *'move online'*:

*"The main difficulty was working with families who only had a mobile phone or were not very tech savvy. It was a lot harder working with families where parents had their own learning needs as these families would normally have been supported by home visits."*

The reliance on online services was also described as negatively impacting on professionals' ability to conduct assessments and provide therapy:

*"In first lock down we were a 'virtual first service' and only able to see clients categorised as 'red or at risk' on a face to face basis. This meant trying to complete equipment assessments, reviews and set ups virtually. It was really difficult explaining how to adjust/use complex pieces of equipment to parents via video call and expecting them to try and follow our instructions to set their child up in a piece of equipment."*

Professionals also raised safety concerns with all provision being online and reported that this had safeguarding consequences:

*"There were no home visits which increases unknown safeguarding risks as nobody is seeing the child in their home environment. The voice of the child obtained through the parent, not directly. Not great in safeguarding arena."*

Professionals also felt that despite families trying their best to manage in challenging circumstances, as many support services *'just stopped'* this left many parents without any opportunity for any kind of a break. This could have been in the form of support groups, coffee mornings or the provision of short breaks or respite:

*"We have missed being able to hold face to face coffee mornings and having drop in sessions for parents."*

**"There were no home visits which increases unknown safeguarding risks as nobody is seeing the child in their home environment"**

*"The respite centres did not open early enough or take enough children and we should have worked more on getting outside space identified."*

The lack of support and access to short breaks was reported as resulting in families reaching crisis levels:

*"We have had an increase in emergency stays in 2021 where families are telling us they can't cope because they haven't accessed our services last year."*

The lack of breaks for parents was often discussed alongside a lack of accessible activities and support for children with SEND during the pandemic:

*"Social and leisure activities were not available, play centres, zoos, park play areas were closed. Physical groups were not available and this has been a barrier for the whole family."*

**"We have had an increase in emergency stays in 2021 where families are telling us they can't cope because they haven't accessed our services last year"**

### **Perceived Barriers to the Provision of Services for Children with SEND**

The largest barrier to the delivery of services to SEND children appeared to be staff shortages. With many SEND staff being redeployed to the 'front line' in the early stages of the pandemic, this 'redeployment of staff meant that almost all services were stopped':

*"There was staffing reduction through sickness and re-deployment - there is limited mention of the NHS England directive to re-deploy staff and stop services which was in direct conflict with the SEND legislation of continuing services."*

**"There is limited mention of the NHS England directive to re-deploy staff and stop services which was in direct conflict with the SEND legislation of continuing services"**

The issues identified persisted even when staff did return from working in front line services, as many staff were reported as returning exhausted and services needed additional resources to restart service provision:

*"When AHPs were redeployed from our service into adult settings we lost a great deal of momentum, relationships and connections with both setting staff and with parents. Our teams returned burnt out, from being placed in such difficult working conditions that were outside of their comfort zone and specialist knowledge."*

Reinstating services for children with SEND later in the pandemic was often not possible due to staffing changing beyond repair:

*"The service had already been cut back significantly - vacancies were not filled purposefully to save money, so even before the pandemic we were in a very difficult position as SEND requests were already increasing. After the pandemic it is impossible."*

Health and social care professionals reported experiencing frustration at the inconsistent advice they were provided with regarding how their service was 'allowed' to run:



*"Huge increase in new referrals has made workload almost unmanageable and lack of government funding means there is no way staffing can be increased. Massive caseloads limit the frequency of support to schools. We are spread very thinly across pupils, some of whom have significant and complex needs."*

## **New Practice**

As described before the main service change which was implemented involved the provision of virtual and online appointments and assessments:

*"Online clinics using attend anywhere has been received very positively by YP and families and many have asked for this to continue. The online interaction was not just with families but also between professionals."*

The provision of services online was reported as incorporating all aspects of a service:

*"MDT discussions via online platforms. Online training to schools and parents. Online parent carer forum discussions. Online appts. Online annual review attendance. Online EHCP panel meetings."*

Professionals also described having to respond to changes in service need and delivery by thinking creatively and creating new elements as part of their service:

*"We created short consultations that we had no waiting list for so parents could have a immediate support, we offered online training to empower parents to understand their child's difficulties, we created a range of other smaller assessments as well to cater for other family needs."*

Health and social care professionals also identified new ways of working collaboratively with multi-disciplinary members and 'greater integration with voluntary and charitable sectors'.

## **The Perceived Biggest Challenges Moving Forward out of the Pandemic**

Health and social care professionals reported what they perceived to be the biggest challenge going forward.

The biggest challenge cited by a number of professionals was that *"under resourced and under staffed"* services have been *"overwhelmed with applications"* and do not the capacity to meet demand:

**"I am worried that the quality of our service offer is at risk as we try to do so much more, with a much reduced resource"**

*"Sheer numbers of children, young people and families needing support. Long waiting lists for mental health support in particular. The services do not have the capacity to meet the demand which leads to children, young people and families going unsupported for long periods and problems then escalating to crisis point."*

*"The high numbers of children requiring assessment and intervention is a major challenge. We have lost some staff and are still carrying vacancies, so trying to offer assessment and meaningful intervention is extremely challenging, which feels like we are spreading the service ever more thinly. I am worried that the quality of our service offer is at risk as we try to do so much more, with a much reduced resource. Staff are also extremely stressed and at risk of burn out."*

**"Huge increase in new referrals has made workload almost unmanageable and lack of government funding means there is no way staffing can be increased"**

Another challenge was for SEND children to be recognised as a priority:

*"I do not feel this group of service users were seen as a priority through the pandemic, therefore resources were re-allocated to other areas. I also do not feel the ongoing effects on this group of service users is being recognised sufficiently and will continue to be an area of challenge for some time to come."*

Health and social care professionals also noted the impact of the pandemic and lack of support on children with SEND and their families:

*"The families remain exhausted, some families are too frightened to send their children back to school. For some the impact will be life long."*

### **Lessons Learned**

Health and social care professionals told us what they would like to see done differently if there was another lockdown. Professionals mainly warned against the redeployment of staff away from SEND services:

*"Don't redeploy people who work in essential roles with children who have SEND e.g. speech and language therapists"*

*"Prioritisation for services for all children with SEND to be protected and continue rather than dismantled, undervalued with practitioners redeployed to adult services"*

Professionals thought that SEND services should not be closed, and statutory requirements should not be relaxed: *"No closing of services or relaxing of statutory requirements"* and *"recognising importance of maintaining access to services"*. Additionally, one professional pleaded that children with SEND have the option of going to school: *"Please keep them in school, especially when that's the only respite families get"*.

Professionals noted that in a future lockdown communication with families of children with SEND would be vital:

*"Direct communication to families where children have SEND to help them understand what is happening and give them the opportunity to feedback their experiences and needs."*

As well as communication, families need support to access online provision in the event of another lockdown:

*"Ensure that families can access provision e.g. by providing the technology to access things online if that is how they are available."*

Additionally, professionals could advise families of the online support available to them:

*"Actively promoting and supporting virtual groups and experiences - there's some amazing resources out there (dance groups, singing classes) all aimed at kids with SEND - but as professionals, we should be coordinating these resources so families know about them"*

**"Staff from all sectors including health and social care [needed to be] in direct with children and families instead of working from home"**



Provision of short breaks was also thought to be important in the event of another lockdown:

*“Increased short break provision generally so that families have enough support to prevent crisis and placement breakdown.”*

Professionals would also like to see more support for working parents of children with SEND during any future lockdowns: *“Support for families who are working when schools close”.*

## **Conclusion**

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 re-deployment of staff to cover COVID wards, staff leaving their posts, and staff sickness due to COVID-19. 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'. A positive many professionals highlighted was that online platforms enabled multi-disciplinary meetings to be better attended and more efficient.

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## Acknowledgements

We would like to thank the education professionals who took part in the surveys, as well as the steering group and public and patient advisory group members for their support in the development of the interview design. We would also like to thank the Liverpool Health Partners for their ongoing support and acknowledge the funders of this study, the National Institute for Health Research.

### Note

Ask, Listen, Act is funded by the National Institute for Health Research (NIHR) Policy Research Programme fund (NIHR202718). The mission of the NIHR is to improve the health and wealth of the nation through research. The NIHR does this by:

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NIHR is funded by the Department of Health and Social Care. Its work in low and middle income countries is principally funded through UK Aid from the UK government. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.