

Forgotten. Left behind. Overlooked.

The experiences of young people with SEND and their educational transitions during the Covid-19 pandemic in 2020



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The views expressed in this report are those of the group.

Foreword

This is the first report of the APPG for SEND. When we formed as a group in early March 2020, we had no idea of the turmoil that we all would face just a few short weeks later as the Covid-19 pandemic hit and the country went into lockdown.

The group formed with the aim of supporting special schools and SEND provision in mainstream school and college settings. This past year has seen young people with SEND, their families and their educational settings needing support and a platform more than ever, as the Covid-19 pandemic has held a magnifying glass to the existing problems in the SEND system. This report serves to highlight their stories; to be a platform for their voice.

When we began thinking about the inquiry, the members of the APPG were particularly keen to focus on how the transitions that young people with SEND face had been impacted by the significant changes in education provision since March 2020.

Moving between education settings, for either a change of phase or for enhanced or different provision, is difficult for all children, but how has this been impacted by the pandemic and what has been the specific experience for the children and young people with additional needs?

While transitions were the focus of the inquiry, it is clear that the needs and experiences of young people and their families are wide-ranging, emotional and often desperate. Many of the submissions we received were raw and anxious - they were reaching out to seek help for their child in a system that has long needed change.



As an APPG we don't have the power to make changes to policy or to systems but, as MPs, we do have influence. This report aims to further that influence and crystalise suggestions of how things can be improved. And they must be improved.

We thank all the organisations who submitted evidence to this inquiry, and we are in the privileged position to be able to bring together evidence and statistics from the important research they have conducted over the past year.

But particular thanks go to the parents and young people themselves, who submitted written evidence but also spoke at virtual oral evidence sessions in front of Members of Parliament and hundreds watching online across the country.

We are grateful to each of you for sharing your experience. We hope this report and our representations can contribute to improving that experience during the ongoing pandemic and beyond.

Olivia Blake MP Chair of the APPG for SEND It is very sad to see that the lives and care of our young people is regarded as so unimportant that the services we rely on for support... were deemed non-essential and closed down for six months.



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Introduction

Members of the APPG for SEND

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Objectives of the inquiry

- To further build the evidence base of the impact that Covid-19 has had upon young people's mental health and wellbeing during transition
- To further build the evidence base of the impact that Covid-19 has had upon learning outcomes during transition
- To examine the impact that Covid-19
 has had upon children and young
 people with SEND during transition,
 specifically in relation to the social
 and emotional wellbeing within the
 community.
- To establish where the capacity and responsibility to address the impact of Covid-19 lies, whether this be with the Government, the sector, parents and young people themselves or a

- combination of all of these
- To make recommendations to Government on its role in mitigating and remedying the impact that Covid-19 has had upon children and young people with SEND during transition

The inquiry

The inquiry was launched at a meeting of the APPG for SEND on 15 July 2020. From there, it was publicised through the APPG's website, the APPG's mailing list and on Twitter.

There was an open invitation to submit written evidence and the terms of reference for the inquiry were publicly available on the APPG's website. At all stages it was emphasised that hearing directly from parents and young people was of particular importance.

An invitation to register interest to submit evidence at the oral evidence sessions was issued on 7 September and there were 49 offers received.

In each oral evidence session, the group sought to hear from at least one young person and one parent as they felt it was important to hear directly of their experiences. To facilitate the evidence of young people, the group contacted national organisations representing and supporting young people with special needs and disabilities. We are thankful to these organisations for facilitating and supporting the young people to give oral evidence.

This is primarily qualitative research, with written and oral submissions to tell a story. We have collated quantitative research that was submitted.

Key dates for the inquiry

Date	Event
15 July 2020	Inquiry launched at meeting of the APPG for SEND and written evidence invited. Terms of reference for the inquiry available on the APPG's website.
7 September 2020	Invitation to submit oral evidence and confirmation of the dates for 4 APPG meetings with oral evidence sessions.
23 September 2020	First oral evidence session with a focus on communication and interaction.
14 October 2020	Second oral evidence session with a focus on cognition and learning.
11 November 2020	Third oral evidence session with a focus on social, emotional and mental health difficulties.
15 November 2020	Deadline for submission of written evidence
2 December 2020	Fourth oral evidence session with a focus on sensory and/or physical needs.

Executive summary

Contributors to this inquiry have used powerful words to describe how young people with SEND and their families have felt during the Covid-19 pandemic: forgotten. left-behind and overlooked.

The Covid-19 pandemic has amplified the problems and issues that were already present in the SEND system.

The manner and speed in which the lockdown and closure of school happened had a negative impact on children and young people with SEND and their families. Many were left without support.

Funding for SEND provision has been of long-term concern with local authorities, school settings and families reporting deficits in the high-needs budget. The impact on schools of Covid-19 related costs and losses of income has exacerbated this crisis.

The government guidance for special schools and alternative provision was frequently published later than guidance for mainstream schools. This led settings and young people with SEND to be seen as, and feel like, an "afterthought".

The Coronavirus Act and the reduction in requirements of local authorities and schools to make 'reasonable endeavours' has had a negative impact of the support available for young people with SEND and their families. There is concern that this impact could be long-lasting.

In some cases, risk assessments were used to refuse attendance in school for young people with SEND. These assessments were often conducted without the input of families or the young people themselves.

Delays in the process of assessing for and implementing Educational and Health Care (EHC) Plans impacted on the transitions of young people with SEND. This meant they started in a new setting without the provision they required or, in some cases, not attending school. Not being able to visit new settings increased the anxiety of transitions for young people with SEND.

Changes to the school set-up and staffing provision has caused anxiety and disruption which has been felt acutely by children with SEND.

Specialist resources and support that are available for young people with SEND in school settings cannot be replicated in the home environment, which has an impact on their ability to learn.

Therapists and technicians who support the provision for young people with SEND have in many cases not been allowed on to school sites due to Covid restrictions.

There are some positive experiences from the impact of the pandemic on learning which emphasises how every child has unique needs. However, they are positive because they mitigate existing issues and problems.

Mental health of young people with SEND, and that of their families. has been widely impacted by the pandemic. Anxiety was frequently reported.

The Government and Department for Education did not do enough to support children and young people with SEND during Covid-19. Our most vulnerable children were failed and schools and families were left to pick up the pieces.

Key recommendations

- 1. That the Department for Education ensures that all future guidance pertaining to schools and other educational settings are fully cognisant of the complex range of needs and challenges for SEND children, schools, families and carers. Critically, that such guidance is timely and considered as a priority both during national emergencies and as we emerge from the current lockdown measures.
- 2. That an urgent and time-bound parliamentary review is undertaken by government in order to assess the impact which Covid-19 has had upon children with SEND in order to ensure that the support provided as we recover from the global pandemic is focussed on the most vulnerable. Such a review to include all stakeholders including children and young people, parents and carers and organisations with a legitimate interest.
- 3. That new and additional funding is made available in the short, medium and long-term to support SEND children and young people with the Covid-19 recovery.
- 4. Specific funding to be given to addressing the delays and backlog in the process of assessments for Educational and Health Care (EHC) Plans.
- 5. That the process of applying and assessing for EHC Plans is made simpler and more compassionate. That families should not have to fight for support for their child, even more so in a pandemic.

- 6. That urgent funding is given to support the mental health of young people with SEND as part of recovery from the pandemic. That all mental health provision is fully accessible for young people with SEND and tailored to their needs.
- 7. An urgent review of high-needs funding is undertaken. This has been long-called for, but the pandemic has highlighted issues in the funding of provision for SEND. Funding will be crucial in the recovery from the pandemic.
- 8. That the Secretary of State for Education publishes the long-awaited SEND review and commits to working with the APPG SEND and allied APPG's in order to ensure that SEND Children and Young People are placed at the centre of government's policies and decision making.
- 9. That support for children and young people with SEND must be a feature of all future pandemic planning.

My input was added once the decision that my son had to stay home had already been made.



Overview of the written and oral responses

Learning at school during the initial lockdown

Despite children with Education Health Care (EHC) plans being one of the groups able to access learning at school during the initial lockdown, several of the submissions said that this was not the case.

A survey by 1Voice, a charity that supports users of augmentive and alternative communication (AAC), found that 83% of respondents did not access school at all between March and July. They cited that this was due to their medical vulnerability and the increased risk they face because of their personal care needs which meant that school felt too risky. Respondents to the survey reported feeling 'forced to choose' to keep them at home, which left them without care support because the lack of testing meant the risk to life took precedence.

Ambitious about Autism also cited health fears due to co-occurring conditions or vulnerable members within their families as a reason for pupils with EHC plans not to access learning in school.

Careers Connects reported that even with specialist settings remaining open during lockdown, the attendance of young people has been low, with many young people and parents choosing not to attend and engage in learning.

Some young people and families were

not given a 'choice', however false, whether to attend school or learn at home. Respondents to a survey² by Adoption UK "expressed frustration" that places were not offered despite their child meeting the criteria. This was felt to add to challenges caused by previous disruptions to a child's education.

The Children's Services Development Group (CSDG), whose members collectively operate over 90 special schools as well as providing foster care and children's homes placements for young people with complex needs. reported that they became aware that a number of non-member special schools had to cease provision during the first lockdown and asked children to return to their families. In some instances, this was sadly triggered by local authority commissioning decisions. (CSDG)

Support stopped or reduced

The Covid-19 pandemic has resulted in the educational and therapeutic support provided to children with SEND being reduced or stopped completely.

Ambitious about Autism reported that 80% of autistic young people and their parents who responded to their survey³ said that support they had been accessing before the pandemic stopped or was reduced. This includes access to vital services such as speech and language therapy, mental health support, and respite care. Services have had to alter, delay or remove provision entirely which has increased vulnerabilities.

¹Voice: survey completed by 12 parent-carers or the young AAC users themselves, who are aged between 8 and 27.

Adoption UK: survey of 674 parents/carers of care-experienced and adopted children in early April 2020

Ambitious about Autism: survey of over 2000 autistic children and young people and parents/carers conducted August and September 2020

Their submission contends that the disadvantage faced by young people with autism can be mitigated by exceptional support provided in education, community services and the perseverance of families, but the capacity to do this has been further reduced during the pandemic.

In oral evidence, Sense highlighted how attending school is more than education. Attending school is often an opportunity for children to receive treatment and therapies and support from additional experts such as speech and language therapists and other healthcare professionals. Not being able to attend school has impacted on the ability of children or families to access that vital care and support.

The initial lockdown period from March 2020 meant that many families lost their access to not only respite through education, but any other respite packages of support they had in place. This put a huge strain on many families, which still continues to impact on them. (Sense)

1Voice found 58% of respondents to their survey had no care support at all between March and July. Only one respondent had the same hours of support as usual. 22% of those who did continue to get some care had 'a lot less than usual.' Without additional care support, these young people depended on their parents for everything. The complexity of their physical disabilities means that they need support with feeding, changing, toileting and facilitation for interaction in online environments: "The levels of physical and emotional stress these youngsters and their families have reported is enormous". (1Voice)

SEN Talk is a London-based non-profit

organisation with an aim to provide better outcomes for children and young people with SEN. They found that families had witnessed a drastic decline in usual SEND provision from the start of lockdown, including all areas across education, health care, mental health, respite care, and social care services. Almost all respondents to their survey reported that their family's special needs support was "significantly impacted" by the pandemic.

During an oral evidence session, Let Us Communicate, a volunteer-led, independent support group in East London, told the inquiry that the NHS providers of therapies such as speech therapy largely came to a halt. This is supported by the Local Government Association (LGA) during their oral evidence, who pointed out that physical development has also been badly hit through not being able to access therapies.

The Royal College of Occupational Therapists (RCOT) reported that faceto-face consultations were limited during the initial phase of the pandemic in March 2020. Again, families with vulnerable children are reluctant to receive people into their homes or visit a healthcare setting even when it is permitted. This has made it difficult for occupational therapists to address the needs of young people with SEND, particularly physical needs that cannot be met through virtual consultations. for example reviewing and adjusting specialist seating or hand splints to accommodate a child's growth.

They also described how social distancing regulations have impacted the number of spaces that meet the requirements for occupational therapists to conduct confidential conversations with young people, parents/carers and educators. Furthermore, a number of

children's occupational therapists were redeployed to adult services at the start of the pandemic. Around one third of the 1500 occupational therapist respondents to an RCOT survey⁴ were deployed elsewhere and others were unable to work because they were shielding or unwell.

A parent who gave oral evidence to the inquiry said: "He needs physio, he needs orthotics, he needs a dentist, he needs speech and language therapy, yet it isn't there. It's gone. He is not prepared to transition, he hasn't the tools he needs to transition."

A survey by Family Fund found that 62% of families said formal support available for their disabled or seriously ill children has decreased due to the Covid-19 outbreak.

"Through our helplines, Tribunal Support Service and training we have heard that children and young people with SEND did not receive adequate support upon their transition to remote or a different kind of education when educational settings closed in March." (IPSEA)

Accessibility of at home learning and differentiation

National Deaf Children's Society (NDCS) reported that remote teaching may not be accessible to some deaf children unless additional communication support is provided such as remote speechto-text or sign language interpreters. "We believe it's unacceptable that accessibility continues to be an afterthought and would like to see a much stronger lead and encouragement from the Department in this area." (National Deaf Children's Society)

National Autistic Society found in a

survey of 4,000 families that seven in ten parents said their child had difficulty understanding or completing schoolwork, and around half said that their child's academic progress suffered.

Sense told the inquiry that parents had reported that they have had no contact at all from their child's school whilst others have had work sent home from school that they're unable to access.

In response to unsatisfactory support from their mainstream primary school, a parent/carer of a child with Autism Spectrum Condition (ASD/C), Attention Deficit Disorder (ADHD/ADD), and Pathological Demand Avoidance (PDA), replied: "School over Zoom just doesn't provide the required support for children with complex needs who already struggle with communication and social interaction." (SENTalk)

54% of respondents to the 1Voice survey did not have work provided in an accessible format. "A picture emerges from the responses of worksheets and web links being sent home which the learners' physical disabilities meant they could not access. The work 'wasn't adjusted at all' and was 'not in grid or clicker.' The online lessons were difficult for AAC users to participate in." (1Voice)

In their submission, IPSEA concurred that children and young people with SEND found it difficult or were unable to access education remotely, either online or on paper. This was because the work set was not appropriately differentiated. was provided using software they could not access and/or they did not receive special educational provision required by their SEN that they would have had at their setting (e.g. the support of trained teaching assistant 1:1 under the supervision of a qualified teacher).

RCOT: survey of 1500 occupational therapists (including 175 occupational therapists working with children and young people) in July 2020

Dinah, a deaf young person, gave oral evidence to the inquiry and spoke of the need to explain to new teachers what support you require, such as reminding them to use the radio aid or to take off their masks: "That takes quite a lot of confidence, it can sometimes be a bit embarrassing as well."

Special Needs Jungle, a volunteer parent-led blog for parents of children with SEND, surveyed over 1,000 parents and carers in June 2020. Only 18% of respondents said that their child's school had delivered enough SEND support to enable their child to complete their work, with appropriate differentiation identified as a major issue. "A significant minority" said they had received no work at all.

Resources at home

A key part of in-school learning are the resources available to children with additional needs which support and enable their learning. While learning at home, there were noticeable gaps in access to these important resources. NDCS reported that some deaf children were told that they can't take their radio aids hearing technology home from school at this time, even though this could support home learning.

Sense reported that, for many children with complex disabilities, remote solutions were not appropriate and the impact of this was increased social isolation for those young people. Furthermore, many of the educational resources and specialist support children with MSI need cannot be replicated in the home. Accessible resources like Braille, Easy Read and Picture Exchange Communication (PEC) symbol systems aren't affordable or available to families at home to continue learning and outcomes. (Sense)

A parent told the inquiry, via an oral evidence session, that: "We don't, as parents, have access to that specialist software. That's all in schools, with speech and language therapists, it's with the people who make the software."

The National Autistic Society told how children who usually receive SEN Support in school "fell into a gap in provision" during lockdown and were left without any additional support at all. These children were mostly at home, and parents reported that they were unable to provide the specialist support their child received at school to enable them. to learn.

Costs for parents

1Voice told how parents had reported buying spin bikes, hot tubs and ijoy riders out of "desperation" to keep their young people as fit and healthy as possible. Parents reported 'huge delays' for new equipment, such as leg gaiters, to enable vital physical therapy at home. A lack of space, equipment and support from NHS services means the physical needs of these learners have not been met during the pandemic, except for through the additional efforts of families who have the resources to do this.

Changes to routines

Both Ambitious about Autism and the National Autistic Society highlighted the impact that the sudden changes caused by the pandemic had on children and young people with autism. The National Autistic Society described the impact as "disproportionate and devastating" due to the intense anxiety that is felt around unexpected change.

Social aspects of school

Dr Shepherd and Dr Hancock of the University of Sussex found in their survey of 502 carers that social aspects of education (interactions and communication) were the most affected by the learning at home during lockdown. Things like taking turns, sharing, group activities and diverse conversations were not possible at home.

Royal College of Nursing highlighted the key role that being in school plays in helping young people with SEND learn social skills, self-value and confidence. They will likely be unable to use technology to get in touch with friends and have limited social opportunities as a result.

Regional variations

The differences in the experience of young people with SEND between regions and areas was cited as a concern by several contributors. National Deaf Children's Society noted that online learning materials, transition support, early intervention support and recovery plans were available but "not consistently across England". In particular, there were gaps around the support for language and communication.

Sense also spoke of a lack of consistency. with many Local Authority Sensory Services sending equipment such as radio aids home to children who were shielding. They raised a concern that insurance coverage may be a barrier to this equipment being taken home. They described a "postcode lottery" of SEND provision and urged the government to revise its approach to local solutions and create a guidance framework for risk assessment that is appropriate, particularly for young people who are shielding.

Other activities around education

Adoption UK reported that Covid-19 restrictions have impacted the type of activities that were allowed in schools. which has resulted in an increase in challenging behaviour. They give the example of one child in a specialist secondary social, emotional and mental health (SEMH) setting, whose parent said their behaviour had become more challenging as the schooling is now more "sedentary" and "academic" than before lockdown.

Communication between schools and parents

Let Us Communicate spoke in an oral evidence session about the need for better communication with parents: "we're often left in the dark".

Adoption UK reported that where communications between the setting and home were frequent and effective during the lockdown, the transition back to the setting has been more effectively managed and better supported.

Government guidance

Numerous contributors to this inquiry cited the guidance produced by government on SEND provision as an issue, both in terms of its content as well as the manner and timing in which it was produced. A recurring theme is that SEND pupils and their needs have been an "afterthought"⁵.

The changing guidance from government has had an impact on young people with SEND, their families, and schools, particularly where routine is needed to support the young person. Ambitious about Autism said

We've gone from 24/7 residential Monday to Friday term-time and PA support at weekends and holidays, to absolutely nothing and home full-time. I'm a single parent and feeling the strain physically, emotionally, and financially. Nothing is being done to support us.



communicating clearly with children and their parents has been difficult with the complexity and ever-changing nature of Government guidance. They also highlight that this guidance has been focussed on mainstream schools and colleges. They said many parents and children have felt "forgotten and left-behind" in decision-making about education.

National Deaf Children's Society pointed out that the Department for Education failed to consult with organisations representing children with sensory impairments when seeking out feedback on draft guidance.

PLASN contended that decision making appeared to be centred around the needs of pupils in mainstream schools and reported a consensus amongst their members that clearer, setting-specific guidance was needed: "special schools needed to be prioritised by the UK Government rather than treated as an after-thought."

IPSEA highlighted that the concerns of parents of children and voung people who live with someone whose health is at a high risk if they contract Covid-19 regarding their return to educational settings were not addressed. Department for Education guidance on how settings should approach situations like this was initially unclear and not updated in a timely manner. (IPSEA)

The timing of SEND specific guidance was also reported as an issue by NAHT. 86% of respondents to an NAHT survey in June 2020⁶ did not agree that Department for Education guidance had been published in a timely manner and 73% of respondents felt that the delays in producing appropriate DfE guidance had affected their setting's ability to make effective planning decisions.

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NAHT cited the example that school transport guidance, required by pupils and parents/families prior to the summer recess in order to establish expectations for successful September 2020 educational transitions, was not published until August - well after the end of the summer term creating wholly avoidable problems for local authorities and providers in communicating arrangements with families.

The content of DfE guidance is also an issue, suggested NAHT. Speaking about the updated guidance provided at the start of November 2020, NAHT said: "there was a sense that, once again, it was broadly mainstream predicated guidance that did not adequately consider special school and specialist setting needs in catering for pupils with SEND."

NAHT said the consequences of delayed guidance suggests to SEND children, their families and schools that they are "an afterthought". It also delays the ability of settings to meet their pupils' needs and puts the schools and children at a disadvantage compared to mainstream schools when purchasing finite resources such as PPE.

The Royal College of Occupational Therapists (RCOT) referred to the inconsistencies between guidance from the DfE and NHS England which has caused problems for allied health professionals employed by the NHS but also working in schools. RCOT said it has been "confusing and, in some cases conflicting". Timing is again raised by RCOT, who said occupational therapists have been required to read and interpret information from both the DfE and NHS and implement guidance often with little notice.

Sense described the guidance around PPE for personal care support as "insufficient", which has resulted in many young people with complex needs who require such care being unable to return to school. They commented that it had taken the DfE and Public Health England "a significant proportion of time" to review the guidance.

An oral submission from Great Minds Together, a multidisciplinary wraparound team supporting families, schools and services, described the guidance as "chaotic and not sustainable for our schools' professionals or parents and carers".

Government guidance recommended the use of class or year group bubbles to help prevent the spread of Covid-19. However, as Pan London Autism School Network (PLASN) identified, this simply did not take into account the unique context of special schools, where pupils from different classes will be mixing on school transport.

Special Needs Jungle said that a large number of parents who commented during their June 2020 survey believed that government had "abandoned or neglected" children and young people with SEND when responding to the pandemic.

Coronavirus Act and 'reasonable endeavours'

The emergency powers provided to the government by the Coronavirus Act 2020 "watered down" the legislative entitlements to support for children and young people with SEND. Section 42 of the Children and Family Act 2014 was amended so that rather than local authorities having a duty to deliver the special educational and healthcare provision set out in a child's Education

and Health Care (EHC) Plan, they were deemed to have met this duty if they had used "reasonable endeavours" to secure the provision. This temporary amendment was in place between 1 May and 31 July 2020.

National Deaf Children's Society expressed a concern that some families were being given messages implying that their EHC plan can be 'ignored'.

Sense reported that this change had a significant impact on many of the planning processes required to support an effective transition back to school for children and young people with SEND.

Sense described the short and long term impact of this amendment as 'significant' for young people with SEND and their families. They were left without vital care and support, and home learning tasks were not differentiated or accessible for their needs. Furthermore. Sense reported the impact it has had on the schools, local authorities and clinical commissioning groups to plan appropriately for these children to return to school safely. Many of the children that Sense supports have not had all the support they are entitled to in their plan reinstated, even beyond the temporary suspension.

National Autistic Society also expressed concern over the long-lasting effects of this temporary suspension.

Both National Autistic Society and IPSEA reported that some local authorities were retrospectively applying the Amendment Regulations to decisions and steps they had been legally required to take before the amendment came into force on 1 May. The Amendment Regulation caused delays to the EHC plans and meant that young people were unable to participate fully in decisions about their transitions to different phases and schools. (IPSEA)

Blanket policies

Polly Sweeney, a lawyer specialising in education, community care, healthcare and medical treatment, told the inquiry via oral evidence that she was seeing too many cases where schools are applying blanket policies which are having discriminatory effects. She gave an example of generic letters being sent for children to sign up to Covid-19 behavioural policies that young people with SEND would not be able to adhere to.

Delays in the EHCP process

1Voice reported that the Covid-19 pandemic has caused delays to EHC plan processes which have had a detrimental effect on children's education, including delays in finalising college places leading in one case to a young person becoming NEET (Not in Education, Employment or Training).

National Deaf Children's Society raised concerns about the cancellation of routine audiology appointments, which can delay diagnosis and intervention, which will impact on language and communication development later in life. They said that there needs to be an urgent action plan to address this backlog and emergency funding should be provided.

Dinah, a deaf young person, told the inquiry in oral evidence of her experience of applying for an EHC plan. She described is as "a stressful, draining and time-consuming process". She highlighted the problems with not being able to have face-to-face meetings during the process: "It felt as if a bunch of strangers were deciding my future based on what they knew about me on a piece of paper. The application process was made a bit more difficult because

of Covid, meaning I couldn't attend the meetings that normally would happen so I had a few that were online."

Polly Sweeney also reported a backlog of EHC plan assessments and decisions during oral evidence to the inquiry. She claimed that one local authority was still dealing with assessments from 11 months earlier, emphasising that EHC plans were "vital" in ensuring educational transitions can be supported and successful. She noted that delays and backlogs were a problem before the pandemic, but the relaxation of timescales would inevitably make the backlog worse. She said that the guidance from government about how to deal with this backlog was not sufficient despite it being an inevitable consequence.

The need for early intervention was also highlighted by Down Syndrome charity Making Chromosomes Count. They described the information provided to families who have a child with Down Syndrome as "sparse", with many families not realising they can apply for EHC plan assessment before preschool age. Making Chromosomes Count also contended that many families are "actively discouraged" from applying, with local authorities claiming that the child is too young.

Transitions

The inability of young people with SEND to visit new settings due to their closures impacted heavily on their transitions. Royal College of Occupational Therapists said this was particularly difficult for young people with physical and sensory needs, and those who find change difficult. The consequence has been a delay in implementing tools and strategies to support their needs, and taking longer to settle in.

Adoption UK reported that, due to the pandemic, barriers have been created to effective transitions in education for young people with SEND. Some were transitioning with no plan in place, and vital information had not been shared, meaning that, in some cases, EHC Plans were not in place.

A parent of an AAC user told the inquiry via oral evidence how the change in staff teams impacts her daughter: "Her TA's, they're not being trained yet to properly support her. And this just exacerbates a problem that happens anyway with transition for children like my daughter, where each year when you change over to a new staff team, it's almost like they go back to square one, re-training all the TAs, unless you're lucky enough to have continuity, which is guite rare. When it's left to September that child is constantly losing probably about half a term every year. Obviously as you say Covid has been a huge impact, but it does happen again and again anyway."

In oral evidence to the inquiry, Let Us Communicate spoke of young people being "lost in the system" and "still waiting in transition". This was due to ECH Plans not being drafted in time and not able to progress because in-person assessments were not possible. This resulted in some children not moving on to their secondary school placements in September.

Royal College of Nursing described how the transition from primary to secondary school will have been negatively impacted by not being able to have transition days and typical end of school/leaving activities. Similarly, they say if young people are leaving school for adult services or employment then the lack of transition is going to make this life event a lot more difficult for

them.

Transitions post-16

Sense highlighted the case of one young person they were supporting, who was in the middle of transition to college, which had the added issue of moving between local authorities for provision. Support had been available at his current school but had been stopped at the last minute. Covid-19 had caused delays in sending the required paperwork and preparing for transition, which had resulted in the new college being no longer able to support him. Sense expressed concern for the long-term impact on this young person if the situation could not be resolved.

Children's Services Development Group (CSDG), a coalition of leading independent providers of care and specialist education services, reported issues with transitions planning during the pandemic for young people scheduled to leave their specialist provision, which created delays in their move into adult services. They told how their members had experienced pressure from local authorities to extend placements for young people up to age 21. without recourse to the resources required or consideration as to whether this would really be in the best interests of the young person. A consequence of this approach is that it creates placement blockages, limiting future access to specialist education and care placements for younger children.

In 2020, CSDG published its report 'Destination Unknown: improving transitions for care leavers and young people with SEND'⁷. This found that a lack of consistent and effective transition support for young people when they reach 18 and leave care and specialist

Destination Unknown: improving transitions for care leavers and young people with SEND http://www.csdg.org.uk/2020/02/26/destination-unknown-improving-transitions-for-care-leavers-and-young-people-with-send/ (accessed March

education is resulting in unacceptable life outcomes. CSDG's own members have experienced instances where support is removed at inappropriate times, making it very difficult for a young person to complete their education or be appropriately supported to live as independently as possible in an adult social care setting.

IPSEA told how intended educational transitions were disrupted by local authorities and settings' responses to the pandemic, leaving children and young people without suitable placements for longer.

"My disabled son has missed out on his final year at school. This has had a negative effect on his mental well-being. He has had no transition into college, and I'm worried how he is going to cope". (Parent via Family Fund submission)

Career Connects found that some young people who were offered apprenticeship opportunities and supported internship placements were told they were no longer available due to the Covid-19 pandemic. Therefore, they have been left without a post-16 option. This has meant that those young people have suffered setbacks and this has again affected their mental health and wellbeing.

National Deaf Children's Society reported how the Treasury had announced a package of measures to support young jobseekers which include a new Kickstart scheme for work placements, an expansion of traineeships and more careers advisors. They emphasised the importance that deaf children were considered in such initiatives.

Return to school post-first lockdown

The prospect of a return to school

following the first lockdown caused anxiety and concern for many young people with SEND and their families. Ambitious about Autism said, via oral evidence to the group, that 70% of autistic children and young people and their parents and carers have lost sleep worrying about their return to education and just over half weren't confident that the support would be in place to meet their needs when they return to education.

The provision required by young people with SEND was often not in place for their return to school in September 2020. IPSEA described it as "lacking" and reported that they had spoken to parents who said there was "no reintegration plan" and that support specified in the EHC plan would not be provided, including 1:1 support.

Polly Sweeney also spoke of cases where the provision outlined in EHC Plans was not being delivered on the return to school, particularly 1:1 assistance and therapeutic support. She also highlighted that there was a lack of targeted catchup, which many pupils with SEND would need if they had been unable to access online learning while at home.

"Going back to college, they didn't have the ability to support me, so I couldn't go back. If I had an Education Health Care Plan they would have put things in place" - a young person with cerebral palsy and learning difficulties via oral evidence.

In written evidence, IPSEA gave an example of a child who was meant to reintegrate into secondary school after being home-educated for a few years. They needed the special educational provision in their EHC plan to be implemented to facilitate a successful transition. This did not happen "due to Covid restrictions at school". They needed a toilet pass but were told

We have been very isolated. The initial lockdown was very confusing to our children and now restrictions have been eased and they are expected to return to school without any support regarding transition etc. Their worlds were already very confusing before coronavirus and are even more so now.



they could not have one due to current circumstances.

External specialists on school sites

Covid-19 restrictions and risk assessments preventing external visitors into school is an issue which has been cited by several organisations and individuals who contributed.

Sense found that whilst some children are now back at school, many settings were not allowing external professionals back in, resulting in children not having access to important therapies. Sense also gave an example of a school refusing to allow a specialist technician on site to fix a radio aid. They noted that there was guidance which said this was unacceptable but that there was little accountability.

Schools being closed meant that occupational therapists could not review accessibility and classroom settings ahead of transitions in September. "Even when schools reopened to more students from June 2020, many were reluctant to receive visitors including occupational therapists." The result of this is that children returned to school in September without the equipment or support they required being in place. (RCOT)

A parent of a child who uses AAC told the inquiry via oral evidence that "none of those staff have been able to be properly trained in using her AAC because as well as other complications, they haven't wanted external therapists to go in. And so her TAs are not being trained yet to properly support her."

IPSEA highlighted that parents were also not allowed on site to help their children transition back to school. They cite the example of one pupil whose anxiety and school refusal started getting worse again because of this.

Alternative support for transitions

Many mainstream and specialist schools did their best to support and aid transitions between settings during the pandemic, with many offering virtual tours and support in lieu of the children and young people being able to visit and spend time there. However, as with online learning, there were accessibility issues for children and young people with SEND.

Royal College of Occupational Therapists reported that some young people with SEND found virtual tours stressful and may not have been able to generalize information they were given to a "reallife context". Some young people were unable to access virtual tours due to lack of access to the internet, limited technical skills within their household and anxiety about using unfamiliar technology. The transitions of young people were affected by not having the face-to-face meetings, as it was more difficult for occupational therapists to build up a relationship with young people during virtual visits and to identify students/families who would benefit from additional support.

A parent via oral submission spoke of how her daughter could not go and visit university as a result of lockdown: "She had to move into accommodation having not been able to see it - we did see a virtual tour, fortunately there was one online - but it's not quite the same as getting a feel for it as well."

There were some positives to a virtual transition identified by Essex Family Forum. They spoke of students from the

Multi-Schools Council who said they had felt very well supported by transition from primary to secondary school. A benefit included that virtual tours were available to watch - and, if desired, rewatch - from home with family and friends.

A head teacher of a special school in London gave oral evidence as to the way his school had adapted their transition process and identified some positives: "Because I couldn't risk Covid mixing - we're a Covid-secure school - we invited families in on the Saturday and, to be honest, it was so good because we could actually focus our time on the families." He spoke about how they had arranged for autistic young people to have special visits where they focussed on important things to make them feel settled, such as where to go and where to hang their coat.

Masks

For children who had been able to be in school or return to school, Sense reported that the wearing of masks had made it difficult for some children to participate. Children who rely on lipreading have had their ability to understand their teachers and other pupils affected.

A deaf young person told the inquiry during oral evidence that: "Socially it can be quite isolating with the whole masks thing because at the moment my school has rules that in communal places everyone needs to wear masks... I'm quite heavily reliant on lipreading."

Risk assessments and refusing attendance

A survey by Special Needs Jungle, conducted in June 2020, of more than 1,000 families who identified themselves as caring for a child or young person with SEND in England, found:

- 75% of respondents said that their child had not had a risk assessment, or they did not know if one had been conducted.
- Of the parents whose children had undergone a risk assessment, only 9% said they had been fully involved.
- Even if they knew a risk assessment had taken place, most parents were not involved at all.
- In their comments a number
 of parents indicated that a risk
 assessment had been used to actively
 dissuade them from sending their
 child in or to prevent their child's
 attendance.

Children and young people with education, health and care (EHC) plans were at home experiencing the above difficulties because their setting refused attendance. (Special Needs Jungle)

IPSEA were also told of settings refusing attendance based on risk assessments with little or no input from parents. Settings were also unlawfully excluding children in response to a perceived inability to meet their needs "attempting to rely on Covid-19 as a reason to justify this". IPSEA also reported parents' concerns that risk assessments were done without their knowledge and many were not aware of the requirements for them to be done. Furthermore, they cite several examples where local authorities have acted unlawfully in putting EHC Plan assessments on hold due to the pandemic.

Sense also report that risk assessments were also often conducted without input from families and they were used "sporadically". Had there been some opportunity to discuss and work together, then perhaps those children could have returned to school rather

than "blanket decisions" being made about their needs. (Sense via oral evidence)

The lack of a proper framework for completing the risk assessments meant that there was regional interpretation and variation. Sense expressed concerns that risk assessments were being used as a means of keeping children with additional needs at home, rather than making reasonable adjustments at school, which has meant some children being unable to return.

Aerosol Generating Procedures

Royal College of Nursing highlighted an area of risk in specialist school settings where children in schools require aerosol generating procedures (AGPs) such as oral suction, tracheal suction or long term ventilation. These pupils are only able to access school if the school environment has adequate provision, the staff have been 'FIT' tested, and the risk assessment supports their safety and that of their fellow class members. RCN members reported that the guidance from Public Health England was very difficult for the school to adhere to. (RCN)

Sense also expressed concern for pupils who require AGPs, describing their return to school as "challenging", with many unable to return in September and missing further learning. Sense contends that the "watering down" of rights and entitlements to support under Section 42 of the Children and Families Act, have led to a lack of forward planning in terms of identifying spaces to carry out AGPs in schools.

Pupils unable to return to school

In oral evidence, Great Minds Together

attested that there were several factors affecting whether children could return to school, such as the school refusing them attendance, the pupil's anxiety, illegal exclusion, and no suitable space in school for a medical device. "I'm almost certain that nobody knows this actual exact figure at all, as was the case even prior to the recent pandemic". (Emma Mander, Great Minds Together, via oral evidence)

Sense were concerned about the impact that not being at school would have on the young person's support plan, as assessments would be missed if they were at home. This has particularly impacted young people who were transitioning to new settings, as they were not able to start in September as planned due to the required support not being in place.

Children who are shielding

Sense also raised concerns about children who were having to shield at home because of complex medical needs and being extremely clinically vulnerable. They are missing out on important therapies, but also achieving person-centred outcomes, such as learning independent living skills, if they are having to shield for a long period of time. Sense contended that they must be given the support to continue achieving those outcomes at home.

Sense also raised an issue about the guidance on shielding not appropriately recognising the needs of those children who were required to shield. Many families have received no risk assessment or alternative support from their local authority throughout the Spring lockdown.

Funding

The issue of funding was raised by the Local Government Association (LGA) in both their written and oral evidence. They said that councils are continuing to report the pressures on the High Needs funding block as "one of the most serious financial challenges" they face. They expressed concern that local authorities would be unable to meet their statutory duties to support children with SEND without additional funding being made available.

"If councils do not receive enough funding to cover the high cost of SEND they will not have the resources to allocate extra funding to highly inclusive schools that take higher than average numbers of pupils with additional needs". (LGA, oral submission)

Children's Services Development Group (CSDG) noticed that the pandemic resulted in commissioning decisions being made on the basis of short-term funding concerns. They gave the example of placements being ended sooner than planned "to mitigate funding obligations for young people with SEND". This meant that children had to return home unexpectedly which meant there wasn't time for a transition to be planned and support put in place.

CSDG also explained that High Needs funding has been a developing problem over many years and is something that has been "exacerbated" by the pandemic. This has led to regional variations based on access to services, available funding and "placement decisions typically now being based on short-term cost considerations, rather than the full needs of the child".

NAHT referenced the funding issues that are being faced by all education

settings due to the exceptional costs they are incurring as a result of the pandemic. However, they assert that this will likely be even more acute in SEND and alternative provision settings. This may lead to schools not being able to maintain acceptable levels of safety.

"This does not appear to be due to any lack of will or commitment from pupils, parents/families nor schools/settings - more frequently it appears to be due to a deficit in each sector related to capacity, inadequate resource, a paucity of mechanisms for effective collaboration and limited understanding between sectors as to what is required for all our pupils to maintain their wellbeing, engagement, progress and learning - this has become particularly clear during Covid-19 (NAHT)"

Local councils

Local Government Association (LGA) reported a positive relationship between schools and local authorities which has flourished during Covid-19. They provide the example of councils supporting schools to interpret the guidance from the DfE, and that it is important that the positive relationships continue.

LGA also referenced the government's SEND review and, from that, there needs to be a clear accountability network created and flexibility around funding. They said that the pandemic has shown the challenges that councils, schools and health care providers currently have in fulfilling their duties to support children with SEND.

Agencies working together

Parents painted a picture of the difficulties they encounter when trying to achieve the support their children's needs. One parent, in oral evidence,

described her family's experience of post-19 transitions as:

"... being caught in the middle of a maelstrom as Education, Social Care and Health argue over who funds what. The system is confused, I'm confused, our families are confused, but most of all so are our young people, as many are still left not knowing what they're doing and where they're going. It seems that everything has ground to a halt. Where is the joint funding? Why are we having arguments between three different departments?" (Parent via oral evidence)

Another parent in oral evidence spoke of the barriers they face with what is classed as education for the Disabled Students' Allowance (DSA) and what is classed as education for the EHC Plan. She told how the CCG wouldn't offer the therapeutic support that was previously provided through the EHC Plan, as it is not classed as educational when it comes to DSA: "there's this big gaping hole that you go from one to the other and there's no consistency".

Exams

National Deaf Children's Society spoke of the worry young people had over the exams being teacher-assessed or based on their mock exams as both can put children with disabilities at a disadvantage. If the performance situation, such as a mock exam, was not fully accessible or their teacher has limited expectation for them due to their disability, then there is a risk of future disadvantage for this cohort.

Positives from the situation

There are some positives from the impact of Covid-19 on learning. Essex County Council said the children and young people from the Multi-Schools

Council are now reporting that, for some children with additional needs, coming back to school in a 'Covid-Safe' manner and the additional structure that this provides is a positive – for example having slightly more space in the classroom and quieter playtimes with less children around them.

Another benefit of the new Covid regulations in schools was reported by IPSEA. A secondary pupil found staying with the same group and in the same room beneficial, rather than having to move around the school.

NAHT also described the Initial lockdown as providing some opportunity for certain children and young people with SEMH to experience a more settled time and actually enjoy periods of less anxiety at home. This was more so at the beginning of the initial March 2020 lockdown. However, over time this initial positive impact did appear to reduce.

This is supported by Royal College of Occupational Therapists who said that parents/carers of young people with SEND reported that being away from the pressure and demands of school benefitted their well-being.

Special Needs Jungle found in their survey that whilst 37% of parents responded that their child's anxiety levels had increased under lockdown, 38% said their child's anxiety levels had decreased. Some parents reported that freedom to learn in different ways away from the school environment had made their child less anxious and better able to learn.

Some young people shared with Essex Family Forum that they enjoyed doing schoolwork from home because it meant they did not experience any bullying. For other children and young people, the time away from school settings was

a positive, with some parents reporting that their child's anxiety level decreased out of school.

IPSEA reported that parents said their children who were struggling to attend school before the closures found being at home easier. They believe that this is likely to reflect inadequacies in their provision before the pandemic rather than there being a benefit to home learning.

One parent said via the Adoption UK submission: "She is a completely different child - relaxed on the whole, healthier, more able to regulate, able to accept consequences for behaviour, playing board games, having a healthier relationship with her sister and dad. She has embraced home learning and is enjoying learning."

For some of these parents, this period at home had prompted them to consider more permanent changes. 10% of respondents stated that they were now 'likely' or 'very likely' to consider home educating their child permanently. (Adoption UK)

PLASN members noted that some partnerships with other agencies were more effective during the Covid-19 pandemic as technology allowed a range of stakeholders to contribute to annual reviews remotely.

"The College were very good. They closed about a week before lockdown and they used Microsoft Teams so she had regular sessions most days - it might not have been for very long but there was that routine there which was very much needed, And actually some positives came from that because we found some more effective ways of support actually during that such as electronic note-taking, which has now

followed on to university because we know it works really well when the notes are taken and can be seen at the same time". (Parent via oral submission)

Exacerbating existing problems

The most common theme throughout the submissions received by this inquiry, was that the SEND system was already problematic, and that Covid-19 only exacerbated existing problems for young people with SEND and their families.

"The pandemic has hit a statutory system that was already in crisis and Covid-19 has only further intensified the issues which children, young people and families are facing." – Polly Sweeney, lawyer specialising in education

1Voice described the pandemic as "amplifying" existing problems for AAC users. Sense reported they were seeing that the inequalities and challenges families already faced in accessing the education and support that they needed has just been "broadened and made more complex" during Covid

Children and young people in unsuitable settings or out of school before the pandemic have not been able to transition to educational settings that can meet their needs. (IPSEA)

National Autistic Society said many of the children on the autistic spectrum were not getting the support they needed before the coronavirus outbreak began⁸. When lockdown began in March 2020, they struggled more than ever, along with other children and families who had the services they rely on removed or reduced. (National Autistic Society)

A parent of a 10-year-old girl with autism reported that schools, local authorities,

^{8 &#}x27;Autism and education 2017', the report of an inquiry undertaken by the All-Party Parliamentary Group on Autism

and healthcare services regularly miss deadlines (e.g. for EHCP turnarounds) but are not penalised. When parents miss deadlines there is often no provision to accommodate.

Mental health and wellbeing

Ambitious about Autism's survey revealed that 4 out of 5 autistic young people experienced mental health issues before the pandemic and 63% reflected that their mental health had worsened due to the pandemic.

Several parents reported during the survey by 1Voice that their young people suffered with anxiety which compounded mental health struggles. The young people themselves highlighted the strain this extended isolation and dependence on their parents put on family relationships. While some have accessed online counselling to try to get some support with this, the majority have not. (1Voice)

Career Connect advisers have reported examples of significant deterioration in young people's mental health and increased anxiety levels have been reported across all settings. This has led to an increase in reported self-harm and increased referrals to specialist mental health services such as CAMHS.

The Multi Schools Council via the Essex County Council Submission said some children reported high levels of anxiety when going to school during the pandemic (as key worker children) because they didn't know who would be there and whether they would have any friends.

In their online surveys of families raising

disabled or seriously ill young people⁹, Family Fund found that 50% said their seriously ill or disabled children were nervous/stressed about returning to school and 81% of families reported their child's mental health had been negatively impacted.

Dr Shepherd and Dr Hancock of University of Sussex found that parent carers reported that a focus on mental health and wellbeing was a top priority for the first term of education. There was also an emphasis on the wider curriculum and a child led, fun, safe, and nurturing learning environment to support wellbeing.

National Deaf Children's Society raised the point that many resources on emotional wellbeing are not always accessible to deaf young people.

Children's Development Services Group also described how their members have struggled to access mental health support for young people in their care. Assessments have been delayed and the wellbeing of young people has been impacted by Covid-19.

Anxiety was caused by the loss of routine for many young people with autism. 68% of family members who responded to a National Autistic Society survey¹⁰ of 4,000 families said their child was anxious at the loss of routine during lockdown and 65 per cent said they were unable to complete online work. (National Autistic Society)

Royal College of Nursing (RCN) described how children with SEND who have returned to school are often hyper vigilant, anxious, and irrational which means that cortisol levels will run high.

⁹ Family Fund: conducted three waves of online surveys: late March/early April, late April/early May, and August 2020. They surveyed families raising disabled or serious ill young people. The sample sizes were 1,574 families, 2,197 families and 2,149 families respectively.

National Autistic Society (September 2020), Left stranded: the impact of coronavirus on autistic people and their families in the UK.

They cited research that shows how high cortisol levels impact memory imprint and have a negative effect on learning.

The impact on mental health and wellbeing of family members who were responsible for caring and educating young people with SEND is an important consideration. Sense reported that many siblings were "significantly emotionally impacted" by having to attend school and in doing so risk bringing the virus home to their clinically extremely vulnerable siblings. Sense highlighted that there had been little guidance on what to do if a child has a clinically extremely vulnerable parent and doesn't feel safe returning to school. Sense

called for guidance for schools to take a flexible approach to authorising absences.

Family Fund identified that 54% of their respondents were not receiving the respite/short break provision that they had prior to the pandemic, which had an impact on the wellbeing of parents and carers.

And all the support we did have, that I had managed to put in place, was just gone.



Hearing their voice: young people and parents in their own words

Support stopped or reduced

"My daughter has SEN, statement and full time 1-1 support but the school have not acknowledged this at all." - Parent via Adoption UK submission

"It is very sad to see that the lives and care of our young people is regarded as so unimportant that the services we rely on for support, such as community learning difficulty team, were deemed non-essential and closed down for six months." - Parent via the 1Voice submission

"Without my live speaker, my ability to get the grades I know I deserve is severely limited. And seven to eight months of no face-to-face contact with my teachers has put me in a heavily disadvantaged position. As a result I've had to do a third year since I know I will not be able to get into my University of choice which would be Oxford." - Deaf young person, via oral submission

"And all the support we did have, that I had managed to put in place, was iust gone. And I think over the entire period of lockdown I had one phone call from the school where he was on the roll, although he was getting what's termed as alternative provision. But other than that. I had no contact from the local authority or from social services' disability team or anything like that to find out how we, as a family were coping." - Parent of a child with diagnoses of ASC and ADHD, via oral submission

"My son had lost all connection with day services, clubs and respite. My son has routine, but his world has been turned upside down." - Parent via Ambitious about Autism submission

Accessibility of home learning and differentiation

"To access learning everything must be differentiated for my daughter. She can use her computer to spell out words and construct sentences and answers, but she cannot hold a pencil, she cannot hold a book, she cannot access worksheets, so if there is a worksheet or a website that needs to be accessed, she can't do that independently.

So, when we went into lockdown, we struggled at home greatly to support her learning because nothing that came from school was made accessible for her. So, there would be a task put up digitally which would say, you know, "look at this website, write a few sentences about your experience with this or what you thought of it".

But for my daughter, she would need us to access the website, press play, find, maybe create a grid on her computer so she could put the words in the right order. None of that was done from school. So, her learning and ability to progress was massively affected by it." -Parent of a child who uses AAC, via oral evidence

"We went into lockdown. Things moved online. I'm not great with technology, so couldn't take part. My tutor was understanding that I couldn't do the work. I felt isolated and couldn't complete everything for the course. I still passed but wish I could finish properly."

- Young person with Cerebral Palsy and Learning difficulties via oral submission

"During the lockdown from March onwards our child received education in a very sporadic fashion. Lessons were not consistent, some not even taking place, language subjects used language videos such as Seneca for the entire lockdown, tests were given at the same time as answers, and there was no marking at all in the whole of the lockdown period. There was nothing to know the child had understood the information received. Quite a lot of the time all they had to do was click a box that stated, 'Marked As Done'." - Parent of a 16-vear-old

"Ask for default subtitling on all video calls - that would make a massive difference because there are so many occasions where I've been in lessons and the subtitles have not been on even though they're very easy solution to have. Also, clear face masks, more awareness, if you could provide funding for schools that can't provide face masks for students that would be a big difference as well." - Deaf young person via oral evidence

Changes to routines

"My son has routine, but his world has been turned upside down." - Parent via **Ambitious about Autism oral survey**

"My name is N and I am 16. I am dependent on routine and structure needing a rigid plan for each and every day. And now, nothing is clear. I am

no longer receiving constant support from CAMHS; telephone calls have been offered but I am deaf, so they aren't accessible. I can't cope with the uncertainty of all this and feel as though I am stuck." - Young person via National **Autistic Society submission**

Social

"Lockdown was great for a while as it took the pressure off. Now of course, he is in a well-established pattern of seclusion." - Parent via RCOT submission

EHCPs

"I also wanted to ask why such a long process to get an EHCP and why there's a very much a lack of support at the same time the applications are going through. To me, it meant taking off a year of school." - Deaf young person via oral evidence

Transitions

"My name is Amy, and I am autistic. This September. I have gone to secondary school and feel more could have been done in the way of transition during Covid-19.

I feel it should be mandatory to have some form of transition that shows how things will look in your new school and introduce you to the staff that will teach a person.

I also think more money should be put into our local council for pastoral support in the classroom. This would be helpful to educate (using the curriculum) students as well as teaching them life skills and supporting them. It was very helpful to me in primary school and is in secondary school too.

If there is more work on transition and pastoral support during a pandemic it will be beneficial for students like me in the future if another pandemic happens it will help others with anxiety." - Young person with autism

"There are no specialist colleges locally, so we have looked at mainstream colleges and we have only been able to do so online watching open days, this really does not give a feel for the college being suitable or give you the opportunity to speak to staff especially SEN support staff.

We need to ensure the college my child attends can provide the support for my child's special education needs and it is proving difficult to speak to the SENCOs at the colleges we are interested in, although I have written to the SEN departments, I have still not received a reply.

The annual review is a slow process finalising professional reports from the school and I am expecting the LA will then slow the process down further by issuing a nonsense EHCP that I will endeavour to ensure has the provision my child needs, so I will once again most likely find that I will have to appeal. This appeal will take place while I am trying to support my child through GCSEs and trying to find a placement that can meet my child's needs. It will be difficult to secure a suitable college without a finalised EHCP." - Parent of a child transitioning to post-16 placement in September 2021

"Transition from primary school to secondary school is vast. It's massive and it takes a little bit of early intervention and if families are not getting that within a mainstream environment, they will be forced to go to a specialist." - Parent via oral submission

"The week before college started, I received a phone call from the taxi company to ask if H was returning to college because she wasn't on their list. This was a surprise to me as this is H's 3rd year at the college and transport has always been in place. I called transport and she wasn't on their list either. The transport team then realised that it was because H had turned 19 and her social worker had not submitted the paperwork needed. After transport and myself had been in touch with the social worker, H's transport was put into place a couple of days before she was due to return. The first week of college I discovered that H didn't have transport on Tuesdays because it's a half day and NYCC will only pay for transport mornings and at the end of the day. For the past two weeks her PA has taken her on Tuesdays. The social worker has been in talks with the transport team and has now managed to get a taxi in place for Tuesdays." - Parent's experience of post-19 transport

"[Named LA] have decided to cease the EHCP in July. My son will be unlikely to return before this, so will have no 'ending', not complete his objectives and have no transition. He also has nowhere to transition to. We've gone from 24/7 residential Monday to Friday term time and PA support at weekends and holidays to absolutely nothing and home full time. I'm a single parent and feeling the strain physically, emotionally, and financially. Nothing is being done to support us." - Parent via Special Needs Jungle submission

"Look at how they managed the transition of children with SEN from primary to secondary. My daughter should have been transitioning for at least 5 months prior to finishing primary and then she should have been having a full week in school holidays getting to

know the teachers and other children. None of which could be done because of Covid-19, but now she is expected to just go straight into secondary school".

- Parent via Family Fund submission

"My disabled son has missed out on his final year at school this has had a negative effect on his mental well-being. He has had no transition into college, and I'm worried how he is going to cope".

- Parent via Family Fund submission

"Some young people are transitioning without finishing courses they were on. And the specialist colleges are reporting they cannot provide for them to finish what they started. The communication between the local authority and families has been non-existent until complaints procedures are started." - Parent via oral evidence

"There are no specialist colleges locally, so we have looked at mainstream colleges and we have only be able to do so online watching open days, this really does not give a feel for the college being suitable or give you the opportunity to speak to staff especially SEN support staff.

We need to ensure the college my child attends can provide the support for my child's special education needs and it is proving difficult to speak to the SENCOs at the colleges we are interested in, although I have written to the SEN departments, I have still not received a reply.

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to support my child through GCSEs and trying to find a placement that can meet my child's needs. It will be difficult to secure a suitable college without a finalised EHCP." - Parent of a child transitioning to post-16 placement in September 2021

Return to school post-first lockdown

"There are hundreds, if not thousands, of children across the country who are transitioning back into education quite apart from the Covid situation.

And more worryingly perhaps are the children who are not able to undergo those transitions because there simply aren't the places available for them."

- Parent of a child with diagnoses of ASC and ADHD, via oral submission

"We have been very isolated. The initial lockdown was very confusing to our children and now restrictions have been eased and they are expected to return to school without any support regarding transition etc. ...Their worlds were already very confusing before coronavirus and are even more so now". - Parent via Family Fund submission

Risk assessments

"My input was added once the decision that my son had to stay home had already been made." - Parent via Special Needs Jungle submission

"The risk assessment was written without our input and had to request a copy. No information about a return risk assessment" – Parent via Special Needs Jungle submission

"We had a letter to say a risk assessment has been undertaken and it is deemed not safe for him to return to school at the present time. I haven't received any further details." - Parent via the Special

Needs Jungle submission

"A risk assessment is in place for her transfer to and from her placement for home visits (alternate weekends and school holidays). I was impressed with the detail the school included." - Parent via Special Needs Jungle submission

Covid regulations

"Ever since the start of the pandemic it was crystal clear that whilst rules were in place to protect social distancing, bubbles, restrictions on movement etc., that my son wouldn't be able to attend school. Not because his behaviour is poor - because actually he's well behaved - but because of his extremely poor understanding and his need to have breaks between sessions of learning. We can't explain to him what has happened. He needs to be able to move around school and access toys, sand, water etc., but he can't any more. There isn't the space - the school has no free rooms or space, the items he usually plays with have been removed, and he can't go into those bubbles. He inevitably would need to be restrained, and that the effects undoubtably will have a long term effect on his health. On top of that, it took him two weeks following schools closing before he stopped putting his school uniform every day and attempting to leave the house. This period of time was very difficult and his stress levels went through the roof." - Parent of a 10-yearold with complex needs including Down's Syndrome, Hearing Impairment, Visual Impairment, no speech and poor communication

"My understanding is that Jay spends minimal time in the classroom, if any time at all. The classroom has been arranged with rows of forward-facing desks, like a Victorian classroom but without spaces between the desks, as the classroom is tight for 29 pupils, 1 teacher and class TA, and two TAs working one to one with pupils with EHCPs." - Parent of a young person with sensory, motor, learning and communication disabilities associated with Down syndrome

"There have been numerous changes to routines, change in classmates and rota. My child was in a constant state of terror, hyper-excitement and not regulated'.

- Parent via Ambitious about Autism submission

Positives

"The huge drop in anxiety by not being at school. He struggles with eating and weight gain but since stopping school has gained 3kg and looks amazing. He is not bullied or left feeling worthless anymore like he does at school." - Parent via Dr Shepherd and Dr Hancock's research

Exacerbating pre-existing problems

"You have no idea what you're actually entitled to and what your child could get. It's almost as if they're hiding it from you because they don't want to tell you what is out there. And obviously that is no help to you or your child." - Parent via oral submission

"It's (Covid) exacerbating previous inequalities that were already there, and failings in the system." - Parent via oral submission

"One of the things that I wanted to emphasise is that when we talk about SEND and the reviews into SEND, the discussion seems to be about fixing a problem. But ultimately what we're talking about is children and young people. And I'm very clear that my child is not a problem to be fixed. The system has systematic problems, but my child is a person, not a problem, and I think that needs to be remembered." - Parent via oral submission

"In November 'I' will have missed a year of secondary school, a bright child who is missing out on his education, but more importantly he has no peer group /friends, no age-appropriate activities with friends, no emotional learning with people his age, no confidence to go out alone meet people etc. He is 13 in December he has missed two years of school (Y3 and Y7) we have no idea if and when he will join a Y8 class. This is only a snapshot of the multiple failures we have met as a SEN family exacerbated by the current situation." -

Parent of a 12-year-old with ASD profile ADHD sensory processing

Mental health

"So how my mental health has been during 2020 is it hasn't been too easy. It's been slightly grim, particularly in the beginning of the March lockdown That was when we were really going to go into draconian measures when we all had to quarantine ourselves in our homes and we couldn't be able to do a lot of the things we always loved doing in our lives." - Young person with autism via oral evidence

"She has no EHC plan, is performing academically four years behind her peers (in mainstream school), has secondary cancer and is getting a welfare call once a week and work sent home that she can't do. She has been told to stay in her room as she is high risk. We are dealing with huge meltdowns and daily verbal abuse. This is all caused by anxiety, uncertainty and no routine." - Parent of autistic teenager via National Autistic Society submission

"You have - there is no other way of putting this - ruined my life. You have put my life on hold for the last two years and I am so sick of it. Every day I hope and dream for a better life but all you have done is shut my life down. How dare you. You are supposed to be there for the youth, to help them grow up into better people. All you have done to me and many others is disgrace and ruin us." - Young person via Great Minds oral evidence

"Realise that if a special needs child attends a residential school and is now home, that this will impact the lone parent and other siblings. Doctors to be more accessible and not have to wait for two weeks for a consultation. I personally found the stress so great I cut my wrists twice! However, this was not flagged up and no help offered! I had to struggle on with two disabled children at home, a daughter who suffered depression with two very small children and an older son who lives on his own with psychosis and schizophrenia." - Parent/carer via SENTalk submission

"One of our parents has had her 19-yearold sectioned last week. He couldn't cope with the confinement of being at home. Ran away several times and was eventually picked up 25 miles away sitting on a bridge." - A local parents' group via National Autistic Society submission

"The impact of this on our child and ourselves as parent carers is going to have a lasting effect. We are both exhausted physically and emotionally. We are still in lockdown due to our child's vulnerability...we are both suffering with anxiety and depression."

- Parent of a child who uses AAC, via the 1Voice survey and submission

She has been told to stay in her room as she is high risk. We are dealing with huge meltdowns and daily verbal abuse. This is all caused by anxiety, uncertainty and no routine.



Summary of recommendations

Adoption UK

- Funding and resources allocated to allow the extension of learning support, including 1-1 support where needed for children with recognised SEND, especially those with SEMH
- Funding and resources allocated to expedite access to higher level support (including progressing EHCP applications and reviews) especially where processes have been delayed due to Covid-19, or SEND needs have become more severe due to missing education during partial school closures
- Funding and resources allocated to provide additional counselling and mental health support for those who need it, and especially those with a history of trauma, or who may have experienced trauma, bereavement, anxiety due to loss of family income and other challenges during Covid-19
- In view of continuing partial closures and bubbles isolating at home, the DfE to provide specific guidance to schools about supporting care experienced children and those with SEND, and SEMH needs during school closures, including maintaining effective homeschool communications, providing differentiated work, and making effective use of Pupil Premium Plus and funding associated with SEND

Pan London Autism Schools Network

Despite providing crucially important provision to some of the most vulnerable young people in society, there was a consensus from PLASN members that special schools were overlooked by the

UK Government during the Covid-19 pandemic. Recent research with mainstream school staff has highlighted the challenges they faced in operating their settings given the lack of guidance (and/or lack of notice of guidance) from the UK Government (Kim & Asbury, 2020). PLASN members felt that these issues were particularly problematic for special schools. As one example, guidance on minimising contact between individuals was introduced in schools across the UK to limit the spread of Covid-19. Mainstream schools were able to address this with the implementation of initiatives such as 'bubbles' (to ensure that staff and pupils in different year/ class groups did not mix), yet special school pupils do not just encounter one another in school but also via school transport services. This reflects how special school pupils often need to travel significant distances to access appropriate educational that meets their needs (APPGA, 2017). Even prior to the Covid-19 pandemic, the coordination and provision of accessible pupil transport services for those with SEND has been reported to be a complex endeavour (Ross et al., 2020). The use of class/ year group bubbles recommended to limit the spread of Covid-19 simply did not take into account the unique context of special schools, where pupils from different classes will be mixing on school transport. As a result, a single positive Covid-19 case in a special school can lead to sizeable numbers of children across different class bubbles needing to self-isolate (as some of the PLASN schools have experienced first-hand).

There was a consensus from PLASN members that clearer, setting-specific guidance was needed for schools, and much earlier. Put bluntly, special

schools needed to be prioritised by the UK Government rather than treated as an afterthought. Research with staff in mainstream schools has highlighted the need for more joined-up thinking from the Government in their Covid-19 educational response (Kim & Asbury, 2020). Mainstream school staff have also emphasised the need for greater clarity in communications to school (to facilitate planning by school staff), and additional opportunities for consultations that include a broader range of stakeholders (Kim & Asbury, 2020). We echo these calls, and further highlight the need for senior leaders of special schools to be centred in such conversations: whilst special schools may cater for a minority of pupils, these pupils have some of the most significant levels of need.

To meet special school pupils' high levels of need, one of the first actions undertaken by PLASN schools (in March 2020, following the announcement of strict physical distancing measures) was the creation and completion of detailed and robust risk assessments, to continue delivery of services to every pupil. The goal was to identify the most vulnerable pupils and families, in order to coordinate the educational provisions on offer to each pupil. PLASN schools emphasised the need to take a holistic approach to support; defining vulnerability not just in relation to SEND, but acknowledging the multiple, intersecting ways that pupils and families could be vulnerable (for example, ensuring that the needs of single parents and/or parents with additional needs themselves were met). Initiatives such as providing food and educational resources to families was encouraged.

Underpinning schools' ability to provide holistic support was the focus on clear and regular communication with families, to build robust partnerships. PLASN members ensured that their schools

facilitated communication with parents via a variety of routes. For example, some schools implemented a policy of weekly calls to families; discussing the highs and lows of the week, any issues, and any important school updates. Parents were encouraged to contact the school if there were any problems and PLASN members emphasised the need to be responsive to parents and accommodate all requests (especially in crisis situations). Conscious of the need to be sensitive to the language barriers experienced by many families living in multicultural London, PLASN schools arranged for staff who spoke the families' home language to call home; ensuring that their needs were truly understood, and subsequently met. Learning more about their school communities and their home circumstances during the Covid-19 pandemic was reported to be hugely beneficial in developing positive home-school relationships. The emphasis was not only on the mental health and wellbeing of pupils, but also striving to ensure the safety and wellbeing of their families. Taking a proactive approach also meant that schools could act swiftly in addressing any issues and/ or safeguarding concerns as and when they arose. Holistic support was felt to be particularly crucial given the high levels of caregiver burden and parenting stress experienced by parents of autistic children with complex needs (Baykal et al., 2019; Postorino et al., 2019). The adaptations implemented as part of schools' Covid-19 responses were found to be particularly helpful in this regard. For example, removing the need for face-to-face consultations with parents proved advantageous to families (e.g., reducing the burden of organising childcare). Some PLASN members reported that, post-pandemic, they planned to have more regular, online parent consultations (as opposed to less frequent, in-person meetings) as a result of this.

Despite these newfound opportunities, the Covid-19 pandemic was felt to expose and perpetuate inequality among an already vulnerable group of pupils and families (see also Pellicano & Stears. 2020). Even before the pandemic. many of the pupils attending PLASN schools (and their families) were felt to be disproportionately disadvantaged and on the margins of society. For example, the stigma experienced by parents of children and young people on the autistic spectrum and/or with intellectual disabilities has been well documented (Mitter et al., 2019). This disadvantage is often compounded by a range of other intersecting factors (e.g., being from a minority ethnic background) and/or factors directly related to having a child with SEND (e.g., financial hardship associated with being unable to maintain employment due to caring responsibilities). PLASN school staff emphasised the need to go beyond the young people's SEND and take a broader approach to identifying need. As one example, technology has become a valuable tool for facilitating education during the Covid-19 pandemic, yet this limited opportunities for those who did not have access to computers or the internet (Van Dijk, 2017). Ensuring all pupils and their families have the necessary resources to access their education - at school and at home - was felt to be crucially important, particularly for vulnerable groups attending specialist educational provisions. PLASN schools ensured that if they were not able to offer the support themselves. they signposted families where needed (e.g., to charities, food banks).

The need for greater support for home learning was also crucial given that not all pupils were able to attend school during the Covid-19 pandemic. This was especially true for pupils in PLASN schools, as even those who were offered the opportunity to continue receiving their education on school premises could not always do so (e.g., due to health concerns). Further, as previously noted, positive cases of Covid-19 could quickly close several bubbles across the schools, resulting in pupils having to self-isolate at home. It quickly became apparent to PLASN members that families did not have the resources necessary to support their children's learning when not on school premises. Many schools therefore provided equipment (e.g., sensory items, books, stationary) to families to support them with home learning. This was reported to be hugely beneficial, in order to transfer learning from school to home. Whilst caution needed to be exerted in terms of not placing too high expectations on parents in terms of providing educational input for their children (especially given the high degree of burden and stress generally experienced by parents of children with SEND), the provision of some limited equipment was felt to be an initiative that would be useful to maintain post pandemic; fostering collaboration between school and home. Collecting feedback on the accessibility and quality of home learning was an ongoing process, with school staff responding creatively (e.g., by training parents in widely used classroom approaches; by providing engaging learning activities for the whole family to participate in).

Collaborative working forms a central part of important legislation for pupils with SEND (as detailed in the Children and Families Act: Department for Education, 2014) and is a major component of the EHC plan process (see Department for Education, 2014). Despite this, some pre-pandemic partnerships have been reported to be fraught with challenges. For example, education providers often lament the lack of input from health and social care providers during the EHC plan process

(Boesley & Crane, 2018). Encouragingly, PLASN members noted that some of these partnerships were more effective during the Covid-19 pandemic. For example, technology allowed a range of stakeholders to contribute to annual reviews remotely. What was disappointing, however, was that it required a national and international crisis to facilitate this practice that is in the best interests of vulnerable pupils. As such, PLASN members felt that more frequent and more authentic collaborative working should be a major strategic priority following the Covid-19 pandemic.

1Voice

- 1. Regular 1:1 online interaction with education staff trained to help AAC users learn
- 2. Provision of learning materials which were accessible
- 3. Access to priority testing for care support workers caring for AAC users
- 4. Maintained access to vital services like physiotherapy, speech and language
- Greater recognition, funding and understanding of the vital part played by services in the lives of this population. Learning disability services, speech and language therapy, physiotherapy and care support are not additional services but meet fundamental needs. These services cannot be closed down and deny access to the people they support.
- Clarity and national standards over who is responsible for IT support needs to access learning for AAC users. This should be detailed in EHCPs and in LA's local offers
- National standards over the differentiation of learning material and curriculum access for AAC users to overcome the postcode lottery.

Ambitious about Autism

- Listen to young people themselves about what needs to change.
- The Government should ensure that autistic children and young people's needs are specifically covered in the national SEND review, and that no child with autism or SEND is held back from returning to education.
- The Government should have an action plan to protect autistic children and young people as the Coronavirus pandemic continues, including how to avoid using powers under the Coronavirus Act that limit duties to assess and meet disabled people's needs.
- Prioritise measures to tackle loneliness and isolation such as online peer support that can make timely referrals to more specialist provision.
- Jointly commission services. Now more than ever, education, health and social care must work together to ensure the most vulnerable do not slip through the net.

Career Connects

- Additional support for Year 11/13/14 leavers with transition, especially those with EHCP's that have not been offered a place in Post 16/18 learning. This funding should be routed through local authorities to ensure it reaches local areas.
- Additional funding to support employers who are able to offer apprenticeship or supported internship provision to young people with SEND.
- Additional support for education providers to work with young people to develop additional coping strategies for young people and parents to deal with uncertainty and increased levels anxiety.

- Additional funding routed via local authorities or voluntary sector organisations to work intensively with young people who have SEND and are NEET to provide support to move into appropriate provision.
- Work with families to provide appropriate opportunities for respite support and community engagement

Dr Jacqui Shepherd and Dr Christina Hancock

- The return to full time education should be a slow and gradual approach that supports the individual needs of children with SEND and their families.
- Teachers, teaching assistants and SENCOs should take time listen to parent carers and children with SEND as they have had unique experiences that can be used to revitalize and improve education.
- Priority should be given to routines, wellbeing and social aspects of education ahead of academic pressure.

Recommendations for the first few days and weeks of school:

- The first few days of education should be a gradual and flexible process that reflect the experiences, preferences and concerns of children with SEND.
- Ensure frequent contact with parent carers to listen to their experience of lockdown for their family.
- Communicate with the children directly to identify unique concerns that need to be addressed.
- Take into account that children have had diverse experiences across lockdown and this will impact their feelings towards returning to school and could affect their engagement and attitude upon arrival.
- Plan highly structured activities across the first few days to begin

- to establish and re-establish class routines.
- Designate time to provide students with opportunities to engage with friendships groups.
- Provide support for those children that are not looking forward to, or anxious about, the return to full time education.
- Ensure all aspects of school emphasise a steady, gentle and gradual approach that avoids abrupt changes.

Recommendations for the first term back at school:

- Teachers and schools should focus on mental health, wellbeing, routines and relationships across the first term of full-time education.
- Time should be given to reflect on the Covid-19 pandemic and the experience of it for individuals and their families.
- Re-assessing the current and developing social, emotional, academic needs of children should be a priority.
- Core subjects need focus but social communication and interaction need fostering across the period of social distancing.
- Technology, phased returns, 1 to 1 support, small group work, social stories, checklist and visual supports are all preferences identified to support children to transition back to full time education.
- Use the home learning preferences and anxieties identified by parent carers and children to redevelop and enhance learning at school.

Essex County Council

The over-riding message from the children and young people from the Multi-Schools Council is that they want

more recognition of how important peer to peer support is to young people. This would include:

- children to have a buddy or mentor on return to school and the opportunity to talk about their experiences
- more opportunities to speak to their friends and more time to get advice from peers who may be feeling the same way
- provision of mindfulness activities, and a chance to try things such as yoga and meditation
- opportunities to socialise and to have some ownership over their social bubbles
- prioritising school sport as it is key for wellbeing
- staff to be mindful that things are different, how this can affect young people and have the correct training for staff in supporting children's mental health
- preparation on what school will look like when children are back so children also know how to follow the rules, including virtual information to be available before returning to school
- easy back into work; not expect children to work at the same speed as before, providing catch up lessons and to have a gradual build-up of work
- ensuring there is a range of school subjects and not just focusing on English and Maths
- embracing technology more
- working in smaller groups as the new normal and make sure they have plenty of opportunities to learn outside

The key recommendations from the Essex Family Forum:

 recognising that transition back to routine will be a long process for some children with SEND and support will need to bridge that whole

- process, not be a short-term support package.
- ensuring the right support is in place to support mental health, which may include provision like play therapists and modified CBT.
- Sensory equipment, videos or webinars may be useful to families while community and school play facilities are unavailable.
- Families with a child with severe health conditions who were asked to shield needed a different offer of support which includes access to parent and/or sibling support, emotional support and video/phone counselling as an alternative to face to face.

Recommendations from the Kooth survey:

- Invest in a range of ways to check in with young people to ask them how they feel: privately in a oneto-one setting when they return to school, over email, on the phone, or anonymised surveys
- A gradual return, including more social time, potentially by extending social time at lunch; a slower pace of learning, and support with workload
- Lessons and resources on mental health, and open discussions to help students with their mental health
- Easy-to-access mental health support within the school, and signposting to support elsewhere
- Peer-to-peer mental health advice and support
- Check-ins with students with a history of mental illness
- Break-out spaces for young people when they feel overwhelmed

National Deaf Children's Society

In the short-term, we believe the Department for Education should set

out how disabled children will benefit from the recently announced plan for catch-up support and formal one-to-one tuition, and how the expertise of specialists such as Teachers of the Deaf, will be mobilised as part of this. We have seen virtually no reference to disabled children in any of the information published so far. A national plan that doesn't meet the needs of disabled children is not a national plan and will not succeed.

Over the longer-term, we believe the Department needs to carry out a full assessment of the impact of coronavirus on disabled children, along with a clear action plan in response. We are particularly concerned about the risk of significant future disadvantage brought about by, for example, late diagnosis for many deaf babies and children, reduced access to specialist support and a lack of support with transitions.

It is also clear that coronavirus has exacerbated existing challenges around specialist support that need to be addressed in any recovery plan. In particular, we continue to face a crisis in the falling number of qualified Teachers of the Deaf – a 15% decline since 2011. The coronavirus pandemic has shown the important role that Teachers of the Deaf have been playing in engaging with families at home and continuing to support home learning. There remains a need for urgent short-term action to fund the training of the next generation of Teachers of the Deaf.

We understand that officials have been continuing to work on the SEND review during the last few months. We are concerned about the lack of transparency over this work and engagement with others.

Family Fund

We recommend families continue to have access to vital formal services and therapies they have assessed to receive such as Occupational Therapies, Psychology, and CAHMS support. Alternative methods such as online or telephone support should be offered when face to face is not possible. The sector needs to ensure families have information on how to access support to ensure they can weather the physical and emotional impact of the crisis. We recommend families continue to have access to respite support from carers and personal assistants. The pressure of 24 hour care has led to additional stress for families. Care providers have begun to develop services which observe social distancing rules such as support outdoors and booking systems for respite facilities. Examples of good alternative models of support need to be shared with providers to ensure safe care and support services can continue for those assessed to receive it. We recommend families are able to retain a small network or 'bubble' of support around their families where it

We recommend families are able to retain a small network or 'bubble' of support around their families where it is safe to ensure they retain some of the physical and emotional support to enable them to get through any similar crisis in future. Additional guidance/express permission will be needed from Government, similar to the 'leaving home guidance' for those with health conditions during the Covid-19 outbreak.

Children's Services Development Group

Our report sets out a number of recommendations, including that all providers (local authority and independent sector) must begin preparing all children and young people with SEND for adulthood from the day they enter specialist education.

CSDG believes that a number of

government guidance means that voung people with SEND are not always getting the right support. For example, the SEND Code of Practice should be updated to state that: • "For a young person with an EHC Plan, the local authority must ensure that the transition to adult care and support is well planned. is integrated with the annual reviews of the EHC Plans, and reflects existing special educational and health provision that is in place." - rather than "should ensure" as it currently states. • "19- to 25-year-olds with EHC Plans must have free access to further education in the same way as 16- to 18-year-olds." - rather than "should have" as it currently states. • "Very few moves from children's to adult services will or should take place on the day of someone's 18th birthday and this should never happen if a young person has not yet completed the academic year in which they turn 18." • "Support should never cease before the end of the academic year, to allow young people to complete their programme of study. In the case of a young person who reaches their 25th birthday before their course has ended, the EHC Plan must be maintained until the end of the academic year in which they turn 25." - rather than "should generally cease at the end of the academic year" and "can" be maintained

flexibilities and leeway in existing

Our report also recommends that to address the provision gaps created by the involvement of multiple agencies in a young person's support, every looked after child and each young person with an EHC Plan should be allocated a personal budget to fund all care, education (separate to those covered by the national funding formula for schools) and health needs.

as it currently states.

Building on this, we recommend that a centrally run 'Transitions Support Bank' should be set up which all care leavers and young people with EHC Plans would be able to use until age 25 to request access to funding to support them into independence. This could include support with living costs, paying for training or upskilling programmes, or contributing to a house/flat deposit or tenancy fees.

Local authorities should also be obliged to provide young people with SEND, who are leaving specialist education settings, with free access to mental health support services. This should be in line with their assessed health and emotional wellbeing needs, up to five years after leaving specialist education. Mental health and social care services must collaborate to ensure there is not a cliff edge of support in access to mental health services.

Making Chromosomes Count

We would like to see the following changes made to the SEND process, with specific reference to children with a diagnosis of Down Syndrome.

- 1. All parents/carers of children who have a diagnosis of Down Syndrome should be sent formal information from their Local Authority SEND department detailing their right to apply for their child to be assessed for an EHCP. We believe this should happen by the time the child is 24 months old in order to allow for the process to be finalised by pre-school entry.
- 2. Any application made, for the purpose of ascertaining if they need an EHCP, for a child with Down Syndrome, must be approved. It must be made mandatory that children with Down Syndrome, who have a clinical diagnosis of learning disability, can access an assessment for their need for an EHCP.

The current process is discriminatory and is failing our population of children with Down Syndrome in the most diabolical manner. The team at Making Chromosomes Count are eager to discuss this issue with the APPG for SEND to seek assistance in how we begin to address this issue in parliament.

Royal College of Nursing

- To fully consider an effective and sustainable nursing workforce better able to meet the needs of this population. Current failures to tackle the nursing workforce crisis are leaving those most in need of care facing the biggest problems in accessing the care that they need.
- To provide greater focus on the identified and unmet needs of this group of children and young people and adequate resourcing provided.
- To strengthen the support for families who require greater help in the care that they offer to children and young people, particularly during this pandemic.
- A recommendation for the APPG might include the promotion of the recently launched DfE Relationships, Sex, and Health Education curriculum; fast tracked to support children with SEND in particular, which would give heart to the curriculum, and a long term statutory framework. It was launched in July by DfE.

Royal College of Occupational Therapists

 Better coordination of guidance issued by the Department for Education and NHS England providing clear and timely information for occupational therapists and other allied health professionals who support children and young people with SEND across health and

- education.
- Occupational therapists to be protected from redeployment to adult services unless absolutely necessary to ensure support for children and young people with SEND can be maintained.
- Schools must remain open and occupational therapists allowed to visit students who need in person support to facilitate positive transitions. While government guidance is that access to health services is specifically allowed at school, decisions are being made at a local level that limits this access.
- Better communication between health, education and social care at a local level to ensure occupational therapists have the information they need to plan and support students with SEND to make positive transitions to new classes or settings
- Access to digital technology for families of young people with SEND and occupational therapists to ensure: Young people with SEND and their families have access to high quality online materials and support as part of a 'blended' offer of digital and face-to-face occupational therapy support at times of transition; and To enable effective liaison between young people, families, occupational therapists and other members of the multidisciplinary team (in health, education and social care) to support young people with SEND at key points of transition

Sense

Children and young people with MSI must still get the specialist educational support, equipment, care and therapies they need to avoid more complex medical needs developing, both in school and at home if they remain shielding. We want to see greater whole family support

for those who are clinically extremely vulnerable.

Government must produce a long term plan and additional funding for SEND provision over the next 6 months so that disabled children are not excluded from the education, care and support they need.

Support should be available to ensure children and young people with MSI are able to safely transition back into school or college, with particular attention to children and young people moving to a new education setting.

Special Needs Jungle

- 1. National government recognises that families with children who have SEND need clear guidance that is timely, unambiguous and written after consultation with a wide range of stakeholders. This should include: 1.1. An independent review of the decision to temporarily modify s42 of the Children and Families Act to consider appropriateness and how the relaxations were used or abused, both before and after the announced easements were put into force. This is crucial to ensure future crises do not leave disabled children without any provision for months. 1.2. A national consultation with all disabled adults and families of disabled children. to understand their experiences during the pandemic and how they could be better supported and protected during national crises.
- 2. A wide-ranging review into how local and national public services for children with special educational needs operated during lockdown. To focus on: 2.1. why some services were unavailable or had limited availability, whether this was avoidable, and if alternatives could have been found; 2.2. how effective communication was with families during this time and how it could have been

- improved; 2.3. the support that was offered to families during this period; 2.4. what worked well during this period and how this can be continued: 2.5. the effect of service disruption on children with SEND and the projected time and costs involved in reversing the effects of these lost services; and 2.6. development of a base service that can be provided in emergency situations, including assigning roles that have extra training and the expectation that these skills will be maintained.
- 3. Research to ensure a better understanding of who needs to shield and how they can be easier to identify and reach. Council disability registers for both children and adults could be used and expanded to support this.
- 4. Ensuring that guidance for clinically vulnerable children is considered equally as important as guidance for adults, and should not be an afterthought.
- 5. National research interviewing the schools that did exceptionally well for their disabled students during lockdown and the reasons others did not. This can be incorporated into well evidenced guidance for remote or blended learning for future crises and to better support children who are unable to go to school. 5.1. That government investment in any online or blended learning offer, such as Oak Academy, includes a requirement for differentiation of lessons.
- 6. Schools should contact their SEND families to ask what worked well and what did not. This feedback should be used to improve the school's offer going forward, including: 6.1. reviewing differentiation for pupils with SEND both in remote learning and classroom learning; 6.2. reviewing how risk assessments were used by the school; 6.3. the support offered for families with children who have SEND, and if this

was the support the families actually wanted; 6.4. how teaching assistants were deployed during this period, specifically those assigned to specific children: 6.5. what worked well for families in lockdown and how that might be incorporated into their educational offer; 6.6. the training or resources the school needs to make better use of IT in education; 6.7. what percentage of pupils have access to the right technology to take part fully in online learning, and what can the school do to support those who do not; 6.8. return to school strategies for pupils that may find it difficult, including offering flexible learning for those who found learning at home beneficial; and 6.9. introduction of an emergency response policy for each school to be instigated if the school is forced to shut down. This policy should specifically outline how the needs of vulnerable children will continue to be met.

Parent of a 10-year-old girl with autism in a mainstream school

- Train and equip professionals: Do more to train and equip teachers, governors and other education and vouth staff in the nature of ASC and other neurodiverse conditions. This should happen in Initial Teacher Training (ITT) and throughout their careers as part of mandatory CPD.
- Provide support: Provide a greater level of support at government, local authority, trust (in the case of MATs) and school to those with SEND and their parents. This should include mandated pastoral care. differentiated pedagogy (see next recommendation) and flexibility in understanding the strain and barriers being / having a child with SEND brings. This should accommodate the differences many SEND children display in different settings, the strain

- on working parents and mentoring through the process of developing Education Healthcare Plans.
- Restructure education: Re-design the approaches used in teaching and learning, including optimising space and learning environment, use of resources to accommodate a diverse range of needs, reduction of pressures through testing and better mentoring during transition.
- Enforce: Where local government, trusts and schools have failed to live up to, often legal, guidance or requirements, policy makers and government needs to hold them to account. This should not be in the form of financial penalties, but in mandated additional support and/or leadership.
- Put wellbeing first: Wellbeing, mental health and engagement in learning should be the key objectives for all policymakers. Policy needs to reflect on how best that could be achieved for children with SEND in the context of ever-changing guidance.
- Focus on gaps: In my daughter's submission, she notes that gaps that were left for her during transition and others have been evident. Where these gaps have occurred, extra effort and resources will be needed to identify and address them.

The impact of this on our child and ourselves as parent carers is going to have a lasting effect. We are both exhausted physically and emotionally. We are still in lockdown due to our child's vulnerability...we are both suffering with anxiety and depression.



Appendices

Organisations that submitted written evidence

Organisation	Website
Adoption UK	www.adoptionuk.org.uk
Ambitious about Autism	www.ambitiousaboutautism.org.uk
Career Connect	www.careerconnect.org.uk
Children's Services Development Group (CSDG)	www.csdg.org.uk
Essex County Council	www.essex.gov.uk
Family Fund	www.familyfund.org.uk
IPSEA	www.ipsea.org.uk
Local Government Association	www.local.gov.uk
Making Chromosomes Count	www.makingchromosomescount.co.uk
NAHT	www.naht.org.uk
National Autistic Society	www.nas.org.uk
National Deaf Children's Society	www.ndcs.org.uk
Pan London Autism Schools	
Royal College of Nursing	www.rcn.org.uk
Royal College of Occupational Therapists	www.rcot.co.uk
Sense	www.sense.org.uk
SENTalk	www.sentalk.org
Special Needs Jungle	www.specialneedsjungle.com

Speakers at oral evidence sessions

23 September 2020 (Focus on communication and interaction)

Farzana Machhada	parent, Let Us Communicate
Andy Smith	a young person with autism
Kerry Fox	parent
Mark Dale-Emberton	head teacher
Emma Mander	Director & Strategic Lead for families, schools and services integration, Great Minds Together

14 October 2020 (Focus on cognition and learning)

Jimmy Langton	a young person with Quadriplegic Cerebral Palsy
Carly Blake	a young person with Cerebral Palsy and Learning difficulties
Alison Dowthwaite	parent
Alice Marshment	parent
Polly Sweeney	Partner, Rook Irwin Sweeny - Public Law

11 November 2020 (Focus on social, emotional and mental health difficulties)

Dominic	autistic young person
Alison Worsley	Director of External Affairs, Ambitious About Autism
Sarah Alexander	parent
Rachel Perrin	Partnership Manager, Family Fund
Rob Williams	Senior Policy Advisor, NAHT

2 December 2020 (Focus on sensory and/or physical needs)

Dinah	deaf young person
Holly	deaf young person
Sarah White	Head of Public Policy and Campaigns, Sense
Poppy Rose	parent and co-founder of SEND National Crisis
Simone Aspis	Policy and Campaigns Coordinator, Alliance for Inclusive Education
Cllr Teresa Heritage	Children & Young People Board Member, Local Government Association (LGA)

All four oral evidence sessions are available to watch at the APPG's website: www.naht.org.uk/appgsend.

Acknowledgments

Thank you to NAHT for serving as secretariat for the group and for collating this report.

We thank all the organisations who submitted evidence to the inquiry and for sharing their own research. conducted over the past year.

We thank the parents who have shared their family's experience during the pandemic.

We are grateful to the following organisations who supported and facilitated the APPG to be able hear directly from young people themselves during oral evidence sessions: National Deaf Children's Society, Ambitious about Autism, Disabled Children's Partnership, KIDS.

In particular, we appreciate the young people themselves who gave oral and written evidence to the APPG's inquiry. We value and hear your voices.

The group acknowledges the extraordinary effort that has come from staff working in schools, and all involved in education and allied professions, over the past year, to support young people during this uncertain time.



All-Party Parliamentary Group (APPG) for Special Educational Needs and Disabilities

www.www.naht.org.uk/appgsend appg.send@naht.org.uk

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