

**"I'm not going to forget this": The impact of COVID-19 on
Young People with Special Educational Needs and/or
Disabilities.**

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This thesis is submitted for the degree of
Doctor of Philosophy in
Community Care

School of Psychology
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95,141 Words

May 2026

ABSTRACT

On March 23rd 2020, the Prime Minister, Boris Johnson, announced a nationwide lockdown across the UK as a result of the global pandemic caused by the disease which became known as COVID-19. The virus was spreading across the world, and other countries had reported high mortality and the danger of their health services collapsing. To prevent the spread of the virus and to protect the National Health Service, the lockdown had been ordered at speed with no time for society to prepare.

Research about many aspects and impacts of the pandemic for children and young people (CYP) with special educational needs and/or disabilities (SEND) began immediately, but due to the restrictions on society these were mostly surveys directed at adults able to respond digitally. Researchers were unable to speak directly to the CYP as schools were closed and mixing prohibited. The researcher was in the situation of having the knowledge and the ability to access this hard-to-reach population. This thesis therefore aimed to help fill the gap in the knowledge society had about the impact of the pandemic on the CYP with SEND by hearing their voices directly. There was information about younger children available, though gained mostly from adults, but there was a gap in hearing older YP's views. YP could remain in education up to the age of 25 if they had an EHCP and so create a distinct group of adolescents and young adults. A qualitative study was therefore conducted involving 46 YP with SEND who were between 14 and 25 years old and in education during the pandemic to gain their perspective of the pandemic years between 2020 and 2022. This was followed by studies involving parents and then professionals to gain their views.

The findings indicate that YP with SEND were affected by the restrictions and consequences of policies and guidance during the pandemic with the impacts extending to their education and social and independence skills. The distinctive circumstances of YP with SEND, who were often completing practical courses and who had specific communication needs, were not considered during the closure of schools by government leaders. Furthermore, parents and professionals felt overlooked and unsupported in their attempts to help the YP in their care despite their best efforts in challenging circumstances. Despite there being a solid thread of resilience for many of the participants in these studies, there was also evidence of trauma for many individuals which had not yet been resolved. Additionally, findings exposed a

minority of YP for whom the pandemic brought improvements in their wellbeing or education.

The thesis ends with suggested recommendations should there be another crisis requiring similar health and safety measures in the UK, as governments do not appear to have learned from past research about pandemics, as can be seen from this quote from the Sprang and Silman paper written in 2013:

Pandemics are infrequent but potentially devastating crises that are likely to affect the lives of many children and their families physically, socially, and psychologically. Responders in public health, health care, and behavioral health must collaborate during pandemics to ensure that disease-containment measures are understood and implemented in a manner that minimizes the potential for negative psychosocial consequences in children and families. (Sprang & Silman, 2013)

ACKNOWLEDGEMENTS

The seed for this thesis was sown after I completed my Masters in Education in 2013, when my supervisor Dr Sue Bentham asked if I had ever considered doing a PhD – I had not. I was the first in my family to attend university and academia was a foreign land. Therefore, I must acknowledge the impact of what, for her, was just a brief comment, as years later it led to this research.

This thesis would not have been possible without the support of my supervisors Michelle McCarthy, Paraskevi Triantafyllopoulou and Glynis Murphy. Thanks go to Michelle for encouraging me when I reached out with the idea initially. Particular thanks go to Glynis for being prepared to support me so near the end of the whole project and to Vivi for staying the course despite major life events. Regular meetings and helpful, supportive feedback allowed me to progress and keep on track over the past five and a half years.

My work colleagues and manager need a mention for their support and interest in this endeavour, which allowed me the flexibility to change days and take holidays at odd moments in order to undertake the studies.

However, the stars of this research are the young people who gave up their time and showed interest and enthusiasm. It was a privilege and the best part of the whole endeavour to spend time talking with them. This was the opportunity to create a record which showed the impact of this time on young people with SEND and I am grateful to all the professionals and parents who allowed me access to these amazing young people. Thanks also go to the parents and professionals who were willing to participate in the research when many really wanted to forget all about the past few years.

Thanks also go to my long-suffering husband Ian, who was baffled by my wish to embark on the PhD but took on a greater share of family, house and dog responsibilities while I was studying. He will be relieved when it is all over and the tasks can be shared more evenly! Lastly, a special mention to my daughter Ella, who when I thought the task was impossible, never lost faith in me and would say, “I know you can do it”. We all need an Ella in our lives.

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Chapter 1: INTRODUCTION

1.1 SETTING THE SCENE

Pandemics have occurred throughout history, for example bubonic plague which occurred in waves throughout the 1300s to the 1900s (Science Museum, n.d.) and the 1918 influenza pandemic (Newsholme, 1919). Emerging viruses can also affect humans at any time but are more likely where there is warfare, poor sanitation, cramped housing, environmental damage or close proximity with wildlife, allowing pathogens to spread and change more easily (Department of Health & Social Care [DHSC], 2020c). The UK had strategies in preparation for a pandemic, but the focus was said to be only on the influenza virus, despite MERS coronavirus emerging in 2012 (DHSC, 2020c). The UK was therefore not prepared for the new coronavirus emerging late in 2019 in China.

The virus spread quickly from China across the world, and March 23rd, 2020, transformed life for the entire population of the UK when a lockdown was announced following several weeks of the spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2 or COVID-19). A lockdown is a period of time when movement is restricted in the interests of public safety or health (Oxford English Dictionary, 2015) and it had occurred across the world to prevent the virus spreading. It was now the UK's turn in order to prevent the National Health Service (NHS) from being overwhelmed and no longer able to provide healthcare to its inhabitants (Johnson, 2020). People were encouraged to 'pull together', and it was said by Secretary-General of the United Nations, António Guterres, that *"we are all in it together"* (Guterres, 2020) in a global sense. However, it seemed likely that, although everyone was affected by the pandemic, the already disadvantaged in society would probably be more affected than those who already held an advantageous position in life, due to wealth, housing, employment or health (Marmot et al., 2020). Depending on the circumstances, this disadvantaged population could include a long list, according to the National Foundation for Educational Research (NFER, n.d.), and at the top of this list are children and young people (CYP) with Special Educational Needs and/or Disabilities (SEND). CYP with SEND are defined in law as those who need support which is different or additional to what other children of the same age usually receive due to a disability or learning difficulty (Children and Families

Act, 2014, s. 20 & 21). The NFER list also includes those living in poverty, pupils with attendance and behavioural issues, those with mental health difficulties and/or medical needs, Roma and traveller families, asylum seekers, refugees and those with experience of being in care. Some CYP could inhabit several of these categories and could have been especially at risk in the pandemic, for example those with disabilities in poverty and therefore in inadequate housing (Children's Commissioner, 2020). It has been found that *"children with SEND from low-income families face multiple disadvantages and increased vulnerability from the very start of their lives. Yet their needs are not always prioritised by schools or policymakers"*. (Shaw et al., 2016, p.4). Even before the pandemic, according to the Social Metrics Commission report in July 2019, nearly half (40%) of all those living in poverty lived in a household where someone was disabled, and it has been calculated that it costs three times as much to bring up a disabled child as opposed to a non-disabled child (Dobson et al., 2001). The poverty which can follow is often as a result of the cost of care for their child combined with reduced income, as this parent explains,

I've had to give up work, and as a result my husband and I have been unable to afford much of the special equipment and support Amy needs. The stress puts a lot of pressure on our relationship and our feelings of isolation from other families are sometimes overwhelming. (Dobson et al., 2001 p.5).

65% of families who have a child with SEND reported feeling isolated either frequently or all the time as reported in the 2011 survey by Contact a Family (Contact a Family, 2011).

According to Broach et al, *"Disabled children and their families face substantial barriers in everyday living and experience high levels of social exclusion"* (Broach et al., 2016, p.3), even without a worldwide health crisis.

During the initial lockdown, there were multiple surveys sent out by organisations to try to gauge how populations who may have been at risk during this time were coping, for example those completed by YoungMinds: *Coronavirus: Impact on Young People with Mental Health Needs* (March 2020), two reports by Barnardo's: *Devalued by forces beyond your control* (2020b) and *Mental health and COVID-19: In our own words* (2020c), The Princes' Trust: *The Prince's Trust and YouGov: Young People in Lockdown Report* (May 2020), National Children's Bureau: *A vision for recovery: Supporting children and young people to recover from the impacts of COVID-19*. (2020) and the Disabled Children's Partnership: *#LeftInLockdown: Parent Carers' Experiences of Lockdown* (May/June 2020). These organisations were able to

publish their findings quickly and provide a snapshot of what happened for families in the first weeks of lockdown. This input was important to ensure the right services and support were available during the crisis, but it did not allow for the natural adaptation to a new situation, as the American Psychological Association (APA) reported, *“people generally adapt well over time to life-changing situations and stressful situations”* (APA, 2020). In addition, it did not allow for the monitoring of either the growth or stress on both services and families which could occur over a prolonged period. The *“ongoing legacy of these days”* referred to in the letter from forty-six CEOs of children’s disability charities sent to the Parliamentary Under Secretary of State for Children and Families on May 29th, 2020, (Council for Disabled Children, 2020) remains unclear. Surveys captured important information in the moment and were a valuable resource, but they did not necessarily capture the voice of the young people themselves, apart from the second Barnardo’s report on mental health (2020c). Additionally, they did not allow time for the YP to reflect on the experience or appreciate the longer-term consequences. However, as Emma Beedon, a young disabled person states in the Education and Training Foundation (ETF) report, *“It is important for people who work with children and young people to hear from them directly as no one knows the experience better than the person themselves”* (ETF, 2020, p.23).

Learning from the past to plan for future events is key, but to hear the voice of people affected and especially marginal groups not usually included is essential (Ferreira, 2024). This virus, or something similar, is likely to be with us for the foreseeable future according to the Max Planck Institute for the Science of Human History (2020) and so learning from the young people’s experiences is vital. Once it is understood how the changes have impacted young disabled people, there is opportunity for progress. It is vital that policy makers and governments learn from the experience of these young people to adapt services for any forthcoming epidemic to safeguard the health, wellbeing and education of CYP (Davidson & Elsley, 2020). The government bears a responsibility to assist families with SEND as:

Given that many of the factors that restrict disabled people are socially created, it follows that addressing these and the consequent exclusion and disadvantage they experience is a core responsibility of the state. (Broach et al, 2016, p.8).

Good quality research to enable the state and charities to make appropriate decisions is therefore crucial (Davidson & Elsley, 2020). It was at the start of the pandemic, while

working with YP and their families, that the researcher thought that someone should investigate the unique and multifaceted impacts on YP with SEND and this researcher realised that they were in a privileged position to do so.

1.2 DEFINITIONS AND TERMINOLOGY

It is important to understand the terms used in this thesis. For clarity therefore, here is a list of general terms and acronyms which have been used but which may not be familiar to all:

Table 1. *Terms and Acronyms used in the thesis*

Term	Explanation or definition
CYP/ YP	Children and Young People/ Young People
EHCP	Education, health and care plan. This is a legal document which identifies the education, health and care needs of a CYP with SEND from birth up to age 25. It is a statutory document for those with needs that cannot be met by what is ordinarily provided within a mainstream setting (Children and Families Act 2014, s 31).
ID /LD	Intellectual Disability is usually referred to as Learning Disability within UK education, health and social care services in the UK and is the term used most often in this thesis (Somerset Council, 2026). Within the UK the terms ID and LD can be interchangeable. However, within an international and academic context, the term ID is often used as LD has a different meaning internationally (LeDeR Programme. (n.d.). Both ID and LD mean that the person has a generalised impairment in overall intelligence and daily functioning.
Learning Difficulty	In the UK and in this thesis, a learning difficulty is used to describe specific educational issues like dyslexia or dyscalculia (Somerset Council, 2026). It is sometimes referred to as a specific learning difficulty (SpLD). However, internationally, these specific issues are known as a Learning Disability (LeDeR Programme. (n.d.).
LA	Local Authority
NHS	National Health Service
SEND	Special Educational Needs and Disabilities – see legal definition in 1.2.1

Setting or placement	The school, college or alternative provision where a student receives their education
Alternative provision	An educational provision for CYP of compulsory school age who cannot attend a traditional setting due to needs relating to behaviour, medical needs, exclusion from their setting, or SEND
Mainstream	State and private schools/colleges which serve most CYP
Special school/ college	CYP who need tailored support to access education and usually have an EHCP may attend this specialist provision
LSA/TA	Learning Support Assistant or Teaching Assistant. An LSA supports the teacher in providing 1:1 support for a CYP. A TA supports groups or the whole class under the supervision of the teacher

1.2.1 Special Educational Needs and Disabilities

In the Children and Family Act 2014 (Part 3, c6. s20), SEND is defined as:

(1) A child or young person has special educational needs if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her.

(2) A child of compulsory school age or a young person has a learning difficulty or disability if he or she—

(a) has a significantly greater difficulty in learning than the majority of others of the same age, or

(b) has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.

This definition is used throughout the thesis for the term SEND, which could potentially include a wide range of CYP from those who, with a few adjustments, can manage in a mainstream environment to those with complex needs who require one-to-one support and may have physical, cognitive and medical needs. Furthermore, some explanation of the term for Autism is needed as Autistic Spectrum Disorder (ASD) is commonly used, but there is disagreement as to whether this should be viewed as a disorder which pathologises the differences and focusses on impairments (NHS England, n.d). Therefore, it is sometimes

known as Autistic Spectrum Condition (ASC) or just Autism which are the terms used in this thesis (National Autistic Society, n.d.). For the term SEND to be used, a CYP needs to be between the ages of 0 and 25 and to be in need for additional support to learn (Children and Family Act, 2014). In this thesis the CYP within the scoping review (Chapter 2) were aged between 5 and 25 and for the qualitative studies (Chapters 4, 5 and 6) the age group under consideration for the CYP was 14 to 25 years old. More detail about the age range is given in the relevant chapters.

1.2.2 Labels

The researcher is conscious of using labels within this research in a way that is at odds with their philosophy of disability as being part of the reality of diverse humanity and nature (Swain & French, 2000). The use of the term SEND on which to focus this research, and the many sub-categories of this label, is however deemed necessary in order to discern the voices of a group who often go unheard. If the voices of the group labelled 'SEND' cannot be discerned, then their distinct difficulties, feelings and barriers could be overlooked. Therefore, there must be a specific intention of gathering data with their voice being the focus and to do this a label that society understands is required (Norwich, 2008).

Many YP with SEND want to be accepted by society as ordinary YP and do not want to stand out (Odell, 2019). They would rather not be labelled as having any special needs or disability and may wish to be seen as the same as other young people. As Odell points out in his report on YP's attitudes to disability: "*Many disabled people, including those with visible disabilities, do not necessarily think of themselves as disabled.*" (2019, p.12) and they often see disabled people as separate from themselves (Odell, 2019).

The researcher does not consider labelling is always a positive experience, but the reality is that labels are currently necessary to gain support (Norwich, 2008). They are necessary as an access point for a CYP, family or teacher to obtain assessments, understand strengths and difficulties of the CYP and for the CYP to receive the support they need (Ofsted, 2021c). However, it has been argued that labels are based on the medical model of disability which seeks to identify deficits and then to remedy them with interventions (Soldovieri & Myers, 2025). Labels put the difficulties within the individual rather than looking at the difficulties

resulting from the society the individual lives in, which is the basis of the social model of disability (Oliver, 2013) and is explored further in the next section.

1.3 THE CONCEPT OF DISABILITY IN EDUCATION

Disability can be viewed as a social construction created to describe some people who are marginalised by those who hold more authority (Baglieri et al., 2011). It can also be understood as part of the natural diversity of human beings (Connor et al., 2008). Within society there exist divergent views, two of which are the medical model and the social model of disability, which have vied for prominence within policy during the last twenty years (Lewis & Mason, 2025). Historically, the medical model appeared earlier, at least in Western countries, and led to the traditional concept of special educational needs, where the goal was to eradicate or cure the disability as much as possible, to make the person appear closer to whatever was considered normal (Soldovieri & Myers, 2025) and to achieve quantifiable educational outcomes based on the results of quantitative research (Lewis & Mason, 2025). The Disability Studies in Education (DSE) framework, however, is a transdisciplinary field that works towards removing what is considered an ableist view of disability and removes the focus from the deficits that are perceived, towards acceptance and equity of provision and opportunity (Baglieri, 2011). DSE has gradually grown out of the wider Disability Studies field since the 1960s, but especially since the 1990s in the UK and has led to the widespread policy of inclusion within education (Moore & Slee, 2019). Both the traditional view of SEND and the social model of disability encounter practical difficulties for society and educationalists to navigate. For example, traditionally SEND can result in segregation as a way of meeting a CYP's needs and can reinforce the SEND system rather than critically evaluate it (Lewis & Mason, 2025). However, the DSE framework can be viewed as impractical for teachers due to the financial and time constraints within the current educational system. This is acknowledged by Lewis & Mason (2025) who recognise that both the social model and the DSE framework adhere to the understanding that within SEND education there is agreement that there exists *“good intent, need for change, perpetuation of harm [the understanding that harm currently occurs for students with SEND], and recognition of constraints”* (Lewis & Mason, 2025, p. 398). It can be argued therefore that both approaches have strengths and limitations, and Lewis and Mason (2025) advocate for a linked middle ground. This would enable those working within the traditional

SEN model to remain critical and work towards the aspirational model of DSE. Additionally, it would allow those working within the DSE framework to appreciate the difficulties of the realities of practitioners who work in the traditional SEN world, resulting in a more collaborative and pragmatic approach. Lewis & Mason describe their framework as 'critical special education' which acknowledges where education stands currently but remains aspirational towards a better experience for CYP with SEND in the future.

1.4 THE HISTORY OF EDUCATION FOR CYP WITH SEND IN UK

The researcher's background in education and working with CYP is underpinned by the belief that all young people should have the opportunity to achieve a fulfilled and rewarding life. Historically this has not always been the case, with many CYP with SEND being segregated or marginalised by society due to their differences from what was considered the norm, resulting in many receiving either little or no education, especially prior to the 1918 Education Act which legislated for the education of disabled children for the first time (Tomlinson, 1982). There was some limited provision for CYP with disabilities which began in the 18th Century with schools for blind and deaf children, with a focus on vocational training, so the YP would be able to contribute to the economy and become self-sufficient (Historic England, 2025). Gradually legislation was introduced that recognised the needs of the disabled child population but in terms that we would consider offensive today, categorising children as crippled, handicapped or feeble minded (Tomlinson, 1982). In the 1944 Education Act, CYP were labelled according to their disability, but attitudes were slowly changing. In this 1944 Act, Local Authorities were required to provide an education for CYP with disabilities, but some were still deemed 'uneducable' and were placed in institutions with no rights to formal education (Education Act, 1944, s 57). The roots of disability movements in the UK started after the second world war due partly to the presence of disabled servicemen in society and the exposure of mass killings of disabled people in Nazi Germany (United States Holocaust Memorial Museum, 2025). From the 1950s, parents started fighting for an education for their disabled children when they were labelled ineducable (Hillier, 2022). The recognition that education was a universal right for all children with disabilities was not enshrined in law until the Education (Handicapped Children) Act 1970. Legislation since the 1970s has developed to strengthen the right to an education and increasingly focussed on the right to be included in a mainstream school and

have needs met appropriately (Education Act, 1981; Education Act, 1996; Special Educational Needs and Disability Act, 2001; Equality Act 2010).

In 1978, what became known as the Warnock Report (Department of Education and Science, [DES], 1978) was published, entitled "*Report of the Committee of Inquiry into the Education of Handicapped Children and Young People*". This was a significant moment for CYP with SEND in the UK because one result of this report was the coining of the term Special Educational Needs. This report was the basis for the Education Act 1981 which made the Local Authority (LA) responsible for assessing a CYP's SEN and resulted in the provision of a Statement of Need. It also encouraged LAs to include CYP with SEN into mainstream schools whenever possible.

Before the Warnock report, disability was seen as an individual or medical issue, with authorities asking what is wrong with the person and how to fix it, rather than what they might need to live a full life (Brisenden, 1986). This medical or individual model can still predominate, especially within health services, maintaining discriminatory attitudes and practices (Scullion, 2010). However, in 1983, Oliver differentiated between the individual and the social models through his teaching of professionals, and the social model gradually gained ground (Oliver, 2013). This model states that although an individual may have an impairment, this does not necessarily lead to disability (Shakespeare, 2006a). Disability, it states, is created by the way society is organised and the barriers that result from this (Shakespeare, 2006a). Barriers can be physical such as access to buildings or to do with attitudes, prejudice and stereotyping (Shakespeare, 2006a). There has been criticism of the social model due to the potentially inflexible outlook and oversimplification of a complex subject and the neglect of the impact of impairments on a person's life (Beaudry, 2016). However, Oliver later stated that he never claimed that *only* the social model should be considered (Oliver, 2013), although that is often what became the focus in the years that followed, creating the impression that the difficulties were all to do with society. Rather, Oliver had stated that it was the impairment of the individual in relation to society's barriers that caused the difficulties and both needed to be considered.

1.5 CURRENT POSITION OF SEND IN THE UK

It was the Children and Families Act 2014 which introduced the Education, Health and Care plan (EHCP), and replaced the 'statements' of SEN. A new statutory SEND Code of Practice: 0-25 years was published (Department for Education [DfE] & Department of Health, [DoH], 2015) and support was also increased to cover CYP from birth to age 25 (previously it had been from age two to nineteen). This allowed earlier intervention and the extra time many YP need to complete their education while still being supported. An EHCP can only be sought if the support the school can provide as their *"ordinarily available"* provision (DfE & DH, 2015, Chapter 6, para. 6.44) has proven to be insufficient. The school is expected to go through the graduated approach of Assess, Plan, Do and Review, when needs first emerge, which is then used in evidence for an EHCP application if needs remain unmet (DfE & DH, 2015, Chapter 6).



Figure 1. *The Graduated Approach. Based on diagram in Learn Together Cambridgeshire, 2025*

If the CYP's needs are able to be met via the graduated approach, then the child remains on the school's SEN support register but does not receive an EHCP (Department for Education [DfE] & Department of Health [DoH], 2015, para. 6.44). If their needs are not met, then an EHCP assessment can be requested although the local authority is not mandated to grant one if they consider it unnecessary (DfE & DoH, 2015, para. 9.14). However, the process of assessment should clarify the needs of the CYP as several professionals are usually involved in this, such as teachers, an educational psychologist and health professionals.

The CYP's and parents' views should be central in the assessment process as they are the ones who know the CYP's hopes and dreams. However, in practice, this is sometimes reduced to a tick box exercise by the LA, seeking the CYP's views but then doing what is convenient within their funding constraints, bringing the CYP and the LA into conflict, often resulting in costly appeals (Keer, 2020). Appeals create an adversarial approach and cause stress for the families, resulting in much of the discontent in the current SEND system (House of Commons Education Committee, 2025). Furthermore, an EHCP is often sought by families as a way of obtaining a diagnosis, to gain funding and access to the resources of support (House of Commons Public Accounts Committee, 2025). However, as discussed above, this diagnostic labelling goes against the social model of disability (Shakespeare, 2006b) as it places the difficulties within the individual rather than in society.

The EHCP has sections which consider the needs of the child and the provision required, with evidence from professionals to support this by way of diagnoses and reports, which is again viewing the problem as within the child. This also creates a situation where a CYP who can show they are more in need will 'win' the resources of the EHCP, whereas a CYP who is struggling but just about managing, may not be seen as deserving of the limited resources even if the needs are similar. In an EHCP application it behoves the applicant to show the CYP in the worst light possible as far as needs are concerned, in order to gain the EHC plan. It is an example of what Brown et al. (2017) have called:

A race to the bottom for scarce resources and a narrowing of entitlement for those who do not conform to commonly held expectations of how 'vulnerable' people should behave. (Brown et al., 2017 p.505).

The 2014 Children and Families Act was well received by families, with families and organisations working with CYP with SEND still considering the legal provision within it well

drafted (House of Commons Education Committee, 2019). As well as laws regarding CYP with SEND included in Section 3 of the Act, the Act also covered adoption, family justice and employment rights. Despite being favourably regarded however, there was insufficient funding and a lack of foresight about the implementation of the Act, especially about how education, health and social care authorities were expected to collaborate (House of Lords, Children and Families Act 2014 Committee, 2022). The disquiet around the current SEND system with costs escalating, non-compliance by many LAs and dissatisfaction of families and professionals, resulted in the Green Paper consultation on the SEND system (DfE & DHSC, 2022). This began in 2019 and included the Select Committee report from the House of Lords in 2022, who reported:

The Children and Families Act 2014 has ultimately failed in meaningfully improving the lives of children and young people. Instead, it has largely sat on the shelf, a piece of legislation which has languished as a result of a lack of implementation, inadequate scrutiny and incessant churn amongst Ministers and officials. All this has been allowed to occur while children and young people continue to suffer through public service failures including poor SEND services, increasing mental health referrals waitlists and creeping delays in family courts. (House of Lords, 2022, p.3)

In March 2023 the government published the SEND and Alternative Provision Improvement Plan (DfE & DHSC, 2023) with the White Paper initially planned for autumn 2025. However, in September 2025, the House of Commons Education Committee published a significant report titled "Solving the SEND Crisis" which described the SEND system as being at a "breaking point" (p3) and recommended greater collaboration between those affected such as families and services and the government before any changes were made. As a result of this report, the expected White Paper was then delayed until spring 2026. In a letter to the Chair of the Education Committee to explain the delay, Bridget Phillipson, the current Education Secretary, stated that

to help us deliver the most effective set of reforms we can, I have taken the decision to have a further period of co-creation, testing our proposals with the people who matter most in this reform – the families – alongside teachers and other experts as you highlight in the Select Committee's report. (DfE, 2025d)

1.5.1 Inclusion

Inclusion has been an explicit part of the ethos of SEND legislation since the 1978 Warnock report, when Warnock moved away from the medical model based on a list of impairments,

to what was then termed integration for CYP with SEN within mainstream education (DES, 1978). By the 1990s, the formal education policy was that of inclusion with the publishing of “*Excellence in Schools*” in 1997 (Department for Education and Employment, [DfEE], 1997) and the creation of the Inclusion Development Programme in 2010 (DfE, 2010).

The term inclusion initially focussed on integration of individual pupils with SEND within schools but not so much on changing the schools themselves (Norwich 2014). It was hoped that inclusion would focus on the social model of disability and the role of schools and institutions in being inclusive and accepting a diverse intake (Norwich, 2014). However, full inclusion has come to be viewed as a utopian view which is unattainable (Grue, 2019) and recent research shows that although a diverse population of students attend schools, this can be seen merely, as Webster remarks, as an “*illusion of inclusion*” (Webster, 2022, p1). This illusion disguises the fact that attendance at a mainstream school does not necessarily provide a truly inclusive experience, and attendance does not mean that the pupil is receiving the same education as their typically developing peers (Webster, 2022). Even in 2011 critics were saying:

Ironically, the promotion of the delusion that being present in a school equates with being socially and educationally included, is one of the most dishonest and insidious forms of exclusion. (Cooper & Jacobs, 2011, p.6)

Moreover, Webster argues that there is structural exclusion in schools which is a result of policies schools feel compelled to follow, in order to meet targets and pass Ofsted inspections (Webster, 2022). Inclusion can be seen as something with different meanings to different people depending on their role in society, for example whether they are a government policy maker, teacher, researcher, child or parent (Rapp & Corral-Granados, 2024). Within education there are four components of inclusive education which Hornby (2015) describes as:

1. *Providing all learners with challenging, engaging and flexible general education curricula*
2. *Embracing diversity and responsiveness to individual strengths and challenges*
3. *Using reflective practices and differentiated instruction*

4. *Establishing a community based on collaboration among students, teachers, families, other professionals and community agencies (Hornby, 2015 p.235)*

However, a policy maker or funder may only look at one of these components or in fact only count the numbers of CYP with SEND attending mainstream schools, which may not be an inclusive environment at all, as Webster (2022) has stated. Parents, however, may look mostly at the second and third component as to how it affects their own CYP. Anecdotal evidence from the researcher's work, that inclusion is not working well for at least some CYP, has been supported by recent research completed within mainstream classrooms by Webster (2022). Webster concludes from his research completed over several years that:

What emerges are degrees of marginalisation that not only render these claims [of inclusion] somewhat illusory, but also raise serious concerns about the model of inclusion evident within English schools. (Webster, 2022, p.47)

He concludes that *"the reality and the rhetoric of inclusion are quite different"* (Webster, 2022, p.53). Very real tension exists within schools of inclusion being thrust upon them as the norm by policy makers, whilst individual teachers struggle with the reality of teaching a class of up to 30 CYP who can differ in 30 different ways and encompass many developmental years (Webster, 2022). This illustrates the tension between the traditional model of SEN described earlier, which focuses on identifying and addressing the CYP's needs, and the DSE framework which fails to show exactly how a teacher can practically teach all the students in their class. Either approach can still cause harm inadvertently, such as that created by stigma or segregation.

It was hoped that the YP with SEND in this research could offer some insights into how the theoretically inclusive education system functioned during this crisis and whether there were some YP who did better or worse. If so, it was hoped it could be shown who these YP were, and these insights could be used to inform school practices to better support CYP with SEND in the future. The policy of inclusion provides the educational context of the YP's education experiences as the pandemic began. It is therefore relevant to this thesis as it was the educational policy under which they attended their settings leading up to the pandemic. If it was working well, it should have provided a safety net during times of crisis, but if not, then any cracks would become apparent (Education Policy Institute, 2020).

1.6 COVID-19

Into this fraught situation for teachers and for families with a YP with SEND, who were already under pressure, arrived the additional stress of a worldwide pandemic. COVID-19 is a coronavirus which causes severe acute respiratory syndrome. It is an infectious respiratory disease which was first found in Wuhan in China in December 2019 when reports emerged of an often fatal but unknown pneumonia which swiftly spread worldwide (Lai et al., 2020). A global pandemic was declared by the World Health Organisation on March 11th, 2020, and the first lockdown in the UK was ordered from March 23rd, 2020, to slow the spread of the virus (Aspinall, 2020). People were directed to stay at home and were only allowed to leave for essential purposes such as buying food or medicines or attending hospital (Johnson, 2020). All non-essential shops were instructed to close and only those who sold essentials such as food, medicine or petrol were permitted to remain open (Johnson, 2020). Only critical/key workers were allowed to travel to work and all others had to work from home if possible. Critical or key workers were those deemed to be essential to the response to the pandemic, such as healthcare workers or those involved in food production or education (DfE & Cabinet Office, 2020). Additionally, some employers offered furlough for their workers which meant the employee did not work but was still paid and their job protected, with the employer claiming 80% initially of the costs of the employment from the government (HM Revenue & Customs, 2020). However, some people were not able to continue their work online or claim furlough, for example those in the entertainment or music industries, and their income simply ceased. Furthermore, schools and colleges were closed from March 20th, 2020, but the children of critical workers and those deemed vulnerable were permitted to attend, but this was at the school's discretion (DfE & Cabinet Office, 2020) (see Appendix A for a full list of those permitted to attend their settings). Further details of the progress of lockdowns are given below in 1.6.2.

1.6.1 COVID-19 and Disability

Warnings were issued that people with underlying health conditions, those aged above sixty-five years and people with disabilities may be more susceptible to the virus and should take extra precautions (Şentürk et al., 2021). This sometimes involved shielding, a policy in place until 1st April 2021, which was a public health measure to protect those deemed clinically extremely vulnerable (NHS Digital, 2022), such as those with a weakened immune

system (DHSC, 2021). Shielding involved minimising all in-person contact, staying at home and isolating.

Initially, however, there was little knowledge about the virus to inform public health decisions but families with CYP with disabilities had to make decisions about school attendance and risk management with potentially much at stake if the CYP had additional health issues (Lightfoot, 2020). Information and statistics began to appear in the news about the additional health inequalities for people with an intellectual disability (ID) and the apparent enhanced risk of serious illness (NHS England, 2020). Prior to COVID-19 there were already shocking inequalities in the age of death for people with ID compared to those without, with the median age for those with ID who died in 2018 being 60 for men and 59 for women (NHS England & NHS Improvement, 2019), as compared to 83 for men and 86 for women without an ID. At the start of the pandemic in March 2020, the Clinical Frailty Scale was used in the COVID-19 critical care guidelines by The National Institute for Health and Care Excellence (NICE) as a way of deciding who should receive treatment and who should be selected for non-resuscitation if resources were scarce (NICE, 2020). However, by March 25th, 2020, this scale was dropped from use for younger people, people with ID or with disabilities, such as cerebral palsy or autism (NICE, 2020) when patient groups argued that the tool could not be applied to disabled people fairly, and after the threat of judicial review (Heslop et al., 2020). The concept of frailty was originally created as a way of assessing the elderly and was viewed as discriminatory when used for assessing people with long-term illness or disability as they were more likely to be considered severely frail due to their normal care needs (Local Government Lawyer, 2020). Individual assessments were then recommended, but one year later on 18th March 2021, the media reported there were still concerns over Do Not Attempt Resuscitation (DNAR) decisions that had been made during the pandemic. The BBC (BBC News, 2021b) reported the findings of a rapid review by the Care Quality Commission which found that 508 DNAR decisions made since 17 March 2020 had been agreed without the knowledge and involvement of the individual or their family, of whom some individuals had ID.

Statistics emerged to show that if someone had an ID, they were six times more likely to die from COVID-19 than someone without an ID (Public Health England, [PHE], 2020c).

Furthermore, if a person with an ID was between 18 and 34 years old, they were thirty times

more likely to die than someone of that age without an ID (PHE, 2020). This is an age group in the general population that was not considered at great risk of serious consequences or death from the disease, and it contrasts with the general population in England and Wales, where 47% of the deaths from COVID-19 were 85 years old or more (Heslop et al., 2020). The reasons behind these statistics are complex. Many people with ID have other health issues which may have made them more vulnerable to serious consequences of COVID-19, and it may be that this group was less able to follow preventative health measures such as social distancing and hand hygiene (Heslop et al., 2020). Social distancing was part of the guidance which the public was advised to follow to stop the spread of COVID-19 by keeping two metres apart, avoiding crowded places and wearing a mask (Cabinet Office, 2020). Additionally, another reason for the higher death rate in the ID population could be that medical assistance was not sought early enough or responded to by the medical profession due to not appreciating how unwell someone with limited communication skills had become (Heslop et al., 2020). Alternatively, when hospitals were under extreme pressure, some people with ID may not have been prioritised for treatment due to the belief that they would not understand what was happening and would not be able to comply with the treatment, as family members were not usually allowed to visit or stay during the crisis (Heslop et al., 2020). The possibility must also be considered that professionals were using the Clinical Frailty Scale when they should not have been doing so (Heslop et al., 2020). Furthermore, many people with ID live in care homes or sheltered housing with others and are visited by several carers over a week, exposing them to more people who may have infected them (Heslop et al., 2020). Also mentioned in the Heslop report was insufficient access to specialist learning disability nurses, access to COVID tests and appropriate advice from NHS 111 (Heslop et al., 2020). Whatever the reasons, it is clear this population was at a far higher risk than their non-ID peers and it must have made grim reading for concerned families in the initial stages of the pandemic.

1.6.2 Impact of Covid-19 in the UK

Once COVID-19 had reached the UK, there were several waves of infection which resulted in separate lockdowns mandated to curb the spread of infection and protect individuals and the NHS (Yang et al., 2022). Further into the pandemic a tiered restriction system was arranged whereby not all geographic areas had the same restrictions imposed and tiers were

assigned with different rules according to how high the infection rate was in a particular area (Smith et al., 2022). This was confusing for people to grasp and left many uncertain as to what tier they were in and what rules they should be abiding by, as they may not be the same in adjacent towns (Smith et al., 2022). By the end of 2020 a vaccine had been found to be effective, and it was gradually rolled out to different groups based on their vulnerability to becoming seriously unwell if they were infected. This resulted in most restrictions gradually being lifted as the population was vaccinated or developed immunity due to being infected. A summary can be seen below of the events in England and Figure 2 shows more detail of the timeline of events in the acute phase.

2020:

- COVID -19 was first documented in the UK on January 31st, 2020.
- All nurseries, schools, and colleges in the UK closed their doors to in-person teaching on March 20th with some exceptions, such as children of critical workers and vulnerable children (DfE & Cabinet Office, 2020) (see Appendix 1).
- The first national lockdown was announced on March 23rd, 2020, and began on March 26th with Boris Johnson, the Prime Minister (PM) ordering people to stay at home.
- Coronavirus Act passed March 25th.
- During the summer there was a phased reopening of schools for certain year groups with all returning in the September 2020.
- Restaurants and pubs gradually reopened from July 2020 with the Eat out to Help Out government scheme running during August 2020 to support businesses after the lockdown.
- In the autumn of 2020, a 3-tier system of restrictions was introduced affecting local areas.
- The second lockdown was announced on 31st October 2020 due to new virus variants causing an increase in infections, starting on 5th November and lasting until the 2nd of December, with schools closing for most CYP again.
- Stricter 4-tier restrictions were introduced on 19th December as numbers of infections again rose after the rules were relaxed and a new variant spread.

- December 8th, 2020, the first person received the new vaccine against COVID-19.
- By December 2020, 60,000 people had died in the UK. This was all registered deaths involving COVID-19 (Office for National Statistics, [ONS], 2021).

2021:

- The new more infectious variant which had emerged in September 2020 spread which brought back the use of facemasks in public settings and schools with some exceptions.
- 4th January Boris Johnson the PM said CYP should return to school but on 6th January the 3rd lockdown was announced and schools again closed to most, having been open for one day of the new term.
- A plan for easing restrictions was published in February.
- The vaccination programme was hastened for more groups, resulting in less severe illness and less mortality.
- 8th March CYP returned to school gradually.

2022:

- Most restrictions had been lifted by March 2022 and free COVID testing ceased.
- COVID-19 still circulated in the community and people were advised that this would be the new normal.
- Booster vaccinations were offered to those most at risk as immunity was not long-term.

(Information source: Keoghs LLP, 2022 and Institute for Government, n.d.)

See page 20 for Figure 2 which gives a timeline for the UK COVID-19 lockdowns.

1.6.3 Education

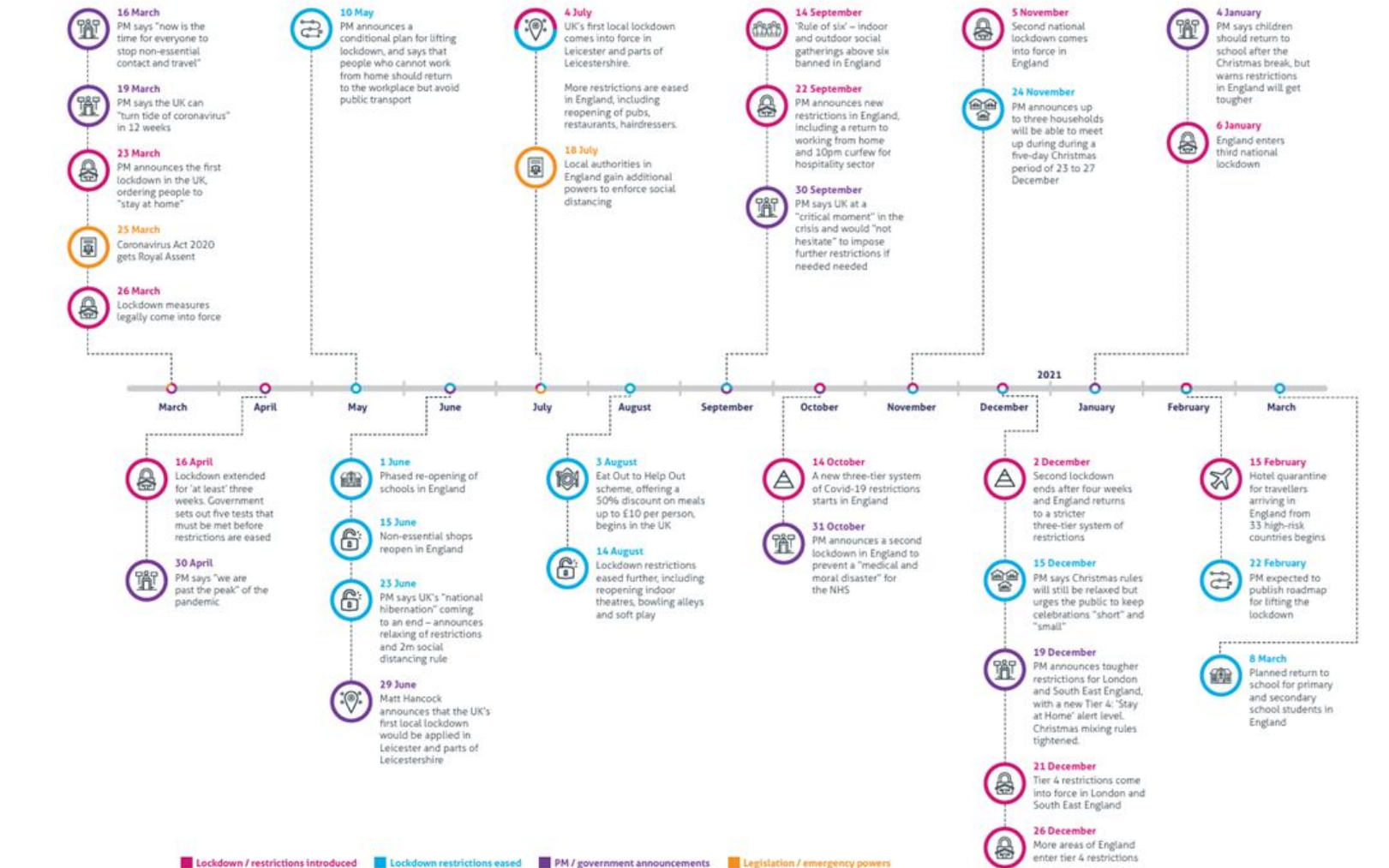
Schools closed to contain the spread of the virus with only two days' notice on 20th March 2020 (DfE, 2020b). The plan was for education to transfer to online digital learning as much as possible with schools open only for critical workers' children and vulnerable children, with

those with an EHCP listed as vulnerable (DfE, 2020b). Furthermore, it was announced that exams, such as GCSEs, would not go ahead in the summer (DfE, 2020b).

On 25th March 2020, the Coronavirus Act 2020 came into force which gave UK departments the powers to shut schools and childcare premises. Guidance was published on remote education but there was no requirement to provide it, nor any guidance as to how much should be offered (Ofsted, 2021b). On 1 May 2020, the Government temporarily relaxed some aspects of the law on EHC needs assessments, such as the time limits required to act and the provision in plans (The Special Educational Needs and Disability (Coronavirus) (Amendment) Regulations, 2020). These changes were intended to give LAs, education settings and health bodies greater flexibility due to the exceptional pressures created by COVID-19. The absolute duty to provide the extra support in an EHCP, which is a legal document, was changed to that of only requiring LAs to do whatever they reasonably could and that if they could not do so due to COVID-19 then the law would not necessarily be considered broken (DfE, 2020a).

These changes were to last until 25 September 2020 when all the usual statutory timescales and requirements returned (The Special Educational Needs and Disability (Coronavirus) (Amendment) Regulations 2020). During the time that the amendments were in place, many children did not get all, or sometimes any, of the provision to which they were legally entitled in their EHCP, especially if they remained at home (Disabled Children's Partnership, [DCP], 2020), creating great stress for families and difficulties with home learning.

Figure 2. Timeline of UK COVID-19 lockdowns March 2020- March 2021



1.6.4 Free School Meals

In the UK, SEND and Free School Meals (FSM) status are deeply intertwined variables, as statistically, children with SEND are significantly more likely to qualify for Free School Meals and experience socioeconomic deprivation than their neurotypical/non-disabled peers (Skipp et al., 2021a). For many YP with SEND, school provides a structure of support, therapies, socialisation, and nutritional stability so when schools closed, this entire protective infrastructure collapsed, creating a compounding intersectional disadvantage (Parnham et al., 2023). Academic literature shows that hunger and poor nutritional quality negatively impact a child's cognitive function, behaviour, and emotional regulation (James, 2024). Therefore, it is likely that some YP's educational attainment will have suffered, potentially in part due to poor nutrition, with early pandemic research highlighting that the educational attainment gap between disadvantaged pupils (such as those in poverty and/or those with SEND) and their peers widened (Education Policy Institute, 2022b).

Free school meals are offered to reduce social inequalities for school children and are also seen as a measure of disadvantage for governments and researchers (Sutherland, 2016). They are offered to all infant aged children in Reception to Year 2 and all pupils who meet the eligibility criteria when a family is receiving certain benefits (Entitledto, n.d.). Schools that had many children receiving free school meals were acutely aware that if those children were not in school then they may be going hungry, as for some, the school meal was the only main meal in the day (Cullinane & Montacute, 2020). Many schools organised their own food boxes and deliveries to families as an option to provide the free school meals (DfE, 2020c) and found that due to more families being unemployed, more needed basic provisions (Cullinane & Montacute, 2020). The government introduced a scheme to provide food parcels or vouchers for families but there were concerns over accessing the vouchers and delays in receiving them (National Audit Office, 2021). Rows later erupted over the government's refusal to offer these vouchers over the school holidays, along with problems with the quality and the quantity of food parcels provided (Whittaker, 2021a). The footballer Marcus Rashford became involved as someone who had experienced food poverty as a child (Richardson, 2020), managing to persuade the government to continue to offer this safety net for the disadvantaged over the holidays during 2020.

1.6.5 Vaccination programme

A vaccine against COVID-19 became available in the UK from 8th December 2020, which gradually allowed some restrictions to ease with the WHO declaring an end to the public health emergency of international concern in May 2023 (World Health Organization, n.d.). However, when the vaccination programme began, it was mainly given to prioritised groups by age and the government were accused of forgetting both people with ID and their informal carers (Thomson, 2021), despite the known high death rates for people with ID and the importance of the carers in their lives (Public Health England, 2020b). Unless they came into the age groups being offered the vaccine, they were not initially prioritised, but on the advice of the Joint Committee on Vaccination and Immunisation (JCVI), the priority order was later adjusted to include those with Down syndrome, carers and those with underlying health conditions (DHSC, 2020b).

In February 2021, it was clear that not all carers were being allowed to receive a vaccine, as Contact, the charity for families with disabled children, produced a template letter for carers to give their GPs to insure they were placed in the correct priority group (Contact, n.d). Also in February 2021, it was recommended by the JCVI that all people on their GP's Learning Disability Register should be included in priority group 6 for their vaccine (Mahase, 2021). Healthy CYP were generally known at this point (early 2021) to be at a much lesser risk of serious disease, but those CYP at increased risk, who had underlying health conditions or disabilities did not seem to be considered, with many shielding for an entire year (Thomson, 2021). Additionally, initially there had been no research on the safety of the vaccine in children, although by February 2021 it was stated that the Oxford/AstraZeneca vaccine was to be tested on children from the age of six and trials were underway to develop safe vaccines for teenagers (BBC News, 2021a).

There also remained the difficulty of some people with ID accepting an injection-based vaccination, with Dan Scorer, head of policy at Mencap, stating in the media that this was a real obstacle for some people with a learning disability (Thorn, 2021). The DHSC stated that Imperial College were trialling an inhaled vaccine (Thorn, 2021), but this remains currently unavailable in the UK, leaving some vulnerable people remaining at risk. Articles also appeared regarding care workers needing to be vaccinated in order to keep their jobs, or to be offered jobs (Carter, 2021), in order to protect the most vulnerable in care homes and the

community, as well as the care workers themselves. However, it also raised ethical issues around compulsory vaccination and discrimination against those who may not be able to be vaccinated for medical reasons (NHS, 2021).

1.7 RESEARCH RATIONALE

Through the researcher's work as a young person advisor with the Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS), the idea of everyone experiencing this pandemic as equals and all being in it together, appeared to be a simplification at best. It was clear from the announcement of the first lockdown on March 23rd, 2020, that some families felt abandoned (DCP, 2020) and others were struggling with accessing the services they needed for daily living (Reaching Families, 2020). Families were already under pressure from lack of support and isolation which were felt more keenly than ever once lockdown began (DCP, 2020). This led directly to thinking about the variety of the CYP's experiences and how they were coping and reacting to an unprecedented event in their, and their parent's/carer's lives. Furthermore, CYP with disabilities are not a homogenous group, and so will not have the same experiences. Those with a visual impairment, for example, have significantly different needs to those in a wheelchair or who have an intellectual disability (Kirby, 2004). Furthermore, inclusion, which the researcher knew anecdotally through their work was not always experienced as the policy intended, is an important lens for this thesis, because it shaped the educational environment in which the YP experienced the pandemic. The policy should provide an equitable experience and protection for all YP in times of crisis, and it was important to consider whether the YP, parent/carers and professionals felt that this had happened (Education Policy Institute, 2020).

These issues highlighted the need to gain the perspective of the YP with SEND themselves through engaging with them directly to hear their voice. This knowledge was then triangulated by investigating the experiences of those closest to the YP, their parent/carers and the professionals who supported them. This is essential for understanding their unique perspective and to prepare for any future crisis.

1.8 THIS THESIS

The overall aim of this thesis was to hear directly from YP with SEND themselves about their experiences during the pandemic, as this did not appear to have been undertaken academically or involving many YP. Chapter 1 has provided the context of both the COVID-19 virus and the SEND education system at the time of the pandemic and summarised the potential interplay between the two. Chapter 2 reports on the scoping review which was conducted in order to examine what academic literature already existed about CYP with SEND during the pandemic. Literature from March 2020 to September 2021 was searched and the aims were broad, with a wide age group encompassing 5 to 25 year olds. This range was deliberately broader than the parameters established in the YP study to effectively identify potential gaps in ages of YP considered to date in the existing literature. Following this, the methodology used for the research is described in Chapter 3 with the reasons behind the choices made for the whole thesis. This leads on to the three studies, involving YP in Chapter 4, parents in Chapter 5 and professionals in Chapter 6. Finally, Chapter 7 discusses the overall work and its conclusions.

Chapter 2: SCOPING REVIEW

What is known from the academic literature about the impact of the COVID-19 pandemic on children and young people's lives who have special educational needs and/or disabilities in the UK. ¹

2.1 INTRODUCTION

As outlined in Chapter 1, the COVID-19 pandemic impacted everyone in the UK when restrictions were put in place to prevent the spread of the disease. However, it was thought that CYP with SEND would be more affected than others due to existing inequalities (Ashworth et al., 2022a). This hypothesis was supported by the initial data gathered by charities and organisations which were able to provide non-academic but immediate qualitative insights into the perspectives of the YP they already knew. This material was an important precursor to developing this academic thesis, as contemporary digital sources were produced early in the pandemic, such as Beatfreeks' webpage (beatfreeksyouthtrends.com/reads/take-the-temperature/). Beatfreeks is an agency which researches youth trends and culture and translates those insights into strategy for NGOs and public bodies, and so were able to quickly produce their report *"Take the Temperature"* (Beatfreeks, 2020) due to pre-existing contacts with YP. Another organisation which had immediate access to acquiring the views and experiences of YP was Barnardo's, which is a UK wide children's charity providing direct support, advocacy, and specialist services to support vulnerable CYP and their families. Barnardo's quickly provided two online hubs for families (Barnardo's, 2020a and 2020d), to help them cope with the plethora of information and to provide a central space for parent/carers and CYPs to access immediate help during lockdown. The Sewel et al. report for Barnardo's, *"Devalued by forces beyond your control: Experiences of COVID-19 lockdown restrictions and visions for the future, from young people who are supported by Barnardo's"* (Sewel et al., 2020) was carried out by external independent researchers using interviews and participatory methods to capture CYP's lived experiences during the early stages of the pandemic. It highlighted the disproportionate challenges faced by vulnerable young people, including increased isolation, disrupted

¹ A version of this chapter has been published: Paterson, J., McCarthy, M., & Triantafyllopoulou, P. (2023). The impact of the coronavirus pandemic on the lives of children and young people who have special educational needs and/or disabilities in the UK: A scoping review. *Journal of research in Special Educational Needs*, 24(1) 12-24. <https://doi.org/10.1111/1471-3802.12608>

routines, reduced access to mental health support, and heightened anxiety about the future.

However, it took time for academic research to be published due to the necessary procedures around academic research, such as ethical considerations. A scoping review methodology was therefore used to ascertain what information was known, and what impacts had been reported up until September 2021 in academic literature in the UK. The aim of this review was to build on the initial findings of the grey literature and to determine what gaps remained for further research.

2.2 METHODS

2.2.1 Development of research questions

The period under consideration was from the start of lockdown in the UK, 23rd March 2020 until 30th September 2021. No specific agenda and an open mind were brought to the review to enable any impacts to be considered and to be open to possibilities not previously considered. The review did not use any pre-defined perception of what the impacts may have been. Information was sought about any impact in any domain of CYP with SEND, apart from that involving purely physical medical outcomes related to the COVID-19 disease. The methodological framework of Arksey & O'Malley (2005) was adopted for this review, and their five stages were followed:

Stage 1. Identifying the research question

Stage 2: Identifying relevant studies

Stage 3: Study selection

Stage 4: Charting the data

Stage 5: Collating, summarising and reporting the results

(Arksey & O'Malley, 2005, p.5).

The additional optional stage of a consultation exercise was not carried out due to time constraints and remaining COVID-19 restrictions.

The only other scoping review known at the time of completing this review (March 2022) was a rapid scoping review entitled "Ask, Listen, Act – Working Together to Inform the Provision of SEND Support for Children after the COVID-19 Pandemic" (Ashworth et al.,

2022c). This review included CYP with SEND aged between 5 and 15 and key stakeholders over three phases and the report developed from this review was then submitted to Parliament as evidence of what would be needed to support CYP with SEND after the pandemic (Ashworth et al., 2022b). This review was not published in a peer reviewed journal but was on the researchers' website and was released as a funded research report and evidence briefings, funded by the National Institute for Health Research (NIHR) and carried out by Liverpool John Moores University, Edge Hill University, and the University of Liverpool. It was completed using grey literature published at the start of the pandemic, reports and some academic articles in June 2021. The ASK review asked about specific areas that may affect CYP with SEND, looking specifically for aspects affecting education and learning, and health and social care provision. The current scoping review, however, was conducted later in the pandemic when more academic papers had been published. The remit was also wider – looking for any impacts and with different inclusion and exclusion criteria. The protocol for this scoping review was registered on 11.10.2021 at the Centre for Open Science (<https://www.cos.io/>) and can be found at <https://osf.io/zgxpdp>.

2.2.2 Search strategy to identify relevant studies

A search strategy was developed to encompass all terms likely to be used to discover the impacts on this population of CYP with SEND.

Table 2. *Search Terms and Alternatives*

	KEY TERM	Alternative Term	Alternative Term	Alternative Term	Alternative Term	Alternative Term
Population	<i>Children and young people</i>	<i>Child* CYP</i>	<i>Young people Youth</i>	<i>Teen*</i>	<i>Adolescen*</i>	<i>Juvenile*</i>
	<i>Special Educational Needs and/or disabilit*</i>	<i>SEN/SEND Learning support SEN support Education, Health and Care Plan/ EHCP</i>	<i>Disab*</i>	<i>Autis*/ ASC/ASD/Asperger*</i>	<i>Physical disabil* Intellectual disabil* / ID Learning disabil*/LD</i>	<i>Developmental delay Global delay Complex needs PMLD</i>
Intervention	<i>Pandemic</i>	<i>COVID-19 COVID</i>	<i>Coronavirus*</i>	<i>Severe acute respiratory syndrome coronavirus 2</i>	<i>SARS-CoV-2</i>	

2.2.2.1 Database search

The following databases were searched for studies published between March 2020 and September 2021:

- Via EBSCO host:
 - Academic Search Complete
 - British Education Index
 - Child Development and Adolescent Studies
 - CINAHL
 - APA PsycINFO
 - SocINDEX
- Web of Science
- Scopus
- PubMed
- Research in Practice
- Social policy and practice
- Social care online

Other sources: citations and websites

2.2.2.2 Inclusion Criteria

Table 3. *Inclusion criteria for the search*

Participants age	5 years to 25 years old
SEN/D	Any disability or special educational need
Location	UK
Language	English
Date	26.3.2020 – 30.09.2021
Type of study	Peer reviewed academic studies

Studies were sought involving CYP aged between 5 and 25 years to include as broad a section of CYP as possible. This also included parent/carers or professionals dealing with this age range if they gave information about CYP's perspective. CYP may have had a formal diagnosis of a disability or special educational need, or they or their families could have

been self-identifying. The CYP may have had an EHCP (in England) or equivalent (Children and Families Act, 2014) or may have been included in SEN support at school (DfE & DoH, 2015). SEN support acknowledges the CYP have additional needs but that they can be met by provision ordinarily provided by the school (DfE & DHSC, 2015). Studies were included where the cohort of CYP with SEND or their parent/carer or professional was either the sole focus or where this cohort is clearly identifiable. Only studies which are about the UK or studies where the UK results or impacts are clearly separate from other countries were included. Additionally, only studies written in English were considered. Studies were included from March 26th 2020 when the first national lockdown regulations became enforceable by law, following the government's stay-at-home announcement on March 23rd 2020 and the first lockdown began, up until 30th September 2021. Additionally, only peer reviewed academic literature was included in the review.

2.2.2.3. Exclusion Criteria

- Studies discussing medical or clinical outcomes of the disease COVID-19
- Editorial or opinion pieces
- Grey literature, books, systematic/scoping/literature reviews or theses

Grey literature was studied as part of the background to this review with many surveys examined as they emerged, therefore informing this scoping review, as discussed in the introduction to this chapter. Many studies were rapidly published in the first few months of the pandemic, making it unrealistic to cover them in detail in this review. The grey literature surveys were a rapid response to the unfolding situation and created a broad picture of what was happening, but this review sought to explore more detailed information gathered within an academic framework. Government papers and guidance, editorials and opinion pieces were also not included as they are not part of academic research. If full articles could not be found or data was missing, the authors of the studies were contacted to check the relevance of the paper.

2.2.3 Study Selection

593 studies were retrieved from databases, and 125 duplicates were removed prior to screening. The titles and abstracts of these studies were screened according to the inclusion

and exclusion criteria. A PRISMA flow diagram was created to show the decision process with the numbers included and excluded at each stage based on these criteria following the Tricco et al., (2018) system for reporting scoping reviews (see Fig 3). Reference lists from articles were examined for inclusion in the review based on their titles. Five further articles were included for screening due to this. Full copies of articles that met the inclusion criteria were then obtained for further reading and charting of the data (Arksey & O'Malley, 2005). Any articles that remained undecided were also checked in full. Once the literature that appeared to meet the inclusion criteria was gathered, it was imported into the systematic review software Rayyan© and two reviewers independently screened those articles. The second reviewer (GM) first completed a pilot review to ensure understanding of the inclusion criteria and then looked at 50% of the studies to be screened. The second reviewer was given a priority list of reasons to exclude and crossed checked with the first reviewer. Any uncertainties or discrepancies between the reviewers were then discussed and no disagreements remained to be decided by a third reviewer.

2.2.4 Charting the Data

Twenty-one papers were selected for the final inclusion into this review and the information charted. The papers were read thoroughly and the data from them was inserted into a pre-defined table. The data selected from each paper were: author and date, aims of the study, population, type of study and methodology, SEND type and the impacts described in the papers on CYP with SEND. The impacts were divided into neutral, positive and negative impacts and listed in the table.

See Table 4 Charting the characteristics of the scoping review papers on pages 32 - 35 below.

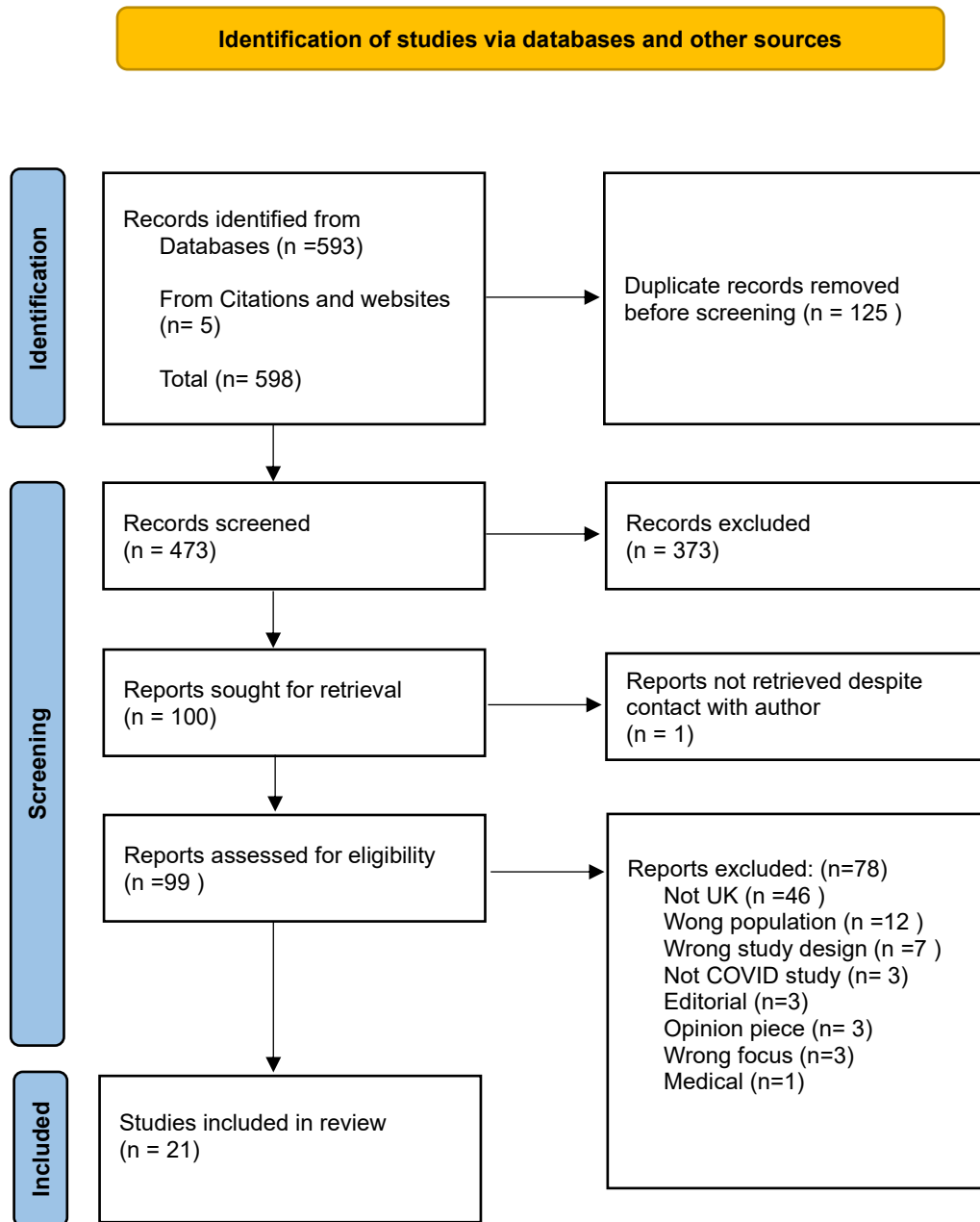


Figure 3. PRISMA 2020 Flow Diagram for Systematic Reviews

Table 4. Charting the characteristics of the Scoping Review papers

AUTHOR and date	AIMS	POPULATION	Type of study & Methodology	SEND Type	IMPACTS: neutral, positive or negative.
Asbury et al., 2021	Impact of COVID restrictions on mental health of parents and their CYP with SEND	N = 241 parent carers of school aged CYP with SEND	Qualitative question as part of a wider quantitative survey.	82% Autistic	Positive: Minority reported no change or improvements in MH. Negative: Loss, worry and parental anxiety. Most concerns specific to those with SEND. Single parent families particularly vulnerable.
Bailey et al., 2021	Psychological outcomes for parents, siblings and CYP with LD during restrictions	N = 397 parent carers of CYP with SEND 5 – 16 yrs.	Quantitative. Longitudinal survey.	Learning Difficulty (LD)	Positive: Wellbeing in families at similar levels as prior to lockdown.
Beaton et al., 2021	Inclusion during restrictions for CYP with LD	N = 6 stakeholders of CYP with SEND including one YP	Qualitative. Interviews.	LD	Positive: Online learning helpful for social inclusion. Parents more understanding of CYP's education. Online meetings positive for most. Negative: Digital inequalities.
Canning & Robinson 2021	Home life during lockdown	N = 8 parent carers of CYP with SEND 5 – 13 yrs.	Qualitative. Interviews and social media responses	Autistic / complex needs	Positive: More time for interests and schoolwork. Those still in school benefitted from routine. Negative: Work not differentiated. Working, caring and home learning impossible for some parents. Changes of personnel challenging. Digital difficulties.
Castro-Kemp & Mahmud 2021	Parents' views of school closure and return to school for CYP with SEND	N = 83 parent carers of CYP with SEND 3 – 12+ yrs.	Mixed methods, Survey.	Various, majority autistic	Positive: 45.8% reported CYP calmer at home. Majority said returning to school was positive. Negative: 54.2% reported school closures were negative for CYP. Minority found returning to school negative.
Couper-Kenney & Riddell 2021	CYP with SEND's rights in the pandemic.	N = 16 mothers of 24 CYP with SEND.	Qualitative. Interviews.	Not stated.	Positive: Time together and less school stress. Parents' knowledge of CYP's education. Negative: No regard paid to CYP with SEND's rights. Existing inequalities exacerbated. Eating disturbances and poorer MH.

Gillespie-Smith & Eaton-Thomas 2021	Psychological distress in caregivers of CYP with NDD during restrictions	N = 120 parents of 43 CYP with NDD compared to parents of 67 TDC	Mixed methods survey	Neuro developmental disability (NDD), mostly autistic	Positive: Calmer and less stress with no school. Negative: No respite for carers. Uncertainty. Parental coping strategies.
Greenway & Eaton-Thomas 2020	Parent experiences of home schooling for CYP with SEND during restrictions	N = 248 parents of CYP with SEND	Mixed methods survey	Social, Emotional and Mental Health (SEMH), communication and interaction 2 main groups. Autistic 73% Attention Deficit and Hyperactivity Disorder (ADHD) 49%.	Neutral: Social Economic Status and SEND type not associated with parents' experiences of home-learning. Positive: 8 parents said home-learning was better for their CYP academically. 13 said better for CYP wellbeing. Negative: Over half said no differentiation. 42% dissatisfied with support for home learning. Parents concerned re impact on CYP of home learning.
Hill et al., 2021	Parent's views of home- learning versus school for CYP with ASC	N = 6 parents of CYP with ASC	Qualitative. Interviews	Autistic and co-occurring conditions	Positive: 5 parents identified benefits of home-learning compared to school. Reduced parental stress.
Ludgate et al., 2021	Parents' experiences of home schooling CYP with SEND	N = 71 parents of CYP with SEND	Qualitative survey.	Not stated	Positive: Improved MH. More receptive to home schooling. Negative: Missing friends. Change of routine. Decline in wellbeing. Parents unable to meet all needs of family. Not enough support from school. No differentiation of work set. Mixed about return to school.
McCorkell, & Lobo. 2021	CYP's experiences of home learning	N = 7 CYP with ASC in school years 8 – 10	Qualitative Interviews	Autistic	Positive: More active and varied learning preferred. Able to create own routine. Negative: Digital platforms difficult to use. Not enough differentiation. Worried about progress. Not enough support or contact with pastoral care team.

					Missed being part of a class.
Morris et al., 2021	Parents' perspective of social communication and physical activity of CYP with ASC during restrictions	N = 176 parents in T1 and 54 in T2 of CYP with ASC 3 – 12 yr olds.	Quantitative surveys at 2 timepoints	Autistic	Neutral: No significant correlation between social- communication and physical activity in lockdown. No notable differences in communication skills or self-regulation on return to school Positive: Physical activity increased on return to school. Negative: Just over half felt not enough support from school in lockdown. Physical activity decreased in lockdown. Most parents said CYP's self-regulation and co-operation skills worsened in lockdown.
Nonweiler et al., 2020	Emotional and behavioural difficulties for CYP with NDD during restrictions	N = 453 parents of CYP with NDD 4 – 15 yrs.	Quantitative survey	NDD- autistic and ADHD	Negative: higher prevalence of emotional and behavioural symptoms for CYP with SEND. ADHD worse conduct problems and ASC less pro-social behaviour Girls with ASC higher emotional symptoms than boys.
Raw et al., 2021	Parent reported changes in CYP's mental health in 1 st lockdown	N = 3,046 parent carers of CYP 4 – 16 yrs.	Quantitative survey	Not stated –some had SEND.	Positive: Some CYP with SEND had improved mental health in lockdown. Negative: MH symptoms more likely to be raised for some groups including CYP with SEND. Some younger children and only children did worse than adolescents.
Rogers et al., 2021	Mother's experiences of CYP with ID in 1 st lockdown	N = 8 mothers of CYP with LD up to 18 years.	Qualitative interviews	LD/Autism	Positive: Some reported positive impacts of lockdown e.g. improved mental health. Negative: Increase in feelings of burden, stress and guilt with no respite. Regression in behaviour of some CYP. Parents unable to work. Decrease in wellbeing for some mothers. Increase in negative attitudes towards CYP when out in public. Home not safe space for some mothers. Difficulty doing the Lateral Flow COVID-19 tests for CYP.
Shaw & Shaw 2021	Parent's experiences of supporting remote learning of CYP with SEND	N = 137 parents of CYP with SEND 4-18 yrs.	Qualitative surveys at 2 timepoints	Not stated	Positive: Less stressed. Better relationship with their child and within family. Negative: No differentiation of work. Conflict of work, caring and education for parents. Stressful with lack of routine. Concern about whether learning taking place.

Spain et al., 2021	Perspectives of Health & Social Care professionals & researchers on impact of COVID on autistic individuals	N = 37 professionals working with people with ASC	Mixed methods survey	Autistic	Positive: Some did better not at school. Some liked physical distancing. Able to create own routine. Negative: Studying at home difficult for some. Problems managing physical health. Some missed social contact with others.
Theis et al., 2021	Parents' views impact of lockdown on physical activity and mental health of CYP with SEND	N = 125 parents of CYP with physical or learning disabilities.	Mixed methods survey	LD and physical disability, 41% autistic	Positive: Higher number of those with a physical disability in the group who reported positive changes. Some CYP did more physical activity in lockdown than usual. Negative: 61% reported reduction in physical activity. 42% rated MH as much worse during lockdown than before and 23% rated it a bit worse. Relationships worse. Over 90% reported negative impacts on mental health.
Thorell et al., 2021	Parents' experiences of home schooling: differences between children with and without mental health conditions	N = 508 UK parents of CYP aged 5 - 19 yrs within study of 7 European countries (6720 total).	Quantitative survey	CYP with and without Mental Health difficulties	Positive: More positives for CYP with MH difficulties than their parents. Some positives of home learning. Negative: More negative impacts on parents than CYP. % of contact time with teacher was lowest in UK and Germany. Younger CYP had more difficulties with home learning than older ones. Most parents of CYP with SEND said support with home learning not sufficient.
Toseeb 2021	Parents' views of sibling conflict in families with CYP with SEND	N = 504 parents of CYP with SEND 5 - 18 yrs, with siblings in family	Quantitative survey	Any but 75% had autism and more than half had more than one SEND	Positive: CYP with more complex needs appeared protected from increase in victimisation. Victimisation decreased when schools reopened. Perpetration did not increase but slight decrease when schools reopened. Negative: Victimisation increased during lockdown.
Waite et al., 2021	Parents' views of changes in CYPs mental health in 1 st lockdown	N = 461 parents of CYP with SEND but 2673 total in study of CYP 4 – 16 years.	Quantitative surveys at 2 timepoints	Any but most in whole study did not have SEND.	Positive: CYP with SEND experienced significant decrease in emotional symptoms. Very small decrease for those with SEND regarding the Strengths and Difficulties Questionnaire for conduct and hyperactivity/ inattention. Negative: CYP with SEND had elevated emotion, conduct, and hyperactivity/inattention scores compared to those without SEND across time points.

2.3. RESULTS

2.3.1 Study Characteristics

2.3.1.1 Participants

The total number of participants in all the papers was 3,918, with a range of 6 to 3,046. Of these, 3,869 (just under 99%) were parent/carers and 41 (a little over 1%) were professionals who worked with CYP with SEND in some capacity. Only two papers collected views directly from the CYP themselves: Beaton et al (2021) who included one young person in their study, and McCorkell & Lobo (2021) whose study was of seven young people, amounting to 0.2% of the participants in all the papers. Other CYP views may have been collected by parents who were involved in the studies, but there is not a direct CYP voice coming from the other papers. Although there are limitations on parents giving views on behalf of CYP, it is considered parents can give a good indication of their views, with research finding that parent-reports are relatively reliable (Rosenberg, et al., 2009). However, this may be more accurate for younger children than adolescents and young adults (Raw et al., 2021). The lack of a direct CYP voice may have been due to difficulties during the pandemic restrictions to engage with CYP, but there were organisations such as Barnardo's (Barnardo's, 2020b; Barnardo's, 2020c; Sewel et al., 2020) and Beatfrecks (2020) who sought out CYP's voices more directly to a greater extent.

2.3.1.2 SEND

Although many of the studies say they are about CYP with SEND generally, the majority are about autistic CYP, which is the most common reason for accessing extra support in education for special needs (DfE, 2020d). This may say something about the parents of CYP with autism and their wish to share their views and find solutions or the way that researchers find participants. Of the 21 papers, 13 are predominantly or wholly studies about CYP with autism or autism with co-morbidities (Asbury et al., 2021; Canning & Robinson., 2021; Castro-Kemp & Mahmud., 2021; Couper-Kenney & Riddell, 2021; Gillespie-Smith et al., 2021; Greenway & Eaton-Thomas, 2020; Hill et al., 2021; McCorkill & Lobo, 2021; Morris et al., 2021; Nonweiler et al., 2020; Theis et al., 2021; Toseeb, 2021 and Spain et al., 2021). Three are about CYP with intellectual or learning disabilities (Bailey et al., 2021; Beaton et al., 2021; Rogers et al., 2021) which often overlaps with ASC, with one paper focusing mostly on CYP with both (Rogers et al., 2021). One concerns CYP with mental

health difficulties (Thorell et al., 2021) and four do not state specifics of the group of CYP with SEND in their sample (Ludgate et al., 2021; Raw et al., 2021; Shaw & Shaw, 2021; Waite et al., 2021). Other SENDs were included, but much of the research to date appears to be about CYP with autism.

2.3.1.3 Gender

When the participants responding to the surveys were the parents, these were usually female and the CYP with SEND included in the studies were mostly male. This reflects the fact that the caring role for children, especially those with SEND, remains largely female in the UK and therefore it is female carers who would respond to a request for participation about their CYP (Contact, 2017). The CYP genders reflect the fact that more boys receive a diagnosis of ASC and at an earlier age than girls (Hull, 2020).

2.3.1.4 Age

The ages of the CYP in the studies varied. Most studies included CYP who were of statutory school age, which in England begins in the school term following a child's fifth birthday and continues until the end of the school year in which they turn 16 (UK Government, 2014). However, three studies included children of three years of age (Castro-Kemp & Mahmud, 2021; Greenway & Eaton-Thomas, 2020; Morris et al., 2021) and five studies went above statutory school age and included CYP up to age 17 plus (Asbury et al., 2021; Greenway & Eaton-Thomas, 2020; Rogers et al., 2021; Shaw & Shaw, 2021; Toseeb, 2021) or up to 19 years (Thorell et al., 2021).

2.3.1.5 Ethnicity

Ethnicities were only recorded in six of the papers (Asbury et al., 2020; Castro-Kemp & Mahmud, 2021; Couper-Kenny & Riddell, 2021; Raw et al., 2021; Toseeb, 2021; Waite et al., 2021) where they were largely white British or white, with very few ethnic minorities taking part.

2.3.1.6 Country of UK

Seven of the studies' participants were entirely from England (Beaton et al., 2021; Canning & Robinson, 2021; Castro-Kemp & Mahmud, 2021; Ludgate et al., 2021; Theis et al., 2021; Shaw & Shaw, 2021; Spain et al., 2021) with two others mostly from England (95% Asbury et

al., 2021; 94% Toseeb, 2021). Nine other studies reported the participants were from the UK but did not specify which areas and two studies were conducted only in Scotland (Couper-Kenney & Riddell, 2021; McCorkill et al., 2021).

2.3.1.7 Methodology and type of studies

Seven studies were quantitative, nine were qualitative and five were mixed methods. Fifteen were surveys and six were interviews.

2.3.2 Impacts Found

The impacts reported in the papers can be divided into six themes: mental health, home learning and life, school, social impacts, physical activity and health, and human rights. This section explores what the papers contributed to each of these themes.

2.3.2.1. Mental Health

Seventeen of the 21 papers mentioned an impact of Covid on CYP's mental health, (Asbury et al, 2020; Bailey et al., 2021; Castro-Kemp & Mahmud, 2021; Couper-Kenney & Riddell, 2021; Gillespie-Smith et al., 2021; Greenway & Eaton- Thomas, 2020; Hill et al., 2020; Ludgate et al., 2021; McCorkell & Lobo, 2021; Nonweiler et al., 2020; Raw et al., 2021; Rogers et al., 2021; Shaw & Shaw, 2021; Spain et al., 2021; Theis et al., 2021; Thorell et al., 2021; Waite et al., 2021). One study reported no change in mental health (Bailey et al., 2021) which could be interpreted as a positive as mental health was not seen to deteriorate despite difficult circumstances. Of the positive impacts on mental health, 13 of those 17 papers reported that a minority of participants had experienced an improvement in their mental health (Asbury et al., 2021; Castro-Kemp & Mahmud, 2021; Gillespie-Smith et al., 2021; Greenway and Eaton-Thomas, 2020; Hill et al., 2021; Ludgate et al., 2021; McCorkill & Lobo, 2021; Raw et al., 2021; Rogers et al., 2021; Shaw & Shaw, 2021; Spain et al., 2021; Thorell et al., 2021; Waite et al., 2021). Sometimes this minority was sizeable, such as the 45.8% of 83 parents in the Castro-Kemp study (Castro-Kemp & Mahmud, 2021). The McCorkell & Lobo (2021) study found that none of the 7 young people in their study expressed strong feelings of anxiety despite many parents in the 20 other studies mentioning that anxiety had increased. It may be that different age groups or SEND type of the CYP were affected differently or that parental reports of their CYP's emotional and mental states were not accurate (Raw et al., 2021), but it is not yet clear from existing data.

Improvements were also reported in mood, sleep, seizures, obsessive and compulsive routines and speech, with some CYP appearing more relaxed and exhibiting less challenging behaviour (Rogers et al., 2021). The mothers who were the participants in Rogers et al., (2021) study attributed these improvements to the reduction of task demands and less pressure as life became calmer. Some parents also reported less stress and feeling more relaxed themselves (Hill et al., 2021; Ludgate et al., 2021; Rogers et al., 2021; Shaw & Shaw., 2021). Some of the CYP found that being able to wear what they liked, get up when they were ready and eat what and when they wanted to, improved their feelings of wellbeing (Spain et al., 2021).

Less than half (34.1%) of the respondents in Shaw & Shaw's (2021) study reported a negative impact on their own mental health, when asked a direct question about this. This may be due to already having coping mechanisms in place which are needed ordinarily to meet the challenges of raising a CYP with SEND (McConnell & Savage, 2015). Emotional symptoms such as fear/worry, clinginess, low mood and undue focus on physical symptoms were found in those with SEND to significantly decrease during lockdown but significantly increase in those without SEND according to Waite et al. (2021). This could indicate that for a significant number of CYP with SEND, school may not be the best environment for their mental health (Castro-Kemp et al., 2021). CYP with SEND do have a higher baseline of emotional symptoms compared to children without SEND however, so their symptoms could remain high despite the decrease (Raw et al., 2021). Ludgate et al. (2021) found that 84% of parents reported some unexpected positive impacts for their families during the lockdowns, which included having fewer pressures resulting in less stress as well as more family time and educational benefits.

In contrast, Nonweiler et al. (2020) found that CYP with neurodevelopmental disorders (NDD) compared to their neurotypical peers had a higher prevalence of emotional symptoms (42% vs. 15%) and conduct problems (28% vs. 9%), and fewer prosocial behaviours (54% vs. 22%). Nonweiler et al. (2020) reported that all groups had worse emotional symptoms during the pandemic than comparable pre-COVID groups, but those with ADHD showed greater conduct problems, and those with ASC exhibited less prosocial behaviours. Autistic females were reported to have higher emotional symptoms compared to males by their parents and all CYP with or without NDDs showed higher levels of parent-

reported mental health problems than comparable cohorts pre-COVID-19 in this study. The pre-COVID data for comparison was obtained from a large national survey of 10,438 children aged 5–15, which provided the official UK normative data from the Strengths and Difficulties Questionnaire (SDQ), collected before COVID-19 (Meltzer et al., 2000).

Bailey et al. (2021) were also able to compare mental health before and after COVID restrictions were introduced as they used data from the longitudinal 1000 Families Study (Hastings et al., 2020). This study had collected data for wave 1 in 2017, then wave 2 data was collected either just before or during the first lockdown in 2020. This inadvertently created a before and after COVID restrictions study of mental health. It was reported that mental health for CYP with intellectual disabilities (as reported by parents) was at similar levels in the first lockdown compared to prior to the pandemic. This could be read as a positive in that there was not a decline, but they were starting from a lower level of wellbeing initially (Broach et al, 2016), and in this study it did not improve either. The authors acknowledged that any impacts may have taken longer to take effect and that there may have been a difference in the participants who chose to complete the survey during or after the lockdown as compared to those who completed it before.

A mixed picture of impacts on mental health is indicated as 10 of the studies reported that for the majority of CYP there were negative impacts to their mental health during the restrictions (Asbury et al., 2020; Castro-Kemp & Mahmud, 2021; Couper-Kenney & Riddell, 2021; Greenway & Thomas-Eaton, 2020; Ludgate et al., 2021; Nonweiler et al., 2020; Raw et al., 2021; Rogers et al., 2021; Theis et al., 2021., Waite et al., 2021). As stated above, this majority was sometimes small but in other studies it was significant, for example in the Theis et al. study (2021) over 90% reported a negative impact on mental health, including poorer behaviour, mood, fitness and social and learning regression. 65% of the Theis et al. (2021) respondents rated mental health as either much worse or a bit worse during lockdown compared to before, mentioning lack of access to school, special facilities, outdoor play and exercise together with a deterioration in relationships. For a majority of CYP, returning to school was reported as having a positive impact on both their mental and physical health despite fears of the virus (Castro- Kemp & Mahmud, 2021). However, a large minority of parents in this study (45.8%) said that their CYP were calmer at home when schools were closed and became more anxious upon returning to school.

Results in the Castro-Kemp et al. study (2021) showed that parents in deprived neighbourhoods were more likely to report negative effects of school closures on their CYP's mental health, and that ethnically diverse parents were more likely to mention impacts on their own physical and mental health. Three other studies also reported poorer parental mental health (Asbury et al., 2021; Gillespie-Smith et al., 2021; Thorell et al., 2021) and all the mothers in Rogers et al. (2021) study said their stress had increased. In the Thorell et al. (2021) study, parents reported that for families with a child with an existing mental health diagnosis there were more positive effects of schools being closed for CYP than for parents and less negatives for the CYP than for the parents. This could be understood as the stress of school and interacting whilst dealing with a mental health difficulty being alleviated for the CYP but the negative impact on the parents being enhanced with less support, less breaks from their children and more duties imposed on them having to juggle work and home learning. However, for families without CYP with a mental health diagnosis there were less positives for the CYP than the parents but still less negatives for the CYP than the parents. CYP without a MH diagnosis may be missing the social elements of school but parents will again be taking on the responsibility for home learning in addition to work, creating tensions. The data is for parents reporting on themselves and for their children however, so the CYP themselves may have had a different view if asked directly.

Parents also stated that the uncertainty of the situation and having to communicate new rules and guidelines with no support, to young people with a low tolerance of uncertainty was very challenging (Gillespie-Smith et al., 2021 and Ludgate et al., 2021). This resulted in increased stress for both CYP and parents and negative behavioural changes in the CYP (Ludgate et al., 2021). Families led by lone adults appeared more at risk of mental health issues than those with more adults present in the family (Asbury et al., 2020). Additionally, CYP also appeared to be more vulnerable to mental health difficulties if they were single children in a family, pre-adolescent, there was family conflict, the parent had mental health difficulties, or the family had a lower-than-average income (Raw et al., 2021).

There were more negative impacts on parents' mental health during the period of home learning than for the CYP in the Thorell et al. study (2021). This was especially true for parents of CYP with a mental health condition but was also true for parents of CYP without an existing mental health condition. The parents' own coping strategies when stresses

increased were also shown to be instrumental in affecting the CYP's risk of psychological distress (Gillespie-Smith et al., 2021). Some increase in stress appeared to be linked by parents to not getting enough support or any break from their CYP, when all support ceased overnight from both formal and informal carers (Couper-Kenney & Riddell, 2021, Gillespie-Smith et al., 2021; Raw et al., 2021). Formal carers are those paid to help with the 24/7 nature of some caring duties such as personal care, mobility, feeding and nursing tasks or by providing residential breaks away from the family (Broach et al, 2016). They could also include short breaks by way of clubs and activities provided by services (Broach et al, 2016). Informal carers include family members and friends who would provide respite for the parents and siblings by looking after the CYP for short periods. This, along with education becoming remote and almost all therapeutic services reducing if not ceasing completely, created a very difficult and unequal situation for parents of CYP with the most complex SEND (Couper-Kenney & Riddell, 2021; Gillespie-Smith et al., 2021).

Additionally, eating disturbances were reported to have increased, with either under or overeating occurring due to anxiety or boredom (Couper-Kenney & Riddell, 2021). Eating was also mentioned as a positive for some CYP, with better eating habits due to less stress and being able to choose where, what and when they ate (McCorkell & Lobo, 2021; Spain et al., 2021).

2.3.2.2 Home Learning/home life

17 papers reported on either home learning or home life during the early part of the pandemic restrictions (Asbury et al., 2021; Beaton et al., 2021; Canning & Robinson, 2021; Couper-Kenney & Riddell, 2021; Greenway & Thomas-Eaton, 2020; Hill et al., 2021; Ludgate et al., 2021; McCorkell & Lobo, 2021; Morris et al., 2021; Nonweiler et al., 2020; Rogers et al., 2021; Shaw & Shaw, 2021; Spain et al., 2021; Thorell et al., 2021; Theis et al., 2021; Toseeb, 2021; Waite et al., 2021). Greenway et al. (2020) reported that they found neither socio-economic status (SES) nor the SEND diagnosis appeared to affect the experiences of home learning. However, the SES was measured by the parents' educational level which may not be an accurate measure in these circumstances as parents with a CYP with SEND are more likely to be earning less than generally expected for their educational level due to their child's SEND making full time or any work possible (Dobson et al., 2001). This finding also contradicts other studies which reported that single parents of SEND CYP (Asbury et al.,

2020) appeared particularly vulnerable to the negative changes of the pandemic especially as regards to parental and CYP mental health which would then affect the home environment and ability to learn. Castro-Kemp & Mahmud (2021) also found a strong association of SES and poorer mental health for the families in their study. Digital inequalities were reported (Beaton et al., 2021; Canning & Robinson, 2021; Couper-Kenney & Riddell, 2021; McCorkell & Lobo, 2021) which would have also been impacted by the affluence of the family. Some families had adequate technology, but many were using one device for multiple children or to work from home in addition to providing home learning (Canning & Robinson, 2021).

Parents complained that there was no coordination between subject teachers to make sure there was not too much work set at the same time, resulting in sometimes too much work being set (Canning & Robinson, 2021; Greenway & Thomas-Eaton, 2020). CYP complained that much of the work set was not challenging and was mostly revision (McCorkell & Lobo, 2021). CYP also commented that although they had been issued with Local Authority iPads, the digital platforms used by schools were difficult to use (McCorkell & Lobo, 2021) and some CYP were unable to view the recordings or resources (Shaw & Shaw, 2021). The technology often depended on a parent's input which put more stress on them and made homeworking or other tasks challenging (Canning & Robinson, 2021).

A major complaint from many families was that there was not enough differentiation for their CYP with SEND and much less than when they attended school (Canning & Robinson, 2021; Greenway & Thomas-Eaton, 2020; Ludgate et al., 2021; McCorkell & Lobo, 2021; Morris et al., 2021; Shaw & Shaw, 2021). This resulted in inappropriate work being sent which the CYP could not do, meaning that parents had to adapt the work and spent time finding relevant resources (Canning & Robinson, 2021; Shaw & Shaw, 2021). Home learning was reported as more difficult for younger children than older ones from the parent's perspective as they needed more supervision and support and therefore time from parents (Thorell et al., 2021). However, some secondary pupils had commented that they had needed more support than was provided by the school to structure the activities, being unable to start or continue with a task (McCorkell & Lobo, 2021).

The home learning experiences were reported as being mostly negative for most families in the six studies that reported on this. Parents said the pace was too quick for their children

when online classes were not differentiated (Canning & Robinson, 2021) and resources were sent that were beyond the developmental age of their child (Shaw & Shaw, 2021). Some CYP found the different professionals they were meeting online confusing and unsettling, and they did not like them coming virtually into their safe home space and they therefore did not want to engage with them (Canning & Robinson, 2021).

Many parents stated that usually their CYP could not engage at home with an activity connected to school, and they refused to do any schoolwork at home (Canning & Robinson, 2021) and responded negatively to their parent becoming a teacher figure (Shaw & Shaw, 2021). A common complaint of the participants in the studies was the lack of support for families from the school or pastoral support teams (Canning & Robinson, 2021; Couper-Kenney & Riddell, 2021; Gillespie-Smith et al., 2021; Ludgate et al., 2021; McCorkell & Lobo, 2021; Morris et al., 2021; Rogers et al., 2021; Shaw & Shaw, 2021; Spain et al., 2021; Thorell et al., 2021). The families were trying to balance the different needs of their family members of different ages and generations, including their CYP (or several CYPs) with SEND along with providing home learning whilst often working from home or having to go outside the home to work with little childcare provision (Shaw & Shaw, 2021). Families were also concerned about their CYP getting further behind than they already were. They were worried about whether they were progressing and what impact this period would have on their CYP's education (Greenway & Eaton-Thomas, 2020; McCorkell & Lobo, 2021; Morris et al., 2021 and Shaw & Shaw, 2021). They also wondered if they were doing the work properly and felt guilty about being unable to provide the support their CYP had in school (McCorkell & Lobo, 2021; Morris et al., 2021; Shaw & Shaw, 2021; Rogers et al., 2021).

For a minority of CYP however, online or home learning was seen as beneficial academically (Canning & Robinson, 2021; Greenway & Eaton-Thomas, 2021; Hill et al., 2021). Hill et al. (2021) found that 5 out of the 6 parents they interviewed mentioned benefits of home learning as compared to their CYP attending school. The three studies mentioning beneficial academic impacts (Canning & Robinson, 2021; Greenway & Eaton-Thomas, 2021, Hill et al., 2021) were all mostly or entirely of autistic CYP, but this benefit was not only found for autistic CYP although it appears to be more marked for them. There is mention of the single YP in the Beaton et al. study (2021) with Down syndrome also doing better academically and taking more agency in her learning as a result of being away from school. It appeared that

the learning support assistant (LSA) had completed work in school for her, and being at home allowed the YP to follow her own interests and learn at her own pace. However, this is a single individual and there is not enough information about this topic to make any conclusions at this stage. Some families felt as though the pressure was off academically and the CYP achieved more without the distractions or difficulties of the school environment (Canning & Robinson, 2021; Greenway & Thomas-Eaton, 2020; Hill et al., 2021; Ludgate et al., 2021; McCorkell & Lobo, 2021; Rogers et al., 2021 and Thorell et al., 2021). However, these studies include a large proportion of autistic CYP and so it is not known if this effect is true of CYP with SEND generally. Parents commented that they knew more about their child's education because of this experience and better understood their child's strengths and struggles (Beaton et al., 2021; Couper-Kenney & Riddell, 2021; Ludgate et al., 2021). Some parents felt they could be more creative with learning, working it around the CYP's interests or inclinations and being able to spend time on their chosen interests in way and at a time that worked best for them (Canning & Robinson, 2021; Ludgate et al., 2021; Shaw & Shaw, 2021) resulting in greater time engaged academically (Hill et al., 2021). The CYP in McCorkill & Lobo's study (2021) stated that they liked the more varied learning they could do at home, using different online or computer programmes and methods rather than just writing which they felt happened at school. This could account for Ludgate et al. (2021) finding that some parents reported their CYP were more receptive to learning while at home. For some families this resulted in improved relationships at home between family members who enjoyed spending time together without other demands (Couper-Kenney & Riddell, 2021; Ludgate et al., 2021 and Shaw & Shaw, 2021). Some felt that remote learning suited their CYP better than school as they were able to mute, switch off the camera or take time out whenever they needed to and yet still be part of the learning experience which Beaton et al. (2021) commented could help with feeling more socially included than when physically in the classroom. However, due to the lack of differentiation mentioned by many parents, this did not appear to have happened for many CYP.

Toseeb's (2021) study was a little different as he investigated sibling conflict within families with a CYP with SEND during the early part of the pandemic. He discovered that the CYP with more complex needs appeared to be protected from being picked on or hurt by their siblings during lockdown. It may be that those who were not verbal or independently mobile

were seen as obviously needing support and not seen as competitors for parental attention (Kowal et al., 2002). However, generally family relationships were reported to have deteriorated (Toseeb, 2021; Theis et al., 2021) with victimisation of a CYP with SEND by their sibling increasing during lockdown but then decreasing once schools were fully reopened for in person teaching (Toseeb, 2021). Perpetration of violence by CYP with SEND towards their siblings was not reported to increase in lockdown but there was still a slight decrease when schools reopened (Toseeb, 2021). Conduct problems generally were found to have worsened for CYP with SEND during school closures (Morris et al., 2021; Nonweiler et al., 2020; Rogers et al., 2021; Waite et al., 2021), with Waite et al. (2021) finding that both children and adolescents with SEND had raised emotion, conduct, and hyperactivity/inattention scores compared to those without SEND across both time points in the study. As well as sibling conflict and violence, there was the risk of child to adult violence mentioned in the Rogers et al. (2021) study. For some mothers, home was not a safe space for them due to the behaviours of their CYP or other family members, making them at risk of violence (Rogers et al., 2021).

2.3.2.3 School attendance

Seven papers reported about the impacts of partial school closures and returning to school by asking direct questions related to this (Canning & Robinson, 2021; Couper-Kenney & Riddell, 2021; Gillespie-Smith et al., 2021; Ludgate et al., 2021; McCorkell & Lobo, 2021; Morris et al., 2021 and Rogers et al., 2021). Schools were to be open for keyworkers' children and vulnerable children only which could include those CYP with SEND. The Asbury (2021) study showed that although 44% of the parents of school aged children with SEND in the study were offered a school place, only 8% had taken it up due to concerns about the CYP catching or transmitting the virus. Despite their vulnerability, some children were prevented attending by guidance from the DfE saying that CYP should only go into school if parent/carers could not keep them safe at home (DfE, 2020b), which was a subjective measure. According to Couper-Kenney & Riddell, (2021) only 1% of all children in Scotland attended school in lockdown, and most of those were keyworkers' children rather than those with SEND (Scottish Children's Services Coalition, 2020). It was felt that those who remained in school during the lockdowns benefited from the continued routine of attendance despite the changes there and also the CYP were less anxious than they would

be if they had remained at home (Canning & Robinson, 2021). One parent commented in the Canning & Robinson study (2021) that their child would not have done any work if he had stayed at home, seeing the two places as separate entities, and he then would have become very anxious about not doing the work. However, some of the parents of those not in school at this time commented that there was less school stress and demands on their CYP who then benefited from a slower, more relaxed pace (Couper-Kenney & Riddell, 2021; Gillespie-Smith et al., 2021; Ludgate et al., 2021; Rogers et al., 2021).

Returning to school after the closures was a mixed or negative experience for some CYP (Castro-Kemp & Mahmud, 2021; Ludgate et al., 2021) but was considered mostly positive by families for the CYP's mental health (Castro-Kemp & Mahmud, 2021). On returning to school, parents were concerned about their CYP catching the virus, or the CYP infecting a family member (Castro-Kemp and Mahmud, 2021; Ludgate et al., 2021). They were also concerned about the fact that school had changed due to the virus restrictions and may be difficult for the CYP to adjust to (Ludgate et al., 2021) or about returning to a setting that was not meeting their CYP's needs (Ludgate et al., 2021). An obvious advantage however of being back in school was that the CYP would have access to the technology, teachers and resources they had not had whilst at home (McCorkell & Lobo, 2021).

2.3.2.4 Social Impacts

Six papers spoke about social impacts for the CYP which also discovered a mixture of positive and negative aspects (Beaton et al., 2021; Canning & Robinson, 2021; Hill et al., 2021; Ludgate et al., 2021; Morris et al., 2021; Spain et al., 2021). The positive aspects were that for some CYP the social difficulties of going to school and engaging with the community were removed entirely. This resulted in reduced or no social pressure (Ludgate et al., 2021) and no bullying or worries about being bullied (Hill et al., 2021). For some CYP it was a relief to introduce physical distancing as it was their preferred style of relating to others (Spain et al., 2021). However, although these were expressed in terms of positive impacts for the CYP and families, it is uncertain how positive it is in the long run to avoid social contact and situations that could create personal growth and resilience (Rubin, 2009). The change to conducting meetings via online platforms such as Microsoft Teams or Zoom rather than in person was seen as positive for many. More professionals could attend as it freed up time due to not having to travel, families found it less stressful and many CYP found it less

threatening (Beaton et al., 2021). However, this was not the case for all families. Changes were often made to the professionals who met with families remotely due to some staff being asked to undertake alternative duties during the restrictions and some staff being absent from work due to caring duties or illness. This was challenging for some CYP to deal with as they were unfamiliar faces with no prior relationship to seeing them on screen (Canning & Robinson, 2021).

Many CYP missed the social contact with others that takes place in a normal week. Social contacts could include friends and professionals at school or after school clubs, therapists and carers as well as contact with the extended family and family friends (Canning & Robinson, 2021; Ludgate et al., 2021). Some CYP had missed being part of a class whilst at home (McCorkell & Lobo, 2021).

There were a variety of perceptions by parents about their CYP's social communication skills during lockdown and on return to school (Morris et al., 2021). Morris et al. (2021) found that most parents believed their child's self-regulation and co-operation skills, but not their communication skills, had worsened during the lockdowns. Communication skills did not appear to have changed and had even improved for some participants during lockdown (Morris et al., 2021) with a possible explanation offered that there may have been more intense and frequent child-parent interactions while at home, preventing a deterioration for some CYP. There also appeared not to be a correlation of activity levels with communication and self-regulation skills for CYP in lockdown (Morris et al., 2021).

2.3.2.5 Physical activity and health

Three papers reported on physical activity changes during the lockdowns and school closures (Morris et al., 2021; Couper-Kenney & Riddell, 2021; Theis et al., 2021). All three found that physical activity mostly decreased for the CYP with SEND during lockdown and Morris et al. (2021) found they seemed to increase for most CYP on return to school. 61% in the Theis et al. study (2021) reported a reduction in physical activity levels. Parents said that the closure of the specialist facilities CYP with SEND needed to exercise or a lack of access to the groups or equipment necessary were the reasons for this (Theis et al., 2021). However, it was also reported that some CYP did more physical activity than usual in lockdown as there was more time and less choice of activities generally (Theis et al., 2021), with a daily

walk being one of the few options available for families in the first lockdown (Prime Minister's Office, 2020). Rogers et al. (2021) also commented that some CYP found the daily walk beneficial. However, one mother commented in the Rogers et al. (2021) study that she had met with negative attitudes from the public for the first time ever when she went out more than once a day with her CYP during lockdown. It was only permitted to be out once a day at this time unless you had a learning disability or autism (Walker, 2020). Questions had been raised to the mother as to whether the CYP was really disabled and should be out.

As stated, it was found that for some CYP, physical activity increased in lockdown with 18% of parents reporting that their child had done much more physical activity in lockdown (Theis et al., 2021) compared to before the restrictions, with 16% reporting positive physical changes (Theis et al., 2021). However, these CYP had been doing less than the other groups in the study before lockdown (Theis et al., 2021). This study also showed that a significantly higher number of CYP with a physical disability were in the group who reported positive changes (Theis et al., 2021). This group may have benefited from being able to take part in the online fitness classes that began in lockdown and some reported spending more time playing in the garden or cycling (Theis et al., 2021). However, Theis questioned whether CYP with disabilities found doing activities in isolation or with others who do not share their attributes, as beneficial to their mental health as to their physical health, as despite the increase in physical activity there was still a decline in mental health reported for the CYP.

50.6% of parents responded in the Castro-Kemp & Mahmud study (2021) that school closures had had a detrimental effect on their children's physical health, with 49.4% saying that it had not (Castro-Kemp & Mahmud, 2021). In the Castro-Kemp & Mahmud study (2021) the two parents whose children remained at school during the lockdown reported no adverse effects of the lockdown on either physical or mental health. Managing CYP's physical health for most parents had been challenging due to the lack of available services, support and access to them (Spain et al., 2021) and doing the actual COVID tests for their CYP was very difficult (Rogers et al., 2021). Parents of children attending special schools and parents of girls were also found to be more likely to report negative effects of school closures on their children's physical health (Castro-Kemp & Mahmud, 2021).

2.3.2.6 Human rights

Only one paper looked at the impact of the pandemic through a children's rights-based lens and that was the Couper-Kenney and Riddell (2021) paper, with research on the situation in Scotland. The paper investigated "the extent to which children's rights have been prioritised during the COVID-19 crisis" (Couper-Kenney & Riddell, 2021, p 1) and found that "*scant regard was paid to the rights of children with ASND*" (Additional Support Needs and Disabilities) Couper-Kenney and Riddell, 2021, p 1), despite legislation to protect CYP's rights existing in Scotland (Scottish Parliament, 2016). It is likely that this was the situation across the UK due to the speed with which restrictions were put in place.

2.3.2.7 CYP views

There were not enough CYP participants involved in these studies to report on what CYP themselves said about the impacts of the pandemic in much detail, but the McCorkell and Lobo (2021) study was an exception to this. Although their study was small, they directly involved autistic CYP in school years 8 – 10 in mainstream schools in the qualitative interviews. The CYP stated that they preferred how school was usually as they missed being part of a class. However, they liked the ease with which they could communicate with their teachers via email or the chat function of the software. They all had access to an iPad through their Local Authority and had enjoyed using a greater variety of learning methods which were possible online. There were frustrations with the digital platforms however, as they did not know how to use them initially and they did not always work. However, they preferred the variety this approach brought to their learning with videos, class sessions, quizzes and games used more often than when they were in school, which they found was dominated by writing and lacked interest for them.

Sleep duration lengthened for some CYP with the acknowledgement that they were sleeping a lot more because there was nothing to get up for. Others mentioned they felt that going to sleep later and starting the day later improved their wellbeing and learning and they benefitted from the ability to create their own routines. Any worries were about the virus itself and about the CYP's ability to keep up with their education. They felt at times that the education was not differentiated enough for them but that it also sometimes lacked challenge.

Beaton et al. (2021) included one YP with Down syndrome, who was interviewed simultaneously with her mother. This YP had taken on more control of her learning at home and was able to organise it and avoid doing things she did not want to do by deleting links. Her artwork also improved whilst at home as she took ownership of what was produced away from the LSA provided at school. As a result, she was entered into the art GCSE exam, which was not planned for before the pandemic.

2.4 DISCUSSION

The aim of this scoping review was to find out what was known from the academic literature about the impact of the pandemic and the attendant restrictions on CYP with SEND in the UK. All impacts on CYP with SEND were considered and the literature highlighted the many ways that families experienced this time. It appears that the existing inequalities for families with a child with SEND had been further exposed and emphasised due to the restrictions put in place (Boddison & Curran, 2022). Some parents reported they felt isolated and forgotten (Rogers et al., 2021) and it was considered by some that CYP's rights were not upheld (Couper-Kenney & Riddell, 2021). For many of the families in these studies there had been considerable negative impacts of the pandemic restrictions which need acknowledging and addressing to be prepared for any future national crisis. There had also been an understandable focus on mental health of both care givers and their CYP with SEND due to this group already being vulnerable to mental health difficulties pre-pandemic (Creswell, 2021). Additionally, home learning was found to be an area where all parents largely felt unprepared and unsupported, especially those whose children required more specialist support. A summary of the difficulties CYP and their families faced during this time is below in Table 5.

Table 5. Negative impacts of lockdown

Negative impacts	Examples
Poorer Mental health	Increase in anxiety and stress with rapid changes with no support for parents and CYP; deterioration in CYP's behaviour; families overwhelmed with home learning and balancing roles; living with uncertainty
Difficulty with Social relationships	Unsuitable accommodation resulting in worsening tensions and domestic abuse
Concerns about Education	Lack of engagement with online or home learning, poor differentiation of work, digital inequalities; parents worried about CYP's education and them falling further behind
Lack of access to other professionals	Support ceased or reduced; support moved online often with unfamiliar professionals, restricted access to health professionals
Greater isolation	Isolation due to no school or groups; no mixing of households; missing friends and wider family contact
Physical health	Difficulties doing the COVID tests with CYP; medical appointments ceased, delayed or online; less activity

However, what this review has also shown is that for many of the findings it is possible to find a conflicting outcome in either another paper or even in another part of the same paper, showing the situation is complex. The studies reviewed here were all completed early in the pandemic when the population was adjusting to the restrictions. There were considerable changes and attendant anxieties at this time, and future studies may discover a different picture once more time has passed. Even for the same CYP or family, they sometimes reported a positive experience within a largely negative experience (Shaw & Shaw, 2021) and for a minority of families, despite the surrounding negative media narratives, they experienced largely positives during this time (Ludgate et al, 2021). As Ludgate et al. point out, and the data in these studies show, there is a small but clear picture emerging of gains for a minority of CYP during the restrictions. Many of these positives were found for autistic CYP, as the studies' participants were largely or solely made up of this group. Looking just at the positive impacts of being at home for some CYP during the lockdown, a summary of the positives recorded in these studies are listed below in Table 6.

Table 6. Positive impacts of lockdown

Positive Impact	Examples
Improvements in mental health and wellbeing for CYP and less parental stress	Slower pace, more control over life, less bullying, no school stresses, less social demands
Improved social relationships	More time with family at a slower pace and less demands on some families. Time to do activities together. Parents understanding CYP better
More engagement with education	Personalised curriculum expressing choice of time, subject and method of learning
Engagement of CYP with professionals	Online meetings, use of chat function, easier to attend and leave when necessary for CYP. Parents understanding CYP's difficulties and strengths in learning
Less isolation	Greater inclusion through online software by using chat function, no camera or muting when desired
Physical health improvements	Eating better and more physical activity

Some CYP therefore, would have experienced an improved quality of life as a result of these impacts. This is an indication that the school environment for some CYP is not conducive for optimal wellbeing. This does not mean that these CYP should therefore remain at home, but that schools should be aware of the extent that their environment can be stressful and consider ways this can be adapted to improve the CYP's experience. It was not possible to know at this point whether these advantages also held for other CYP with other disabilities. For a CYP with complex needs who requires specialist support to learn, the picture may not be so positive, but it is not known currently as the studies did not gather sufficient differentiated information from this group. However, there are some indications that there were benefits for a larger group of CYP with SEND than just those with ASC. For example, more physical activity occurred for some CYP with a physical disability (Theis et al., 2021) and more engagement with learning for some CYP with MH difficulties (Thorell et al., 2021). Whether this translates into better health, higher academic attainment and less isolation is not yet known.

Discussing the positive impacts is not to overlook or dismiss the hugely difficult situations many CYP and their families found themselves in which are documented here, but to balance the rhetoric and learn from it. Both positive and negative experiences need to be

noted and investigated further. What emerges is that the experience was not a uniform, equal experience for even those grouped together under the SEND banner. This was due to the diverse nature of the participants, their families, needs and situations. There are findings that apply to the majority, but then the minority may have experienced the opposite, and this is sometimes a substantial minority. For any policy or event in life, there will be some who experience loss, some who gain and some for whom it makes no difference. As in a medical intervention, policies and life events will have side effects for the population that experience them (Zhao, 2017) and attention needs to be paid to those side effects to mitigate the negatives and enhance the positives. Care needs to be taken not to overlook the minority experience amongst the substance of the majority, as lessons can be learned from looking at all the CYP and their experiences to improve their everyday lives at home and at school. For example, many CYP expressed relief at not having to go to school and reported improved mental health, as did some parents who in normal times were trying daily to get the CYP to school. What would make education a more palatable experience for these CYP? Shaw and Shaw (2021) hoped that schools would be able to provide “*greater equality and inclusivity in educational provision, by developing blended models for in-school and remote learning*” (Shaw & Shaw, 2021, p1). This currently remains unknown, but it is considered only a partial answer to the problem that some CYP with SEND have with attendance (Ofsted, 2021b). Pre-pandemic, parents have increasingly been choosing to send their CYP with SEND to special schools despite the intention to make UK schools more inclusive (Black, 2019). It therefore appears that parents do not agree that mainstream schools are always inclusive for their CYP with SEND (Castro-Kemp & Mahmud, 2021), but from this research it is not possible to say exactly why this is.

CYP expressed that when they were allowed to have more control in their environment and learning methods, they engaged with and enjoyed their learning more than when they were at school (McCorkell & Lobo, 2021) and this was also reflected in some of the parent’s views (Beaton et al., 2021). Having greater autonomy is an important aspect of motivation for learning and growth according to Self Determination Theory (SDT) (Deci & Ryan, 1985) which states that autonomy, relatedness and competence all impact a person’s sense of wellbeing. However, CYP with SEND can feel even more than their peers that they have little control in their school environment reflected in both the attainment gap (Education

Endowment Foundation, 2025) and the rights-based concerns about agency and participation (Couper-Kenney & Riddell, 2021). Regarding relatedness, or having a connection with the people around you, it is possible that for some CYP, better connections were made with their peers and teachers when online than when in a busy school. Using the chat function, being able to contact a teacher discreetly or connecting with peers via social media may, particularly for those who identified as selectively mute or autistic girls, have increased their feeling of relatedness and wellbeing (Beaton et al., 2021). This, however, is set within the bigger picture of technology as a barrier to learning and engagement for many CYP (Beaton et al., 2021; Canning & Robinson, 2021; McCorkell & Lobo, 2021).

For some CYP the perception of their competence, the third strand of SDT, could also be raised by having more control and as they were doing more of the work themselves in the absence of learning support assistants, and even by purposely 'losing' work they did not want to complete (Beaton et al., 2021). However, it is also clear that many CYP struggled during the time of remote learning and needed the structure and routine of school to engage and learn (Greenway & Eaton-Thomas, 2020).

Most parents found home learning challenging and the majority do not wish to do this ever again (Greenway & Eaton-Thomas, 2020). It would also not be realistic for all those wishing to home educate to do so due to family logistics, nor necessarily desirable due to safeguarding concerns (Schooling, 2017). Some parents, however, have said that they would like to continue with home learning post lockdown having been forced to try it during the pandemic (Ludgate et al., 2021), as they felt their CYP were calmer and did better academically and they bonded with their children during this time.

The overwhelming majority of the studies were from an adult perspective despite the research being about CYP. There was a need to engage more with what CYP think and feel as well as what the adults around them think they think before the pandemic (Education Endowment Foundation, 2020). During the pandemic the lack of directly hearing from the CYP was at least partly due to the difficulties presented with the lockdowns and restrictions, together with time constraints in rapidly gathering views as events unfolded. However, in the future, the voice of CYP themselves needs to come across not just from the voluntary and charity sectors, but within academic research, to hear directly about their experiences and ideas (Castro-Kemp & Mahmud, 2021).

It is also important to note that it is probable there is still a section of the SEND community which was not reached by any of these studies to date. This is the section of SEND families who hover close to crisis point even without a worldwide health crisis. These families will have been trying to survive and may not have had the ability, resources or the inclination to share their views, but it remains important for future research to try to find out what their experiences have been.

2.5 STRENGTHS AND LIMITATIONS OF THE SCOPING REVIEW.

The studies were reviewed very soon after they were published, while the pandemic was ongoing. This means that the information reviewed reflects the earlier part of the pandemic and so may provide what will appear an incomplete picture in the future. However, due to this, the findings in the studies revealed people's experiences at the start of a novel situation, with feelings and memories not having time to dim. Most of the participants were parent/carers of autistic CYP which means the findings may not be generalisable to other groups of CYP with SEND. By gathering studies for CYP aged 5 to 25 years, it is hoped that the review will provide a broad understanding of what has been found for CYP with SEND in the UK. However, most of the research was of school-aged children and so the older age group's views may not be accurately reflected here. As few CYP of any age were directly engaged with much of the research, further research is needed to explore whether the views expressed extend to an older age group that is still in education. Additionally, as most of the reviewed research was done online during the pandemic, the studies will not have been able to engage with families of CYP with SEND who do not have access to technology or do not have the ability for whatever reason, to participate in this way. Therefore, the views expressed will not be representative of the whole SEND community.

2.6 CONCLUSION

It is hoped by studying the effects of this pandemic on CYP with SEND, that improvements can be made for the future, whether this is in more usual times or during another crisis. There is a wealth of data within these 21 studies, and more studies will be published over the coming years which will help create a fuller picture of what longer term impacts the restrictions had for families of CYP with SEND. It is a chance to reflect on what has happened

and investigate further what appears to be some contradictory and potentially valuable findings. As a result of the findings in this scoping review, the views of older YP will be sought as this appeared to be missing in the data so far. The three studies in chapters 4, 5 and 6 focus on the voice of the YP with SEND and those who support and care for them.

Chapter 3: METHODOLOGY

3.1 INTRODUCTION

The studies examined in the scoping review undertaken during COVID-19, largely used online surveys or the telephone due to the restrictions in place at the time. Any online interviews involved small numbers of stakeholders, such as Couper-Kenney and Riddell (2021) and there were only two studies directly involving very small numbers of YP with SEND (Beaton et al., 2021; with one YP, and McCorkell & Lobo, 2021; with seven YP). The YP interviewed were up to age 15 in the McCorkell and Lobo study and unknown in the Beaton et al. study, creating a gap in knowledge about older YP with SEND, which this thesis aims to examine. This chapter will set out the research methodology for the thesis and provide the rationale for the methods used to investigate this subject.

3.2 RESEARCH QUESTIONS

The questions for the thesis were developed based on the findings of the scoping review, relevant grey literature and contemporary media reports published at the start of the pandemic. The questions were:

- How did YP with SEND experience the COVID-19 pandemic?
- What support and information did YP with SEND receive during the pandemic?
- In what ways did young people's pre-pandemic experiences of autonomy, competence, and belonging shape their lived experiences during the pandemic?
- Were the families and organisations who delivered services and care to YP with SEND given the resources to enable them to cope with the pandemic?

The following sections will explain the methodology used to answer these questions.

3.3 METHODOLOGY

3.3.1 Research Philosophy

Research can be undertaken in various ways depending on the researcher's ontological views concerning their beliefs about what exists in the world and how it can be understood. This then forms the basis for epistemological beliefs, of whether knowledge is considered to be definitive, or whether it is regarded as variable and open to interpretation (Cohen et al.,

2011). Differences in ontological and epistemological assumptions have resulted in different beliefs about the best way to engage in research, resulting in the emergence of two paradigms. Positivism is described by Bryman as the *“application of the methods of the natural sciences to the study of social reality and beyond”* (Bryman, 2004: p.13) and assumes the social world can be investigated and a theory generated that holds in all circumstances. However, this appears to be an unlikely premise for a full understanding of humanity in all contexts and it can be considered that a positivist approach will give only a partial picture when used in social research.

An alternative paradigm is the interpretive philosophy, which believes human behaviour is too complex to be reduced to universal laws and views reality as something constructed by individuals (Bassey, 1999). An interpretive researcher focuses on descriptions and meanings, appreciating that the rationality of one observer will not be the same as another (Bassey, 1999). An interpretivist will use qualitative data, usually based on observations or interviews, rather than the quantitative data used by the positivist. Whereas a positivist will develop a hypothesis which will then be tested, an interpretivist will explore an area to see what themes can be discovered (Braun & Clarke, 2019). As Kvale (1996) argues, people are not like objects in the natural world, as they are conscious and purposeful, and therefore their actions need to be understood by understanding their point of view. Additionally, Bassey considers the positivist view of language is as an agreed system for describing reality, but for the interpretivist, it is seen only as an approximately agreed symbolic system with huge differences in interpretation (Bassey, 1999). However, the two approaches can be seen as complementary by some researchers (Cohen et al., 2011), and they would argue that both can join to create an understanding of the social world. However, other researchers would disagree that the approaches are complementary and believe the integrity of qualitative research can only be maintained by a purely qualitative outlook (Braun & Clarke, 2019). Quantitative data can be useful within social sciences to find the scope and shape of a phenomenon initially, which is what occurred during many of the initial studies into the impact of COVID-19, but this will not expose the whole picture, necessitating further qualitative investigation to provide the detail and the personal experience which brings the research to life. This study’s aim was to understand the experience of the pandemic and

how that impacted the YP with SEND from their perspective and so an interpretivist approach was deemed appropriate.

In this thesis, insight is sought about the subjective and individual experiences of the YP within the complex social phenomena of the pandemic, with the aim to understand more about their lived experience. Therefore, a qualitative approach was deemed the one most likely to gain the nuanced data required which can then be used to complement the information gained by the early quantitative research. There was a gap in the literature for qualitative research which gave YP with SEND a voice, and the purpose of this research was to uncover the views and experiences of YP with SEND during the COVID restrictions and its aftermath. The aim was to hear YP's voices directly to enable their voice to affect future decision making should there be further civil restrictions necessary for any reason.

3.3.2 Research design

Due to the time constraints of this project, a cross-sectional design was used to capture the views of the YP, parents and professionals at the point of the interviews post-pandemic. This was in 2023 for the YP and in 2024/2025 for the parents and professionals. The project would inevitably span at least three years to cover all participant groups, due to being a part-time endeavour. However, as previously stated, there was a significant amount of information about the initial impact of the pandemic, but far less was known about its aftermath for this particular group of YP. Therefore, this thesis will extend the evidence base offering deeper and new insights into the experiences of this age group.

The main focus of the thesis was on YP, but in order to find out more about their lives, especially in the educational and domestic setting, it was important to also include parents and professionals. Their experiences also revealed more about the impact of Covid-19 generally, the impact on the parents and professionals as supportive adults in the YP's lives and how they perceived the pandemic impacted the YP's lives. Triangulating the data using different participants perspectives, can increase the validity of qualitative research, as it is important to consider the data from multiple sources to ensure credibility (Cohen et al., 2011). Triangulation is the use of two or more methods, sources or investigators for example, to reduce the impact of bias in qualitative research and also provide a richer data base from which to enhance the understanding of the research.

3.3.3 Data collection

As most data collection on this topic to date had been conducted via surveys and online methods, the researcher sought to engage directly with YP with SEND in order to hear their perspectives in person. This was especially important after two years of restricted in-person activity due to COVID-19. Although the country opened up gradually during 2022, many people were still hesitant about the risks involved in returning to their normal routines. The researcher was in a position to contact groups of YP via gatekeepers (education and SEND professionals) and was considered a trustworthy person to speak to the YP due to past experience in the field of SEND.

The sampling strategy was non-random and therefore non-representative. YP with SEND aged 14 – 25 during the pandemic were specifically sought, making purposive sampling the most appropriate approach. Additionally, snowball sampling was used in order to reach more YP with SEND. In snowball sampling, initial contacts in the field of SEND helped identify further potential participants. This is a useful approach when participants are considered hard to access due to not using digital methods of contact or when they may be mistrustful of researchers (Cohen et al., 2011), both of which could be true of YP with SEND.

As the study was qualitative and the aim was to gather the personal perspectives of YP, parents and professionals, interviews and focus groups were considered to be the most appropriate method of data collection. Focus groups are a method of generating qualitative data by a small group who share certain characteristics and who discuss a specific topic to aid its understanding (Krueger & Casey, 2015). It can be understood as *“fundamentally a way of listening to people and learning from them”* (Morgan, 1998, p.9) which aligned well with the aims of this thesis. However, organising a focus group can be time consuming and needs clear communication with gatekeepers to function effectively (Robinson, 2020).

Facilitating a focus group also demands the ability to develop a good atmosphere and rapport with the participants, sometimes in circumstances that are not ideal, such as a busy or noisy environment (Robinson, 2020). The facilitator also has to be able to multi-task using their judgement about which aspects to follow up and which to close down, and how to do this if comments made by participants are irrelevant to the research. The added complexity of having participants with SEND who may all have different communication needs, makes

this a challenging task. However, as the researcher has many years of teaching experience, this challenge is not dissimilar to the normal classroom environment and therefore was approached with some knowledge of the potential pitfalls. This approach also allows for a greater number of YP to be involved in the research, including those who might be hesitant to engage in a one-to-one interview. Guidelines for the numbers of CYP in a focus group differ (Adler et al., 2019), but as CYP with SEND require more time to express themselves and the role is more challenging for the facilitator, the numbers were kept small wherever possible. It was regarded as an interview when one or two YP were participating and a focus group if there were three or more. This was to minimise the possibility of sensory or social overwhelm and allowed the facilitator to adapt to the varying cognitive and communication needs inevitable in a mixed group and to ensure every YP's voice was heard (Bacter et al., 2025).

Semi-structured interviews were also used with both YP and the parent/carers and professionals. As the research was exploratory, albeit designed with the foundation of the knowledge of previous early studies, it was important to allow the data collection to be interactive and for the researcher to be able to follow emerging topics (Alshenqeeti, 2014). A semi-structured interview allows for new knowledge to be shared about the participant's views within the relatively naturalistic setting of a conversation, with the conversation focussing on a specific topic of interest to both the interviewee and the researcher (Kvale, 1996). An interview schedule was used to ensure coverage of all the key research questions whilst still allowing the interviewees the freedom to introduce new elements of which the researcher may not have been aware (Berg, 2007).

Barbour and Schostak (2005) suggest that the value of the exchange with the participant is explained to potential interviewees and that trust is engendered by clear communication and expectations before the meeting, together with following ethical guidelines (see Ethics section 3.6 below). They also suggest that that *"the shorter the interviewer's questions and the longer the subject's answers, the better an interview is"* Barbour and Schostak (2005, p.43). Good practice also suggests that interviewees are given the opportunity to ask questions about the interview beforehand, to talk about it with the researcher if they wish after the interview and to be thanked for their contribution (Cohen et al., 2011).

3.3.4 Analysis

The interviews were transcribed, either manually or via transcription software, depending on the mode of recording. They were then uploaded to NVIVO, which is software designed to help organise qualitative data, allowing researchers to group themes and commonalities within the data more easily. The data analysis approach taken was that of thematic analysis which looks for themes and patterns of meaning within data and can incorporate the participants experiences and opinions (Clarke & Braun, 2013). It is an exploratory process and can be time consuming, but it is suited to the type of research questions that were asked and the type of data collected.

The six phases of Braun and Clarke's thematic analysis (2006) that were used in the analysis of the data are shown below:

Table 7. *Phases of Thematic Analysis*

Phase	Description of the process
1.Familiarising yourself with your data	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas
2.Generating initial codes	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes	Collating codes into potential themes, gathering all data relevant to each potential theme
4.Reviewing themes	Checking if the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis
5.Defining and naming themes	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells, generating clear definitions and names for each theme.
6.Producing the report	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis

3.4 POSITIONALITY

Any researcher is part of the world which they endeavour to study, making objective reality impossible to achieve (Cohen et al., 2011) and they bring their own experiences, views and

biases to a project. I do not view the researcher's subjectivity within qualitative studies is necessarily a weakness. It can be seen as a resource if it is acknowledged and reflected upon (Gough & Madill, 2012). Research is always a reflection of the researcher's own position to an extent, and different positions can bring different insights (Braun & Clarke, 2019). I therefore acknowledge that my own experience and profession will inevitably have an impact on the position taken in this research. I have worked in education with CYP and adults, both with and without SEND, for many years. Initially this was as a teacher in primary and nursery schools and then in Further Education colleges and at university level. I was both teaching YP and adults with SEND and educating other teachers, health and social care students and TAs about SEND. More recently I worked in an advisory capacity for a statutory service, the SEND Information, Advice and Support Service which offers impartial advice to CYP with SEND and their families and other professionals. I saw the disadvantages disabled people experience on a daily basis and heard the responses to these disadvantages from the point of view of CYP, their families, schools, the local authority, social care, healthcare and the government. I appreciate the many facets of enabling CYP with SEND to live their best lives, and see that although circumstances are far from perfect, they have moved forward since the notion of CYP being 'educationally sub-normal' or ineducable in the 1944 Education Act. I cannot forget the experiences and knowledge acquired over the past years which is then brought into this research project and it is likely that this knowledge has impacted the development of the research. This wealth of experience can also provide insights and connections that may not occur to someone without this background. Providing this is recognised and there is sufficient reflexivity at each stage of the research, this should not be seen as a problem but as an enrichment (Gough & Madill, 2012).

I am also the parent of young adults with SEND which gives me firsthand knowledge of what it is like to raise a child with differences and the impact that has on the family dynamic and the relationships with an educational setting. This combination of parent and professional knowledge and experience meant I was in a valuable position to explore the experiences of YP during COVID-19 further. It was while working with YP and their families at the start of the pandemic that I thought someone should investigate the unique and multifaceted impacts on them and realised that I was in a privileged position to do so.

3.4.1 Reflexivity

Qualitative research involves human beings studying other human beings and researchers *“bring their own biographies to the research situation and participants behave in particular ways in their presence”* (Cohen et al., 2011, p.225). Reflexivity is the practice as a result of the self-awareness that a researcher’s positionality brings. A researcher will bring their own biases and values to a project as a result of their own experiences and need to be self-aware as to the impact of these and monitor their responses and assumptions continually throughout the project (Musgrave, 2025). Reflexivity needs to be *“a thread that runs through each aspect of the research process”* (Musgrave, 2025 p.184). This can be done by reflecting on the details of the research, from the type of information that is given to prospective participants to how the data is collected and analysed. In this project the close connection between the researcher’s career and the topic of study brings both the benefit of insider knowledge but also the possibility of biases, such as greater empathy towards certain participants who resonate with the researcher’s own experience. One way of practising reflexivity is to keep a research journal and field notes so that thoughts can be recorded at each stage which can then be reflected upon to examine for bias (Berger, 2015), a method that was used in this research.

3.5 VOICE

People from oppressed and minority groups are often not heard due to not being asked, not being listened to or their opinions not acted upon (Spray & Hunleth, 2020). It is also more challenging to reach some groups directly, such as children or disabled people, and not all researchers have the required time or experience to do this (Whyte, 2006). Engaging with YP with SEND can take longer to hear what they have to say (Wickenden, 2011), but participation in research can increase self-esteem and confidence for YP, which is especially important for a group who often lack confidence (Schwartz, 2020). In the researcher’s work as a young person advisor, it took longer to deal with YP than parent/carers, as it takes time to build understanding and trust with YP and longer to allow them to explore their thoughts and to speak (Wickenden, 2011). This could be due to differences in language processing, speech production or cognitive challenges, or to do with fatigue or wariness of professionals (Whyte, 2006). It can often seem easier for researchers to seek out the adult voice for speed and clarity rather than enter the more challenging world of YP with SEND (Stafford,

2017). However, YP with disabilities are able to express their views and thoughts and have something to tell us (Stafford, 2017). Therefore, to hear the YP's voices directly means engaging with YP with SEND directly and not just through their caregivers or teachers. Listening to what others' say involves a certain amount of mediation and exploration to ensure that the researcher is understanding not just what words are used but what is the intention of those words (Daher et al., 2017). Language can be an inexact method of communication if people do not share the same values or expectations and care must be taken to understand that what is said in reply to questions is understood as it was intended (Bassey, 1999). This is especially so when a participant may view their world very differently from the researcher. There is therefore a responsibility on the researcher to challenge their own assumptions (Chenail, 2011). They must also unpack the questions asked to make them easier to understand and check the answers to ensure they accurately reflect the intention of the participant (Bassey, 1999).

Most previous studies focussed on the adults' views or interpretation of CYP's views. A parent/carer's interpretation has been shown to be a fairly accurate portrayal of their CYP's views for younger children (Rosenberg, et al., 2009). However, for adolescents and young adults, this is not necessarily so accurate. YP of this age do not always share their views with their parents and are more mindful of upsetting them by telling them unpalatable truths or by creating stress (Raw et al., 2021). Additionally, as Brown et al. state,

Much research focuses on theoretical debates and policy critiques and there are many fewer accounts that centre the empirical realities of vulnerability from the perspectives and experiences of various stakeholder groups, such as practitioners, service managers and service users/clients. (Brown et al., 2017 p.506)

3.6 ETHICS

The four main principles of ethical research are respect for participants, beneficence, non-maleficence and justice (Berkovic, 2023). Informed consent should be part of all four of these aspects so that participants are completely aware of the purpose of the research, what will take place, potential risks and benefits and understand that participation is voluntary. The participant's right to be part of the research or not and to reveal what they wish must be part of the autonomous decision to participate. They must also be informed

that they can withdraw up to an agreed point of the research, such as the start of the analysis, with all data then being deleted. It is the researcher's responsibility to make it clear and straightforward to withdraw with no penalty and no pressure should be applied to try to persuade a participant to continue.

Information sheets were shared with potential participants which explained the study, confidentiality and the right to withdraw. Participants were offered the opportunity to ask questions about the research and meet the researcher online before their interview took place. They were also able to see the questions beforehand if they wished, so there were no surprises, and they could prepare answers if they wanted to do this. This was an important aspect to offer, especially for neurodivergent people or those with anxiety who may have greater intolerance to uncertainty (Jenkinson et al., 2020).

Beneficence is the principle which ensures the wellbeing of the participants and should consider what benefits there will be for the participants and for society. This beneficence is not merely avoiding harm but also to positively benefit the participants in some way. This research project gave an opportunity for YP with SEND to tell the researcher about their pandemic experiences directly, which can increase participants' self-esteem and confidence (Schwartz, 2020). It was also hoped that the information gained from the research will allow policy makers and professionals to learn from what had happened and to be better prepared for future emergencies.

Additionally, any benefits should outweigh any potential risks to the participants, which is the principle of non-maleficence – to do no harm. There should be no harm caused by the method of the research and no harm caused by the data handling and storage. All interviews are an intrusion into the participants' lives, demanding their time and personal responses (Cohen et al., 2011). As a result of the confidential setting, there was the potential it could have led participants to disclose more information than they were comfortable with (Alshenqeeti, 2014), making it important to offer the opportunity to reflect on their contribution at the end of the interview and a debriefing session offered. There was the risk of psychological distress for participants in this research if they recalled difficult issues during the restrictions, but to try to alleviate this risk, they did not have to answer any questions they were uncomfortable with and were informed of this at the start of the interview. Information was also given to each participant about further support at the

end of the interview, tailored to the participants' age and role, for example YP, parent, teacher or psychologist.

Justice is the equitable and appropriate treatment of participants who should then have fair access to the benefits of the research with no exploitation of them in the research process, especially if they come from vulnerable populations (Berkovic, 2023). YP with SEND and their families are considered vulnerable (Alston, 2024), and the research should be relevant to this community. This research aimed to broaden the discussion around the impact of COVID-19 on YP with SEND which may help YP in the future and those who work with them, thereby reducing the injustices they receive both in a crisis and normal times.

The issue of payment for research participants is a debateable issue as some believe the participants should be rewarded for their time and others see that a payment could be seen as inducement to participate and therefore not be entered into freely (Corrales, 2023). This would be more likely if the value of the payment is high rather than just covering costs. For this thesis, payment for the YP was considered inappropriate as there would be too many participants to pay individually and the ethics committee did not think the YP would understand the concept of being entered into a prize draw. As the YP were not being paid, then the researcher felt it would not be correct to offer payment to the parents and professionals, as this would imply that their contributions were more valued which was not the case.

3.6.1 Vulnerability

Within research, a group of people can be viewed as vulnerable due to many factors, for example their cognitive ability, if they have a disability, their health, social status, lifestyle or age. For research purposes, vulnerability is often connected with the risk to the individual if they become involved in research. Corrales (2023) gives the example of people with intellectual or physical disabilities with relevant ethical concerns for these populations being the capacity to give consent, communication challenges and the risk of coercion which are genuine issues for a researcher to overcome. However, Corrales sees that this legitimate concern about risk can act as a barrier to some groups becoming involved in research as gatekeepers seek to protect them. This then excludes them from research and prevents their voices being heard, making them more marginalised (Corrales, 2023). Therefore, it is

important to acknowledge the risks involved but make every effort to overcome them so their opinions can be heard.

Additionally, those considered vulnerable do not always see themselves as such, and the label of vulnerability should be considered, as Bauman proposes (2004), as the result of existing social inequalities and the exclusion and marginalisation resulting from this. Safe spaces can be created, and materials and time can be used to ensure that vulnerable people can take part in a research project, although it may take longer than with other groups and require more knowledge and sensitivity of the researcher.

3.6.2 Confidentiality

It is paramount that all data collected is anonymised and stored confidentially and that this intention is communicated to the participant along with the times when confidentiality cannot be adhered to. All personal names and identifiers were anonymised, by using pseudonyms for all participants and the names of places or educational settings removed. Participants may inadvertently mention names, even if encouraged not to, which then becomes the responsibility of the researcher to ensure no identifiable information is communicated in the thesis. Once data analysis began, only the anonymised data was used and recordings were destroyed after the transcription process.

However, there were some circumstances when complete confidentiality could not be assured. It was made clear that although focus group members were asked not to share information outside the session, there could not be a guarantee of complete confidentiality when using focus groups (Berkovic, 2023). Additionally, the only reason for the researcher not keeping information confidential would be if the participant said they were either at risk themselves or to others. This exception was explained in the information sheets provided for the study and reiterated at the start of each session. Any concerns of the researcher regarding this would be referred on to the YP's school or college or to the Local Safeguarding Board for the local authority area.

3.7 Limitations

All research has some limitations, and each study in the following chapters will outline the particular limitations for each one. The overall limitation for this thesis could potentially be that of time. The research took place after the pandemic had passed and when people

wanted to get back to their normal lives. This may have affected the recruitment of participants in each study and also the ability to remember salient points from a time which began two to three years earlier, depending on when the interviews were held. With this in mind, the first study was conducted with the YP as they were the focus of the research and the researcher wanted to hear their views as soon as possible and while they were still involved in education or had not long moved on. The parents' and professionals' studies then followed. Research already existed from the initial phase of the pandemic as seen in the scoping review, but at the time of writing there had been less investigation at this later time point. This could expose different views and perspectives as the height of the crisis had passed, and people had time to reflect on what had happened. It may be that this study would reinforce the findings from earlier studies or contradict them, but it was thought to be useful to see what peoples' views post-pandemic were, while their memories of the period remained.

3.8 Conclusion

This chapter outlined the overall methodology of the thesis and presented the researcher's perspective, but detailed methods for each study are provided within the respective chapters. Chapter 4 examines how YP with SEND experienced COVID-19 restrictions from their own perspective. Chapter 5 investigates the parents' experiences and Chapter 6 explores the views of professionals who worked with YP with SEND.

Chapter 4: Perspectives of the pandemic: The views of Young People with Special Educational Needs and/or Disabilities.

4.1 INTRODUCTION.

Chapter two reported on the scoping review which set out the extent of the knowledge at the commencement of this study regarding YP with SEND during the pandemic. This highlighted the existing gap of the voices of older adolescents and young adults with SEND attending education. Building on current knowledge obtained from the scoping review, other academic and grey literature to date, the current study is exploratory in design and examines the key part of the thesis. Chapter three set out the methodological rationale for the thesis, explaining the choice of a qualitative study based upon acquiring the participants views directly.

This study was completed first as the voice of Young People (YP) with SEND was the main focus of the research and also the researcher wanted to interview them as close to the main pandemic years as possible, to minimise the impact of fading memories and the possibility that YP may have become less willing to take part once they had moved on from this time. At the time of the study in 2023, YP could return to in-person education and society was finding a way to resume its usual routines or create new ones. However, people were still in a period of re-adjustment after the lockdowns.

4.1.1 Research Concerns

The predominant purpose of this study was to hear directly from the YP with SEND about their experience during the pandemic and the overarching research questions were developed using the knowledge gained from the scoping review in Chapter two. Additionally, they were developed using background information about the current SEND system in the UK and the response in the UK to the pandemic outlined in chapter one. The key questions for this thesis were:

- How did YP with SEND experience the pandemic?
- Did the YP receive appropriate support and information?
- In what ways did young people's pre-pandemic experiences of autonomy, competence, and belonging shape their lived experiences during the pandemic?

- Were the families and organisations who delivered services and care to YP with SEND given the resources to enable them to cope with the pandemic?

This first study focusses on the first three research questions, with study two proceeding to examine the parents' views and study three the professionals experience.

4.2 METHOD

Due to the restrictions imposed during Covid-19, which made contact face to face impossible, and in order to quickly capture the broad picture, previous research had been mostly through online surveys. Therefore, once restrictions were removed, it was important to uncover a more nuanced picture of the experience of YP with SEND from the YP themselves to allow their voice to be heard. Surveys usually advantage more cognitively able YP, whereas an interview allows more YP the chance to express their own views (Kooijmans et al., 2022), therefore this was the approach taken for this study.

4.2.1 Participants

YP were recruited through advertising to schools, colleges and charities based on the following inclusion criteria:

- YP with a diagnosis that meets the criteria of SEND as described in the 2025 Code of Practice (DfE & DoH, 2015) or YP who self-identify as having SEND.
- YP between the ages of 14 and 25 during the pandemic (2020 -2022).
- YP who were in education for at least some of 2020 – 2022.
- YP able to understand the purpose of the study and give their consent.
- YP with sufficient communication ability to understand and contribute their views.

46 YP were involved, 29 male, 15 female and 2 identifying as other. All but two of the YP came from the southeast of England despite the researcher seeking a wider participant group. Their ages are shown in Table 1.

Table 8. *Number of Participants in each Age Group at the time of Data Collection*

Age: 16 -18	19 – 22	23 - 25	26
12	20	12	2

Most of the YP who participated came from two sources, a mainstream Further Education (FE) college (29 YP) and a specialist SEND FE college (14 YP). Additionally, three more YP responded independently. The YP had attended a mix of special and mainstream schools/colleges during the pandemic, but the YP were not always clear about the kind of provision they had attended previously (this is discussed later). The majority of the YP had an EHCP, with all YP at the specialist FE college having this.

The mainstream college had become part of a large group of colleges over the past 5 years. It had a thriving special needs department and comprehensive support services for those with SEND or an EHCP. There was a separate building which housed the personal tutors who had regular support sessions with the students. There were also counselling services and a wellbeing team. Students known to the Learning Support manager could access the space when they wanted to and would attend group learning support or tutor time there. They also provided drop-in sessions most evenings for students to access support. A speech and language therapist attended for 2 days a week for students needing support for language and communication skills which was funded by LA high needs funding through the EHCP. The college was rated as Good by Ofsted in 2025.

The other college was a small alternative specialist provision at the time of the data collection but was in the process of becoming a specialist FE college, a status that was awarded shortly afterwards. It provided employment training and supported internships which aimed to find paid work for the internees at the end of their courses. It was highly regarded by professionals and parents and also provided continued support after the course ended for those in employment who needed this.

The YP were asked on the demographic form what kind of disabilities they had. This may have led to some inaccuracies, as not all disabilities could be listed on the form and some YP may not have been aware of the name of their disability. Additionally, speech and language disorders are very prevalent in the population of YP with SEND, but this is not a diagnosis

that is made as frequently as it could be (McGregor, 2020), meaning that many YP may not be aware that they have this difficulty. Furthermore, some YP had multiple diagnoses and may not have recorded all that apply to them. The information therefore is presented as how the YP view themselves and what they have absorbed from the adults around them. The category of 'other' was included in case the YP felt that the disability they had was not listed, as it was impossible to cover every condition.

Demographic information is presented in the tables below for each of the participants in the focus groups and interviews, for each setting, along with the online interview participant information. The different methodologies (focus groups, individual interviews in-person, or online) are described under Measures below.

Abbreviations in the tables are as follows: ASC stands for autism; ID for intellectual disability; ADHD for attention deficit hyperactivity disorder; sensory for visual or hearing impairments, MDC for Medical or health difficulty; PD for physical disability; LD for Learning difficulty e.g dyslexia or dyspraxia; MH for Mental Health difficulty; WB White British ethnicity; OW Other white ethnicity; ME Mixed ethnicities.

Table 9. Focus Group Participants at Mainstream FE College

Group	Gender	Disability	Age group	Ethnicity	Discussion time in mins	Accompanied by tutor or LSA
Group 1					25	Tutor
Alice	F	ID	16-18	WB		
Alex	F	ASC	19-22	WB		
Adam	M	ASC, ID, ADHD	23-25	WB		
Abdi	M	ASC	16-18	WB		
Group 2					41	Tutor
Bea	F	ID/D	16-18	WB		
Beth	F	Sensory/ID	19-22	WB		
Bill	M	ID	23-25	WB		
Group 3					43	Tutor
Finley	M	ASC	23-25	WB		
Felix	M	ADHD, ID, Other	19-22	OW		
Flynn	M	No response	16-18	WB		
Fraser	M	ASC	16-18	WB		
Femi	M	ID	19-22	Mixed		
Frankie	Other	Other	16-18	WB		
Freddie	Other	ID + Other	16-18	WB		
Group 4					39	Tutor
Daisy	F	ASC, ADHD, ID, Other	19-22	WB		
Declan	M	ASC, ADHD, ID	19-22	WB		
Dez	M	ASC	19-22	WB		
Darren	M	ASC	19-22	WB		
David	M	ASC	16-18	WB		
Group 5					32	Tutor
Eric	M	ASC	19-22	WB		
Evan	M	ASC	16-18	WB		
Elias	M	ASC	16-18	Mixed		

All names are pseudonyms

Table 10. Focus Group Participants at Specialist FE College

Group	Gender	Disability	Age group	Ethnicity	Discussion time in mins	Accompanied by tutor or LSA
Group 6					90	None
Perry	M	ASC, ID	19-22	WB		
Paul	M	ID	19-22	WB		
Peter	M	ID	23-25	WB		
Group 7					40	Tutor
Sarah	F	ID, Sensory	23-25	WB		
Sean	M	ID	19-22	OW		
Sam	M	Other	19-22	WB		
Stuart	M	ASC	23-25	WB		
Simon	M	ASC, ID, PD, MDC, sensory +other.	23-25	WB		
Steve	M	ASC	19-22	WB		

All names are pseudonyms

Table 11. Interview Participants at Mainstream College

Interview	Gender	Disability	Age	Ethnicity	Discussion time in mins	Accompanied by tutor or LSA
Interview 1					12	None
Charlie	M	ASC	19-22	WB		
Interview 2					20	None
George	M	ASC, ID	23-25	WB		
Interview 3					19	Tutor
Harry	M	ASC	19-22	WB		
Hamish	M	ASC	16-18	WB + other		
Interview 4					41	Tutor
Jess	F	ASC	16-18	WB		
Jacob	M	Other	19-22	WB		
Interview 5					29	LSA
Kim	F	PD	19-22	WB		

All names are pseudonyms

Table 12. Interview Participants at Specialist FE College

Interview	Gender	Disability	Age	Ethnicity	Discussion time in mins	Accompanied by tutor or LSA
Interview 1					40	None
Martha	F	ID + LD	26	WB		
Interview 2						LSA
Nora	F	ID	23-25	WB	40	
Nessie	F	ID, ADHD + other	23-25	WB		
Interview 3					20	LSA
Olivia	F	ID, MDC, sensory	23-25	WB		
Interview 4					60	None
Rob	M	ID	19-22	WB		

All names are pseudonyms

Table 13. Online Interview Participants

Interview	Gender	Disability	Age	Education in COVID-19	Ethnicity	Discussion time in mins	Accompanied by tutor or LSA
Interview 1						45	None
Lisa	F	LD: dyslexia	19-22	Mainstream school	WB		
Interview 2						44	None
Tilly	F	ASC, ID, MDC	26	HE	WB		
Interview 3						28	None
Vicky	F	MH	19-22	HE	OW		

All names are pseudonyms

As can be seen from these tables, 87% responded that they were of White British heritage. 6.5% were of other white heritage and 6.5% were of mixed heritage which included black or other minority ethnicities. Of the 46 participants, 32.6% were solely diagnosed with ASC, while a further 17.4% had ASC as part of their diagnostic profiles. Therefore 50% of the participants had autism as at least part of their picture of needs.

Of the 46 participants, 60.9% had a single diagnosis and 30.4% had more than one diagnosis. 6.5% indicated they had another disability not listed so it was not possible to tell what that was or whether it was one or multiple disabilities. Additionally, 2.2 % (1 participant), did not complete that section of the form.

Overall, 30.4% indicated they had a learning disability (intellectual disability) or learning need and 2.2% had a learning difficulty (dyslexia).

4.2.2 Measures

This study aimed to gather the opinions and experiences of YP with SEND during the COVID-19 restrictions in 2020 and 2021 and up to the date of the data collection in March 2023. Focus groups and semi-structured interviews were chosen as the measures to use for this study, with the question schedule being created specifically for this study. Participants were offered the choice of taking part in a focus group or interview.

4.2.2.1 Focus groups

The main method of data collection was through focus groups, which collect qualitative data from a group through facilitated discussions. A focus group can be defined as *“a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment”* (Krueger & Casey, 2015, p. 2) and they were used as they allow people to tell their own stories in their own way which is core to this study. Focus groups are also useful for discovering information *“with populations that often get bypassed in larger, quantitative studies”* (Kroll et al., 2007 p690) due to their flexible format. They can be used when a topic is a new area of interest or to build on initial quantitative data and to prompt new questions for research (Kroll et al., 2007). This makes a focus group an ideal starting point for this study. However, little research has been done on the use of focus groups with CYP, but they are understood to remove some of the power imbalance between adults and CYP due to there being more CYP involved, making it a less intimidating environment (Adler et al., 2019). There is some caution in using mixed gender groups with older CYP, as it has been shown that group dynamics can be negatively affected due to a combination of interest in the opposite sex, attitudes and maturity (Heary & Hennessy, 2002). However, if the group is already known to each other and are similar in age, this

does not appear to apply (Daley, 2013). The groups at the colleges involved in this study were familiar with each other and of a similar age.

Additionally, it was appropriate to keep the groups small to allow time for the YP to express themselves and for any communication challenges to be overcome. Groups for YP with SEND in any setting tend to be smaller than an average class of YP as the YP with SEND need more support (Government Digital Service, n.d.). Therefore, as teaching staff were aware of this need, and after discussion with the researcher, groups suggested by the colleges were all between three and seven YP. This is within the Youth Sport Trust guidance of less than ten YP in a focus group for those YP with SEND (Youth Sport Trust, 2014).

4.2.2.2 Semi-Structured interviews

In order to allow the voice of CYP to be heard in greater depth, semi-structured interviews were also offered for YP who preferred an individual interview or who were not able to take part in a group. These could take place either in-person or online. A semi-structured interview *“allows depth to be achieved by providing the opportunity on the part of the interviewer to probe and expand the respondents’ responses”* (Hitchcock & Hughes, 1995, p.157). It also allows the researcher a great deal of flexibility in their approach (Drever, 1995), which is especially important with CYP with SEND. An interview can be considered not just the collection of data but also a social encounter between the researcher and interviewee (Cohen et al., 2011). It involves careful construction of questions that are not leading and will answer the research questions whilst being clear for CYP with SEND to understand and be able to answer (Cohen et al., 2011). It then requires careful listening by the researcher, which is as unbiased as possible, therefore necessitating reflection during and after each interview to challenge any assumptions (Clough & Nutbrown, 2012). An interview could be preferable for some CYP as it is more private if they are shy or embarrassed to speak in front of their peers. However, for other CYP it can be a more intense experience than a focus group, especially if they are wary of unfamiliar adults.

4.2.2.3 Online interviews

These were offered to any YP who replied independently and who lived too far from the researcher to be able to be interviewed in-person. Initial research by Anthony et al. (2025) shows that there is little difference between in-person and online interviews in terms of the

rapport that is possible, especially if the interviewee has some knowledge of the topic and is familiar with the technology.

4.2.2.4 Interview and focus group questions

The actual interview questions are not the same as the research questions, as that would be inappropriate and inaccessible for the YP. The questions asked were designed to elicit the information necessary to answer the research questions and to probe further into any areas not previously considered. Below are the interview questions for the YP. A more detailed record with the prompts used, if necessary, is given in Appendix B. An advisory group was sought in order to formulate and test the questions asked (more information under the Procedure section below). These questions formed the basis for the interviews and focus groups, but the language used was adapted during the sessions according to the ability and responses of the participants. After all the questions were asked, the YP were asked if there was anything else they would like to tell the researcher about this time in order to discover any additional information the researcher may not have asked about but were important to them.

Table 14. *Interview and Focus Group Questions for YP*

Interview questions for YP	
1.	Tell me about your experience of lockdown: was there anything good or bad about it?
2.	How did you find out what was going on during COVID and what you should do?
3.	Do you like going to school/college?
4.	Do you usually feel included in your school/college community?
5.	Did you feel part of your school/college during lockdown?
6.	Did you change school or college during COVID?
7.	How are things now you are back at school/college?
8.	Do you like what you are doing at school/ college?
9.	Do you think you are doing ok at school/college?

10. Do you feel that the adults around you at school/college and home listen to your views and what you need?

11. Is there anything else you would like to tell me about your life during the pandemic?

4.2.3 Procedure

4.2.3.1 Ethical factors in working with CYP with SEND.

The power dynamic is not equal between YP and a researcher and although this needs to be kept in mind during the research, it is impossible to eliminate entirely (Cohen et al., 2011). Other power dynamics exist in a YP's life, for example, those between them and their teachers, parents, TAs and peers, and YP should not feel they are coerced into taking part by adults or peer pressure, as ethically their participation needs to be completely voluntary (Cohen et al., 2011). It was stressed to the YP that there were no adverse consequences if they declined to take part or withdraw, and their decision would not impact any service they used or their educational prospects, as these are areas that can worry CYP when they take part in research (NSPCC, 2022). As is advised for research with CYP with disabilities (Whyte, 2006), ethical approval was sought and obtained from an independent Ethics Committee, in this case from the Tizard Centre at the University of Kent and was granted on 13.11.2022 (see Appendix C).

A YP could potentially try to please a researcher, giving answers they feel are 'correct' (Cohen et al., 2011) or alternatively, they could be withdrawn due to reserve or mistrust and therefore not answer questions adequately (Ibrahim et al., 2021). Care needs to be taken regarding the information given to participants to ensure they understand the reason for the research and their part in it (Alderson, 2005). Therefore, having another trusted adult present could support the YP, enabling them to feel at ease (Whyte, 2006), which is what was offered to all YP and some did choose to do this (see page 84 under Data Collection heading). The researcher ensured that on the day of the focus groups and interviews, the YP were present willingly and remembered what the research was about. They had the opportunity to ask questions or withdraw their consent at that point and were informed they could withdraw at any point up to two weeks after the data collection without giving a

reason. They were also given information about how to complain or give feedback (See Appendix D(i) and an easy read version D(ii)) (Whyte, 2006).

One way that YP can take control over a situation if they do not wish to answer a question is to change the subject (Stafford, 2017). If this happened in an interview or group, this was recognised and respected as a form of control and the subject was not then probed further (Stafford, 2017). However, some YP with SEND find attention and understanding challenging, and it is difficult at times to differentiate between lack of focus and avoiding a question. It was also considered that there could have been a risk of distress for YP if they recalled difficult issues during the pandemic. However, to mitigate this, at the start of the sessions YP were informed that they did not have to answer every question and could take a break if needed (NSPCC, 2022). In focus group 3, individual YP requested to leave the room at times to have a short break due to their attention needs, and they all returned after a few minutes. Additionally, the potential to go off subject may be greater in a focus group when the group dynamics may be such that there are some who dominate the discussion, and this had to be managed carefully to ensure all who wished to contribute were able to (Cohen et al., 2011). However, some YP can find taking part with their peers more comfortable than on their own, finding an individual interview more daunting (Stafford, 2017).

Furthermore, there are safeguarding issues for the researcher to consider when interviewing YP, and care needs to be taken to ensure the interview is conducted in a place visible to others and yet the conversation can be private. The interviews with individual YP took place in busy college areas with the door open or with staff being able to see into the room in adherence with the NSPCC guidance for interviewing CYP (NSPCC, 2022). In the focus groups, and some of the interviews, there were tutors present and so the YP had an ally (NSPCC, 2022). For online one-to-one interviews, the researcher requested that the interview took place in a communal space if at all possible, or that there were adults around (NSPCC, 2022). The online interviews for this study all involved older YP who were in shared accommodation which meant that others were present in the vicinity but not actually in the room, allowing for confidential conversations but with others nearby.

Confidentiality cannot be absolutely guaranteed within a focus group or if other people are present in the interview. This is due to the risk of personal information regarding the participants' individual disabilities and opinions being leaked by another attender which

could cause distress to the participant and a breakdown in trust with the researcher, supporter or peers (Whyte, 2006). To mitigate this, all participants and supporters were asked not to share, record or film anything that took place in the focus groups or interviews to maintain anonymity. No recording by anyone except the researcher was also mentioned on the consent form (which can be seen in Appendix E(i) and easy read version Appendix E(ii)) and at the start of each session as a reminder (Whyte, 2006). As an additional layer of confidentiality, participants were assigned a pseudonym when the data were collected with any further identifiers such as name of setting being anonymised (Cohen et al., 2011). Links between real names and pseudonyms were kept separately from the transcripts and recordings were destroyed after transcription (Cohen et al., 2011) with only the anonymised data being used in the thesis (UK Data Service, 2022).

The only reason for not keeping information confidential was if the participant declared they were either at risk themselves or a risk to others, which was conveyed to the participants as part of the information sheet sent to them and reiterated at the start of each session. This is standard safeguarding practice for professional interactions with people potentially at risk (Family Rights Group, 2022). Any concerns of the researcher regarding this would have been referred on to the YP's college or university safeguarding team or to the Local Safeguarding Board for the local authority area. (Please see Appendices F(i) to F(iv) for information sheets used for different readers).

At all times sensitivity was required to 'read' the YP's responses as to whether they wished to elaborate or not (NSPCC, 2022). At the end of the session YP were offered a debriefing session if this was necessary, but none requested this. Information was also given to each participant about further wellbeing support in case this was required (Whyte, 2006). YP were informed about organisations that could provide online or in-person counselling and advice services such as The Mix (www.themix.org.uk) and Time to talk Next Steps (www.ndti.org.uk/projects/time-to-talk-next-steps). They were also given information for a crisis situation, such as the Samaritans (www.samaritans.org/), Anna Freud Centre (www.annafreud.org/on-my-mind/afc-crisis-messenger/) and Papyrus UK (www.papyrus-uk.org) (See Appendix G for full information).

Once the data had been analysed, feedback to the YP was given through an accessible and anonymised summary of the findings (Whyte, 2006) either via their colleges or directly to them (See appendix H).

4.2.3.2 Advisory group

A group of CYP with SEND was asked to act as an advisory group for this study as although the author has considerable experience in this area, it was not possible to be certain that the questions would be appropriate without asking the group themselves (Whale, 2017). This group of young people already met regularly and were asked for their views by the LA on policies and publications about matters concerning them. LA departments confer with this group to ensure that the materials used for CYP are accessible and relevant. The group was asked to volunteer to check the research materials and to act as a pilot group to test the questions, to ensure clarity and that the relevant information was gathered. Piloting can refine questions that may seem obvious to a researcher immersed in their research but less clear for someone approaching it for the first time (Cohen et al., 2011). It can also open new lines of inquiry through discussion about the topic that the researcher had not previously thought of (Kvale, 1996). However, only one YP was able to give time to the request, but his input was valuable in clarifying the information given and the questions asked. He was keen to be part of the study but unfortunately was just outside the age range for inclusion but was assured his role in piloting the study was valuable.

4.2.3.3 Recruitment.

The sample was purposive and convenient with the possibility of snowballing, using participants already agreeing to take part to inform other YP (Cohen et al., 2011). Participants were sought via national participation, Voice and inclusion groups such as the Disabled Children's Partnership, Council for Disabled Children or FLARE.² Local colleges and schools were also contacted to see if their foundation students would be interested in participating. The expectation was to gain an understanding of the older age group's

² The Disabled Children's Partnership (<https://disabledchildrenspartnership.org.uk>); the Council for Disabled Children (<https://councilfordisabledchildren.org.uk>), and FLARE (<https://councilfordisabledchildren.org.uk/what-we-do-0/evidence/involving-young-people/our-projects-and-programmes/making-participation-1>)

experiences, with all ethnicities, genders and disabilities included, with the aim of recruiting a diverse group of YP. However, it was not possible, despite advertising widely, to recruit a wide ethnic mix. The YP also needed to have capacity to consent and the ability to understand the topic. They needed to be able to communicate with the researcher in English or by using augmentative and alternative communication (AAC) such as eye gaze technology or a speech generating device.

Flyers were produced to display in public places or publish in newsletters to advertise the study to YP themselves, parent/carers, leaders of YP's groups, professionals who worked with YP and later to advertise for ethnic minority YP (See Appendix I for an example).

Information sheets were then sent to those who showed initial interest in the study, together with an easy read version for those YP who needed this (see appendices F(i) to F(iv)). If they subsequently agreed to participate, a consent form (see Appendices E(i) and E(ii)) and a demographic form (Appendix J) were sent to be completed before the interview or focus group took place. The demographic form originally asked for the YP's educational setting during the pandemic, but this proved to be a very confusing and time-consuming question for them, and so was later removed from the demographic form.

The YP were given the opportunity to include another YP or adult of their choice to aid communication or for support, in both the focus groups and the individual interviews (Stafford, 2017). They were also given an opportunity to meet the researcher before the session to ask questions and to decide on participation (Whyte, 2006) or to see an interview schedule of the questions if they required this. This also allows participants time to think about their replies, which is useful for CYP with SEND as they can take longer to process and articulate their responses (Webster, 2022) and one YP did prepare her answers before the focus group. Additionally, knowing what will be asked before a session can help the CYP feel they have more control and thereby reduce some of the power imbalance between the researcher and the CYP (Whale, 2017).

4.2.3.4 Data collection

Data collection took place between March and June 2023 which was as soon as it was possible to have in-person access to a setting. Once participants had been identified and offered to take part, the college managers then explained the study to the YP and the

information sheet and consent form were explained. Obtaining informed consent respects the rights of YP to make their own decisions about their lives and the researcher should not assume they will or will not wish to take part (Cohen et al., 2011). However, it can take longer for a researcher to obtain consent and to explain the research to YP who do not know them and who may have challenges with receptive or expressive language (Stafford, 2017). It was therefore beneficial for the YP to hear about the study from their tutors who they knew well. Focus groups were then arranged and additionally, parents of YP at the specialist college were informed of the study via their college newsletter. As the sessions were taking place during the mainstream college's usual timetable, parental consent was not requested as the research was considered an enrichment activity which is a normal part of their educational provision. At the colleges the focus groups had been set in their tutor time, rather than in the YP's subject class time or free time, which resulted in good participation with only a few opting out. This meant there was a tutor present throughout; they did not contribute but were someone the YP knew well, which was a safeguarding precaution for the colleges and supportive for the researcher and students.

Only one of the focus groups was a true focus group where participants responded to each other as well as to the researcher throughout, which was Focus Group 6 at the specialist college. The other focus groups had episodes of reciprocity between YP, but they largely became group interviews as participants wanted to respond individually to the questions more than they interacted with each other (Gill, 2008), a situation that may have occurred as a result of the YP's social and communication difficulties. YP with autism in particular, struggle with social communication norms and find the give and take of a conversation challenging, especially in a group situation (National Autistic Society, 2025).

It was hoped that by offering to meet up with the YP and their caregivers before an interview, that they would feel more comfortable to take part (Whyte, 2006), but no-one requested this. However, some YP did wish to invite a trusted adult to their interview and asked a tutor to stay. Interviews 3, 4 and 5 at the mainstream FE college and interviews 2 and 3 at the specialist college were conducted in this way. There are differing guidelines around how many should be in a focus group of CYP (Adler et al., 2019), but for the purposes of this study with YP who would need more time than peers without disabilities, it

was considered an interview if there were one or two YP present and a focus group if there were three or more YP.

Some of the YP from the specialist college attended outside their college hours and made a special journey back to college on their day off to be interviewed. The efforts of both the managers in securing these interviews and of the YP who were willing to give their views was much appreciated. Additionally, there were three YP at the mainstream college who introduced themselves to the researcher and requested an interview on the day of the focus groups when they realised what was happening, and the college made a room available at short notice for this.

All three of the online interviews were with YP who were familiar with using online technology during the lockdowns as a result of attending university or being in work. They were therefore familiar and willing to use this method and appeared relaxed and engaged during the interview.

The data collection sessions lasted between 12 and 90 minutes, depending on the engagement of the YP and the time available in their educational settings, with a mean time of 38 minutes. The shortest interview was with a YP who wanted to speak with the researcher but only had their break-time to do so. The longest interview was focus group 6 at the specialist college, where the three participants were enthusiastic and appreciative of the chance to express their views. The researcher had to bring the interview to an end and on leaving, the YP commented that they would like to be able to do this sort of thing more often.

All in-person focus groups and interviews were audio-recorded on a voice recorder and notes made to give context to the sessions before and afterwards. Notes were not taken during the data collection as it was not possible to concentrate on the YP and be responsive to them as well as to make notes. The online sessions were recorded using the integral Teams recording software.

After the sessions, each YP was asked if they would like a certificate of participation to add to their portfolio which YP gather during their education as evidence of achievements to show potential employers. All but one took up this offer and the certificate can be seen in Appendix K. They were also given a comments form if they wished to give feedback about

how they felt the group or interview had gone (Appendices D(i) and D(ii) and a list of potential services for further support as previously mentioned (Appendix G).

4.2.4 Analysis

Braun and Clarke's (2019) reflexive thematic analysis was used for data analysis, and their guide was followed which includes six phases as shown below:

1. Familiarising yourself with the data
2. Generating initial codes
3. Searching for themes
4. Reviewing themes
5. Defining and naming themes
6. Producing the report

All data were transcribed as part of the familiarisation process and uploaded to NVIVO where line by line coding took place. As the data were reread, relevant codes were allocated which were then grouped into potential themes. The themes were constantly reviewed and changes made as necessary, with a final decision once themes had clear definitions. They were then used for the production of the chapter.

The main difficulty with this was transcribing the data from a voice recorder. It was challenging to hear everything all the YP had to say because the rooms were not always ideal for recording. For example, one focus group took place in the crypt of a church where the YP met for their activities that day. The acoustics made it difficult to hear clearly at times, but with careful repeated listening it was eventually possible. Each individual was named when they spoke which made identifying who was speaking possible. However, several of the YP had speech difficulties which meant without the visual clues of being present in the room with the YP, it could take some time to correctly identify what had been said. Completing the transcriptions soon after the interview helped, but it meant automatic transcription software was impractical for most of the YP's contributions, resulting in the necessity of painstaking work to complete this.

4.2.5 Reflexivity

All through the interviews and focus groups and the analysis of the data, the researcher reflected on their position as someone who dealt with YP with SEND and their families who were in difficulties with their education or life generally. This necessitated purposely putting aside any assumptions that the YP interviewed would also have experienced difficulties and having an open mind as to what their experiences had been. However, the researcher's experience also allowed them to be perceptive as to when to follow up a comment and when to let something go, when to steer the topic and when to allow a YP free reign, providing the YP the best chance to express themselves fully. A reflective journal was used for this purpose after each session to document what had occurred during the interviews and additionally, the time spent transcribing also allowed greater consideration of what the YP had said and to look for any evidence that may challenge initial interpretations.

4.3 FINDINGS.

(Quotes show age ranges of YP in brackets at time of interviews/focus groups in 2023; pseudonyms match those in the participant tables).

Five main themes were created from the participants' data which are numbered in this chapter for clarity. Figure 4 below shows how the themes are arranged.

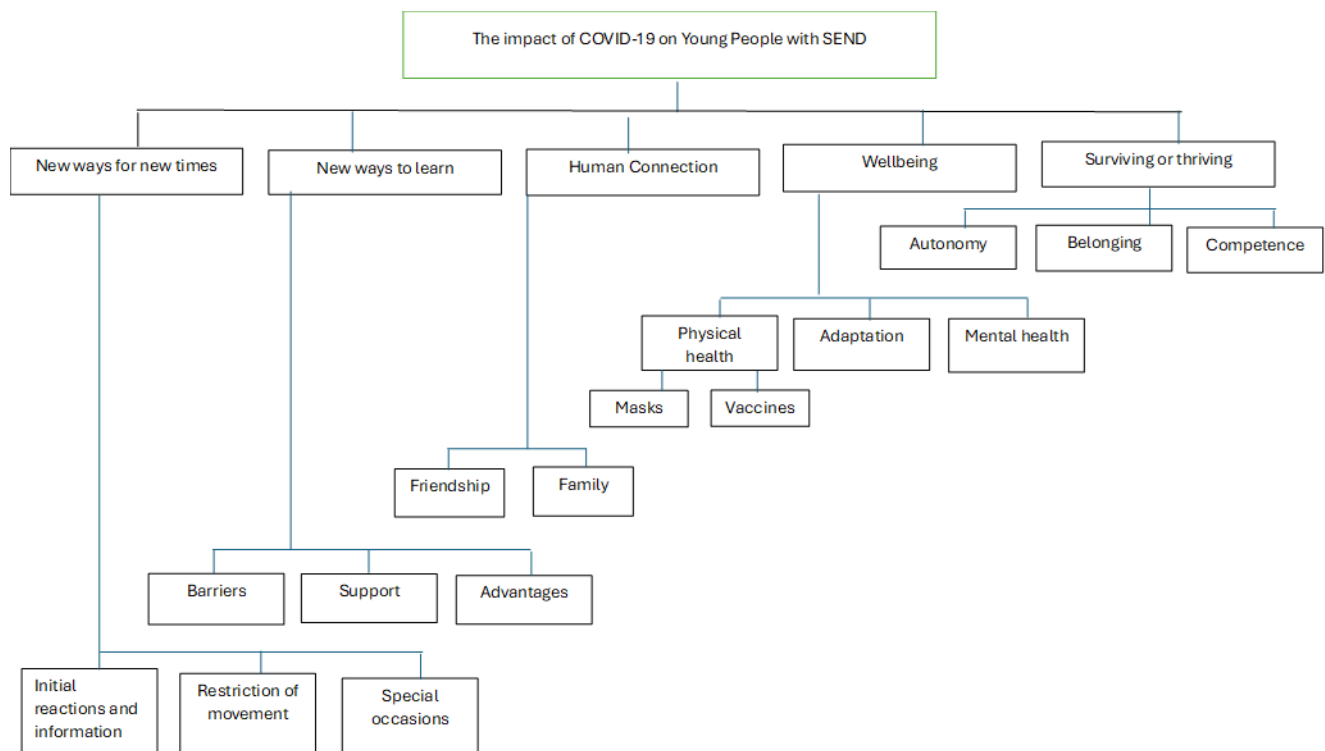


Figure 4. *Diagram of themes and sub-themes for YP Study*

4.3.1 Theme 1: New ways for New Times: Everyone's in the same storm that we don't know how to get out (Paul, 19-22)

The COVID-19 pandemic caused disruption to daily life on a global scale, with changes impacting individuals' routines in unprecedented ways. A dominant thread running through all the findings was the impact of technology and digital solutions to issues arising out of the pandemic restrictions. Novel ways were developed for education, health, social interactions and entertainment. Many YP mentioned they had received new devices or had used their phone more during the pandemic than before and they used technology or software that was new to them. However, the technology was not useful for YP who lacked an appropriate device or for those attempting to connect with older family members who were unfamiliar with it. More about digital use will be reported within the different themes as they are explored in this chapter.

Overnight many aspects of daily life were restricted and the majority of YP tried to adhere to the government and NHS guidance and understood the rationale for its introduction was to

keep people safe. The YP's initial reactions to the pandemic are the first subtheme considered here.

4.3.1.1 Initial reactions and information: *Confused would be mainly the word. (Lisa, 19-22)*

At the onset of the pandemic many expressed shock due to the abruptness of the restrictions imposed. Most YP did not follow the news or politics and were unaware of COVID-19 until it was discussed by teachers or family members shortly before it impacted the UK. YP's general understanding had been that COVID-19 would remain in China where the virus began. Their understanding of the global spread of disease was limited, often drawing on historical examples such as the SARS outbreak in 2003, which spread from China to only four other countries (World Health Organization, 2024), the Spanish flu epidemic of 1918 or the Bubonic plague of 1348. Even when it was evident the virus was spreading more widely, YP did not at first think it would affect them:

Initially I thought oh, you know, isn't going to be anything too crazy. But it turned out, oh, yeah, this is like a huge, massive thing that's gonna, you know, be part of the news for the next two years. (Steve, 19-22)

As the pandemic progressed, some YP became aware of more details, for example, the distressing reports of overwhelmed healthcare systems in Italy, where a rapid surge in hospitalisations significantly strained resources (Azzolina et al., 2023). This growing awareness was attributed to discussions within their families and exposure to the news. One participant, Martha, demonstrated particularly detailed knowledge as she was not only aware of the Chinese origin of the virus, but also of the doctor who had tried to alert the world to its seriousness. She felt that it would not have spread to the UK if the Chinese government had allowed him to share this information with other countries.

However, many YP acknowledged that leaders were navigating an unprecedented situation and understood that people were doing their best in challenging circumstances. The majority of YP said their information source was the TV news or their families:

I think this is when we were talking about the plan for the future, for us stay at home we had you know [...], some weekly inform updates by Boris, [Johnson, the Prime Minister] um, about what's going on, what we're trying to sort out, what we're at. (Paul, 19-22)

Educational institutions played a limited role as sources of information for the YP, and only a small minority reported they had obtained information online. A few mentioned receiving updates through radio broadcasts or their workplace but many YP thought they had sufficient information to understand the situation. They were often alerted to the crisis via changed routines, such as family members working from home or the public health measures such as the two metre distancing rule. These visible signs indicated to YP the seriousness of the situation, prompting some to watch the news for further information despite not having done so before. While there was an understanding that the pandemic was a novel situation, the YP still sought clarity:

But there were lots of conspiracies like, oh, you know, if you're this you might get it or if you do this in life you might get it...there was all that rubbish that people promoted.....for me it's really hard as well when it was all going on because I didn't, I don't completely trust in news. (Elias, 16-18)

Some YP were using less reliable sources for their information, such as social media, Wikipedia and YouTube but most seemed to be aware that these were not reliable:

And I'm like, imagine like, talking about COVID and things, like people searching out facts on TikTok (sounds incredulous). Are we not talking about that? Like, isn't that scary - isn't that scary? (Peter, 23-25)

YP wanted to know on what basis decisions had been made, and why they kept changing. Some detected the tension between the perspectives of politicians and scientists, and it was evident that one individual's name stood out and his advice was trusted:

*Simon: Bloke called Whitty, tells everyone to stay at home. That's what he said.
JP: Did you trust him - Chris Whitty?
Simon: Yeah. Trust him. Go listen to him now. (23-25)*

During the focus groups and interviews, 15 of the YP made comments about how they felt the pandemic had been managed by leaders, although questions were not directly asked about this. This was often volunteered at the end of the interview when asked if they had anything else they wanted to share. The strength of their feelings on this issue was notable, particularly from YP who had struggled to articulate their thoughts on other topics. They expressed a lack of trust and disappointment in leadership, and anger over the severe restrictions imposed on them. Despite these feelings, YP generally understood that the

unprecedented nature of the situation meant that there were no clear answers. They may not have liked the decisions made but generally sought to do what they saw as the right thing by following the guidance. However, they were particularly distressed when they perceived others, including politicians, were not following the same principles.

4.3.1.2 Restriction of Movement: *It wasn't fun ...being stuck in the house all the time (Bill, 19-22)*

An immediate and unwelcome disruption to YP's lives was the mandate to stay at home. Some found this challenging, with a negative impact on many, with Paul calling it "*a bit like house arrest*" and David extended this analogy:

but lockdown was really just like, like a mental prison. Well not a mental prison but just generally a prison. (David, 16-18)

Similarly, Vicky was a university student during the lockdowns and mentioned that her movements on campus had been heavily restricted by security guards who policed students' movements enthusiastically:

It's just I feel like it gave them this kind of feeling of the power. (Vicky, 19-22)

which she felt was unnecessarily authoritarian and made the difficult situation worse. Others stated they needed physical activity or time away from family to maintain emotional regulation, which became challenging while confined to their homes. However, a minority experienced the situation very differently:

Not much really changed, as I say, I don't really go out too much. (Eric, 19-22)

And some YP found that spending more time with family at home was positive, allowing them to have fun and strengthen their relationships. For certain families, the reduced external demands and responsibilities led to a more manageable pace of life, which alleviated some of their previous stresses.

4.3.1.3 Special Occasions: *There were a few birthdays that were a lot different. (Rob, 19-22)*

During the pandemic the YP experienced several birthdays, some of them milestone birthdays, such as 18th or 21^{sts}, as well as occasions like Christmas. For some, it was apparent that these had been lonely events:

So over my birthday sometimes I get cards, but I unfortunately people who were worried to send me a card because I worry about cross contamination. So a lot of people sent like Facebook Messenger or sent messages [...] and then Christmas is quite, quite depressing because you see all these adverts, oh, all together, all having fun and you know, like a nuclear family kind of style, but everyone's having a good time then me and my mum, we didn't really get much presents we just, it wasn't, it didn't feel Christmassy. (Paul, 19-22)

It was also a lonely time for Nessie who felt isolated away from family in her residential college during the lockdowns. This was made worse as most YP at her college did return home for Christmas as they lived closer to the college, making it an isolating experience for her. Some YP tried creative ways to mark special occasions for their families, such as making or receiving birthday videos, but the usual markers of adolescence such as learning to drive, trips with friends or attending a school prom were either postponed or cancelled, resulting in disappointment.

Several YP also mentioned the emotional impact of being unable to share difficult times with their families, such as the illness of relatives and the inability to visit them in hospital or care home. Some mentioned the distress of the death of loved ones during the pandemic and not being able to attend the funeral:

But I couldn't travel up there. And I was on zoom on, like, on an iPad and actually seeing my grandma's coffin, and it made me feel bad because I'm not there, celebrating her life. (Nessie, 23-25)

4.3.2 Theme 2: New ways to Learn: It was a bit of a struggle (George, 23-25)

A criterion for inclusion in this study was to be in education during the pandemic; therefore education formed a core part of the YP's lives and was a critical topic of investigation. The theme New Ways to Learn reflects YP's views and experiences of the changes caused by the closure or restriction of education placements and the transition to online learning. Further related findings are then reported under the sub-themes of Barriers, Support and Advantages.

Most YP did not attend school/college during the lockdowns even though many were eligible to, as most of the YP in this study had an EHCP. In practice, only three participants continued to attend throughout the lockdowns, as schools had to prioritise those who attended due to health risk concerns and lack of staff. In this study, those who attended

were in a residential placement, had parents who were considered key workers, or were in the care system. The rest of the YP remained at home and learnt via digital means.

There were mixed opinions about this sudden change, with some finding it positive but most finding it challenging. The greatest difficulty was if the YP lacked the technology or skills for online learning. If they were unable to engage with online learning, they reported completing little or no schoolwork during lockdown, except when parents offered activities. Initially, some YP received worksheets in the post which they completed and subsequently discussed online. Over time, assignments were primarily online and involved using new software with varying success:

So it was online and sometimes I didn't get the work completed but I had to work for ages and it was really stressful. (Elias, 16-18)

Although not preferred by many of the YP, most eventually adapted to online learning which created a sense of structure in their lives. However, some expressed frustration at the lack of clarity of the guidance from their schools. Those due to take exams were particularly anxious about whether exams would take place, as it affected how they approached their work. Was every piece of work important if the final grade was judged on it or was a focus on revision for an end of year exam needed? Although teacher assessments seemed a fairer method of grading to some, others felt disadvantaged later by the lack of experience of sitting formal exams:

COVID-19 started um, towards the end of my year 10. [...] So I didn't get to do proper GCSEs because of it, so it made it harder, like last year when we did go back and we did proper tests. That was a lot harder because I didn't have like the GCSEs as practice. (Jess, 16-18)

There were changes in the operation of schools when YP returned after the lockdown, with the use of masks, social distancing and other innovative practices, such as ringing a bell for access to a narrow staircase. Screens were also often used around desks at colleges:

There are a lot of barriers in there involving that big screen. And you just can't hear what they're saying. (Rob, 19-22)

Some YP felt out of practice at socialising and needed time to readjust when schools reopened. They also expressed concerns about interacting with larger groups due to both

social and health considerations, having been isolated with their families for an extended period:

I could see more than five people and I was like, oh God, like. (Tilly, 26).

4.3.2.1 Barriers to the new ways to learn: *You just do the work without teachers explaining it to you. (Sam, 19-22)*

Most of the YP in the study had access to a device or managed to obtain one early in the lockdown. However, some were unable to access learning in this way, due to devices being unsuitable for fulltime online learning or having unreliable Wi-Fi. Issues included screens freezing at important moments, leading to confusion about the task, or losing work they had spent a long time on. Additionally, YP struggled with unfamiliar online platforms, difficulty seeing what the tutor was doing and understanding or keeping up with the work:

Because there was like, you need to finish this, and I was like, oh my god, how am I gonna...how'm I, how can I do this? I got special needs! (Elias, 16-18)

Courses like catering and hair and beauty were changed to a format where YP watched demonstrations and then replicated them at home. This required not only digital access but the availability of materials and the ability to work independently - skills not all the YP possessed. It became evident that vocational subjects were significantly more challenging to do online than academic subjects. Many of the YP were doing practical courses such as performing arts or mechanics, which were particularly challenging to provide remotely:

.... some stuff was ok but some experimentation and things like that... doing stuff out of clay or something like that couldn't really do much with that. (Finley, 23-25)

For some subjects, assessments had usually been weighted towards practical assessments with fewer points given to theory, which meant the curriculum had to be changed. Even in more academic subjects, exam boards had to adjust the course in order for YP to be able to complete them online:

Whereas before we needed the knowledge of like 1 through 10 practicals, now it was only 1 through 3. So then actually they just changed the overall A level to a lot more theory. Which was good that we didn't have to catch up, but obviously a lot of those practicals are used to understand the theory. (Lisa, 19-22)

YP found that online learning included long periods of screen time and being spoken at with little interaction. Many had chosen their course based on their strengths, whereas online learning emphasised areas they struggled with:

I find all the reading obviously quite intense, but I did two science A levels which normally is a lot of practical based learning which is great for me. But online, again, none of that. (Lisa, 19-22)

Many of those conscientiously completing work online found it uninspiring and repetitive and mentioned it was not always marked. They also commented on new information not actually being taught, instead YP were required to click on links and complete worksheets with no support:

...It's like giving, giving a kid a workbook, but, and then expecting them to do it. (Peter, 23-25)

YP would ideally have liked to have received some teaching about the online platforms before the crisis, and for their teachers to have been more knowledgeable about them themselves. Others mentioned inconsistency amongst teachers in how they used the software, making it confusing and difficult to navigate.

4.3.2.2 Support for the new ways to learn: *It was a challenge (Lisa, 19-22)*

Overall, YP did not feel supported adjusting to online learning, despite the best attempts of their teachers. This was likely due to the unexpected nature of the changes, compounded by the complex circumstances evolving in people's lives at home and work. The lack of available support was problematic for those who normally had access to a Learning Support Assistant (LSA) in class who would clarify and differentiate for them. Some reported that LSAs continued to check in with them, but for most the work became undifferentiated:

So it was sort of more of one like capsule lesson so had to work for everyone. And I think at that point it was their one goal was to get the content across in, in just some way rather than maybe being in the best way it could have been for all of us. (Lisa, 19-22)

Lack of differentiation made the YP more reliant on caregivers to support them, but this was not possible for all, creating inequality in their home-learning experience. It was a major reason why some YP felt adrift with home learning, despite good intentions from schools.

Additionally, some YP found their mental health prevented them getting online due to anxiety about the work:

I was just getting way too paranoid about the work itself and I was being like, I'm going to fail, I'm going to fail. I'm going to keep on like, not being able to do this and because it got so overwhelming, which was at the point I was just like, I can't do this, I literally cannot look at the screen without ending up having a panic attack. (Frankie, 16-18)

YP observed that some peers had left their course during the lockdowns due to difficulties or dissatisfaction with online learning. Although most continued, many felt they had not received the anticipated educational experience:

But I just missed going and getting my hands dirty – working on the cars and I was only in, being honest, 5, 6, 7 days through the whole year during the COVID-19 business which was such a shame because I felt like I missed that year out. (George, 23-25)

The college that provided supported internships enabled the YP to complete an additional year, ensuring they had the full benefit of that year, as the work placements, integral to the programme, had ceased during this time:

So this course we were doing was a two year course. With COVID-19 we had a free year. For me that was a lot easier because I learned a lot more with work experience and knowing what I want to work and what I don't want to work. (Paul, 19-22)

The support YP appreciated focussed more on keeping personal connections with the students rather than education. These included enjoyable activities such as quizzes and online art, sport or photography competitions. Some were organised by the student union, while others were arranged by staff or student groups. Those who had participated found these activities enjoyable and helpful for staying connected with peers, offering a way to pass the time and add structure to their week:

The PE staff really were doing great. They had a few like who could do the most, like keepee uppies or things like that. (Lisa, 19-22)

4.3.2.3 Advantages of the new ways to learn: *I could just do it at home.* (Bea, 16-18)

Although most YP found home learning challenging, some YP reported advantages. Sometimes these were positives amongst mostly negatives, and at other times it was a totally positive experience for them. Some were able to concentrate better, complete tasks more efficiently, and work at their own pace due to fewer distractions outside the classroom environment. They could also explore and develop personal interests, often with parental encouragement. Additionally, they could take breaks when needed, eat when they wanted to, avoid early morning starts and eliminate travelling. For a few, the experience was a revelation in what they could achieve academically with more individual support from their family:

It got to the point where I felt like I was doing like, you know, working towards targets, it felt better for me to work from home. I wanted to carry on with that. (Bea, 16-18)

One YP mentioned that as English is her second language, online tuition was particularly helpful because her university's videos included captions which could be paused or rewatched. This allowed her to improve her English alongside learning the subject matter. Others mentioned that being able to pause and replay recorded content helped them process and absorb the information more thoroughly. For those shielding or cautious about infection, online learning enabled them to continue their studies without in-person interaction.

Additionally, there were those who expressed relief at not attending school, as they found the school environment challenging, due to being bullied or socially excluded. These stresses created anxiety which was alleviated by not having to attend. While some of these YP reintegrated back into education after the lockdowns, it appears that nationally, many YP have not been able to make this transition back (Education Committee, 2023).

Post lockdowns, a positive change for education was mentioned by some:

I think also, there's more arrangements for like online learning and things. So even if, so I miss lessons sometimes....all the lessons are uploaded online. (Jess, 16-18)

Furthermore, the change to online learning was beneficial for YP facing physical or mental health challenges that made attendance difficult. An interesting side-effect at university was that, in theory, there was no compulsion to attend lectures if they were available online, even after the lockdowns ended. However, those who mentioned this used the online format to reinforce learning or to catch up, but they knew of students who never attended lectures in person due to this provision but acknowledged this flexibility could be helpful for some. Another change mentioned at the university level, was that post lockdown, practical sessions were filmed and viewed online, rather than the students conducting them themselves which for students who needed active learning, was not deemed as effective.

4.3.3 Theme 3: Human connection: *We're all supposed to be social creatures (Paul, 19-22)*

The circle of contacts for YP with SEND is usually smaller than their peers in typical times. Friendships and casual connections which bind society together are often fragile or non-existent for them (Friedman & Rizzolo, 2018). However, most YP expressed sadness at the loss of social contact during the lockdowns, even those who struggled with socialising. Friendship was a major topic for many of the YP, with the discussion ranging from what happened in the pandemic to their past struggles with making friends, with some YP feeling excluded due to lack of friends. However, for a minority, the reduction of the pressure to engage in social relationships in the pandemic was a relief. Family was very important, often more than peers, and was mentioned in terms of support, being friends and part of reciprocal caring relationships.

Online or physically distanced contact replacing in-person interaction was one of the hardest things YP experienced. Casual encounters were also much reduced, resulting in increased isolation:

I think I was really lonely. Because I have struggled with loneliness, I think more harder because it means I was even more restricted. Because during when I was younger, at school, at least I could go out and try to meet friends or do clubs or any social groups. (Paul, 19-22)

YP missed physical contact at an important age of exploring identity and relationships, as online interactions failed to meet basic human needs:

Nessie: It was very hard, because I'll have to go FaceTime them (friends) all the time on Zoom.

JP: And did that work? I mean, was it alright?

Nessie : It was alright. But it's very hard to not, like, actually hug them. (23-25)

Online contact, although appreciated, was experienced as second-best. However, it did open up the digital world for socialising to many YP for the first time. Additionally, it fast-tracked developments in the educational use of technology.

4.3.3.1 Friendship: *It wasn't nice, not seeing any of my friends. (Bill, 19-22)*

YP described the loss of in-person contact with friends as “*upsetting*” or it had left them “*feeling lost*”, though most eventually adapted to online communication:

We have like a weekly scheduled weekly big facetimes with all my friendship group which was nice, but obviously it's not the same when we're trying to talk over each other. It's not, not quite as good. (Lisa, 19-22)

However, online chats could become time-consuming and intense in the absence of other ways of interacting. Consequently, some YP recognised that it was not always a healthy use of time. Conversely, not all YP moved to online communication, as some saw no need for it or felt uncomfortable using it. For some, being at home with family was enough social contact, and others noted their friends did not go online. Additionally, communication challenges such as not knowing what to talk about online was highlighted, as Peter (23-25) reported:

And then social, socially really difficult. Because like you couldn't interact with anyone. So it's like, so it's like common ground kind of thing. But the only thing I had as common ground was COVID-19. And it's like, what else do you talk about?

For some YP, social interaction was usually limited to school/college, with no socialising during their free time. Consequently, school closures not only affected education but also YP's primary source of social engagement:

I couldn't go to college and that was the only place that I socialised, and not many people er, really wanted to socialise with me so that impacted it even more. (Elias, 16-18)

Some enjoyed the greater opportunity for online gaming, which was usually a more marginal activity, resulting in increased social time for those who engaged with this. Tilly also noted that she enjoyed more social time with friends than usual, as she had more time to talk online due to not travelling to her placement during the lockdowns. She also observed that her peers made more effort to connect online and showed greater concern for each other during the pandemic. Additionally, two YP experienced the blossoming of new romantic relationships during the lockdowns over Zoom.

There were some who considered the use of phones and social media had made it more challenging to make friends in-person after the lockdowns, with the phone acting as a barrier. Paul described this as everyone being “*in their own little box*” and he found it made it more difficult to interpret social cues as to who was open to overtures of friendship. There were also some friendship casualties once the pandemic restrictions ceased, for example Vicky realised the university peers in her flat had used alcohol as a prop during the lockdowns. At the end of the lockdowns, she no longer wanted to engage in this behaviour, resulting in the loss of that friendship group. Other relationships were lost due to different responses to the pandemic:

Martha: And then, like when COVID-19 happened that was it We stopped playing games together, we stopped going to the cinema together, we stop playing, we stopped talking to each other.

JP: Why do you think that happened then?

Martha: I think she was more stressed out. (Martha, 26)

4.3.3.2 Family: *I think it was mostly because I had my parents. (Jacob, 19-22)*

Family and support at home was crucial for most YP in navigating the changes. This support included online learning and mediation between the educational setting and the YP, particularly if the schools provided insufficient support or inappropriate materials. However, the most important aspect of family support was that it was a shared experience, ensuring the YP did not feel alone:

Fortunately like my brother and stuff they, like, I had some family around me. For the first part, like for the first lockdown..... it would have been a bit of a different story I think if, if I was on my own. (Peter ,23-25)

Families (not necessarily birth families), generally provided stability, shielding with them or visiting and contacting them if they were living away from home. Some YP enjoyed time at home and being able to spend time with their families, despite not enjoying lockdowns.

Moreover, some relationships, such as with siblings, became more valuable:

My biological brother, he used to come into my bedroom every morning just to see if I was alright and I was just like, you don't normally do this! (Freddie, 16-18)

However, tensions inevitably arose due to the enforced restrictions on families, with parents experiencing concerns regarding work, finance, health, childcare and education. YP described sibling and parental relationships as “up and down” with some having the additional pressure of extra people staying with them. Furthermore, for some it was a tempestuous time, especially if the family had pre-existing difficulties:

...with me it was pretty difficult with my family as we don't have like the healthiest family dynamic. Um....so it was ... there was a lot of screaming and a lot of praying! (Frankie, 16-18)

Additionally, differences of opinion emerged between some YP and their families about interpreting government guidance, which changed often and was frequently unclear:

I had a debate with my dad, and he said it's not stupid [the restrictions] because look how many people are affected, I don't care what it's at, I'm still going to call it stupid because I'm not having a good time and it's ruining my life. And he said, he disagreed with me, then we got, we were having arguments every day about it. (Elias, 16-18)

Contact with wider family, especially grandparents, became more challenging due to the reported vulnerability of older people as households were instructed not to mix with those they did not live with. This left older relatives and those vulnerable to infection isolated from the rest of the family. People were concerned about transmitting the virus but also wanted to check on relatives to ensure they had company, groceries and healthcare. Many YP really missed seeing their grandparents, especially if they had been part of their regular routine, but families found creative ways to maintain contact. YP mentioned open air distanced visits and to a lesser extent, the use of technology. Although some made contact digitally, the YP understood that not all older relatives were competent with technology:

They didn't always understand the FaceTime. So I think it was all hard sort of to keep in contact as much as we would have liked during those times. (Lisa, 19-22)

4.3.4 Theme 4: Wellbeing: *I didn't cope with being stuck at home (Jacob, 19 -22)*

The theme of wellbeing includes the subthemes of physical and mental health, as both are essential for a healthy life. Restrictions meant YP lost jobs or work experience placements along with the closure of schools and colleges, creating a void potentially impacting both physical and mental health. While many of the YP adapted over time, it was challenging for most, especially initially.

4.3.4.1 Physical health: *I had a fear of like people passing away throughout the whole entire year (Bea, 16-18)*

Many YP had had COVID-19 by the time of the interviews, some of them multiple times. Most had had mild symptoms, and none had been hospitalised, although they knew of adults who had. The main concerns expressed about physical health were for their friends and family rather for themselves, but some YP expressed awareness of the extra danger of COVID-19 to people with disabilities:

There's some people, if they have like a disability, cos I have Down syndrome and I had a hole in my heart, and so if young people have a disability and if they had COVID-19 during that time, it's not really the best thing (Alice, 16-18)

I heard lots of stories about people with learning disabilities and autistic people who had coronavirus who did not receive the treatment they needed and unfortunately passed away. (Tilly, 26)

One of the government health recommendations was the practice of shielding, which was a scheme designed to keep safe those considered more vulnerable to the virus (NHS England, 2020). Only one of the YP in the study mentioned she was shielding:

Yeah, I got like a letter saying, like even before majorly the lockdown came in saying like you're advised to stay in for at least three months. Don't share the same bathroom, don't go out in the garden. Look at the garden through the window. (Tilly, 26)

The letter gave clarification for Tilly about what she should do, however some of the suggestions were impossible for her. She lived in a flat with one shared bathroom, therefore using separate bathrooms was impossible. At the time of the interviews, two of the YP with Down syndrome had not had COVID-19, whereas many of the other YP had. These two YP didn't call it shielding, but Bea said she was "*Stuck in so couldn't share germs*" which may

have meant they were shielding, as people with Down syndrome were on the government shielding list. Conversely, it may have meant that like many families, the YP were informally protected by their families restricting contacts.

It appeared some medical appointments continued in-person between the lockdowns, for example Olivia had major surgery at the end of 2022 and orthodontic treatment continued for some YP. However, during the lockdowns, most medical and therapeutic support went online or was offered through telephone appointments, as professionals moved to providing a distanced service. This caused delays in some routine medical procedures, such as blood tests, meaning that a deterioration in Tilly's condition was not dealt with for several months, when it normally would have been picked up within the month.

Due to the restrictions and removal of usual routines, YP struggled to create new structures in their lives. This resulted in some YP watching films, being active on social media or listening to music late at night. They then slept late the next day, as for some there was no reason to get up at a certain time. Initially, some YP behaved as though it was a holiday from school and were not concerned what they did:

I was like, ok, it's not gonna be long until I go back, I'll just play with my friends online and stuff, so it's more like a sociable online group. But unfortunately, I didn't go out as much, so I noticed I started gaining a lot more weight and generally started to be a bit more lazy and everything. I thought it would be like a halftime break, I think, ok, maybe it'll be one or two weeks. we didn't get that much err, exercise. We didn't do as much like eating healthy food, we were getting Deliveroo's and get more like junk at that time. And my mental health, I might, like my sleeping, I was very overwhelmed. I just, it was a very, it was an unhealthy to live like that for a long time. (Paul, 19-22)

4.3.4.1.1 Masks: We're still wearing masks sometimes (Hamish, 16-18)

The use of masks was a way of keeping society open to some extent. This was voluntary initially, due to uncertain benefits of their use at that time (Hobbs & Bunn, 2020). However, they became mandatory as the pandemic progressed in certain situations such as in hospitals and shops, except for those wearing a sunflower lanyard, which indicates a hidden disability (such as autism) that may exempt the person from wearing a face mask. Mask use became a new routine, which many of the YP observed as a symbol of the gravity of the crisis:

So I saw someone, and it was very unusual at the time because, bear in mind it was quite prior to locking down coming, with quite a clinical mask on their face, which was quite scary. (Tilly, 26)

Some participants noted that wearing a mask was challenging, including discomfort from heat, difficulty interpreting facial expressions, and sensory issues with covering the face or specific textures. However, most YP adhered to the guidance around mask wearing, but it was not clear if they knew of exemptions on disability grounds. Many mentioned the discomfort of wearing a mask all day when they returned to in-person education.

Some advantages of wearing a mask were also mentioned, with those wearing braces or feeling self-conscious about their appearance reporting reduced anxiety. At the time of the interviews, two YP continued to wear masks around college despite it no longer being required. Those YP explained it was partly to do with ongoing infection concerns but also because they felt less anxious when wearing a mask. Other health and safety measures YP mentioned were sanitising hands, learning in small groups (bubbles), avoiding travel, going for walks, using screens in school, social distancing and COVID-19 testing. It was interesting to note that no one mentioned basic handwashing.

4.3.4.1.2 Vaccines: *I had like four different ones (Sean, 19-22)*

There were disparate views about COVID-19 vaccines, but most were in favour of them and had been vaccinated. This topic was not specifically addressed in the study, but information was volunteered by the YP. Being pro-vaccination was despite some fearing needles, stating the vaccination had hurt and experiencing side effects. They were happy there was some protection available for themselves and their older relatives, and that it meant a more normal life could resume. However, there were a small number that disagreed with vaccination or were strongly against it being compulsory:

I don't even know if you can sort of fight for a free society any more...I mean the fact that you could have a vaccine passport! Oh so let's just discriminate against the unvaccinated then...and let's just ignore the fact that natural immunity's a thing and all of that. (David, 16-18)

One YP had to leave his work placement due to the vaccination rules there, and found people became judgemental over his stance. He was a YP who had followed all the rules up until this point and was shocked over the response to what he saw was his choice:

I got kicked out because I didn't have it. And I feel like it was a bit like papers, please, kind of like very Nazi or would you have this certificate and stuff. (Paul, 16-18)

4.3.4.2 Adaptation to the pandemic: *Just think of a plan B, I thought. (George, 23-25)*

Over time, most young people developed new activities that contributed positively to both their physical and mental wellbeing such as the increased use of social media and online activities which maintained some connections. YP also mentioned making videos, running, swimming and trampolining. Peter spoke of sport usually creating opportunities for him to talk with his peers about a shared experience, but this was lost in the lockdowns. Daily walks were mentioned as a permitted activity during the lockdowns, and many enjoyed this rather unlikely teenage pursuit, as a means of getting outside. Some turned to YouTube and joined Joe Wicks' free livestream exercise class, which went out every weekday during school closure from the beginning of lockdown (<https://www.thebodycoach.com/blog/pe-with-joe/>). Joe Wicks online became a fun way to pass the time and join in a shared activity, creating a feeling of community. For some, this was the start of a new fitness regime that continued after the lockdowns ended, with some joining a gym or continuing with Joe Wicks videos.

Many YP, possibly due to sensory differences or neurodiversity, sought ways to remain active and found creative ways to fulfil that need:

So, I thought try and maybe walk around the house a bit sort of and try and do some steps to a certain amount of time and that, which is what I did and sort of going up and down the stairs as well cos that's supposed to be good as well. (George, 23-25)

However, there was a small group for whom nothing much changed, as their routine continued as usual. These YP were generally those who did not normally go out much, and were either happy staying at home or felt they had no choice:

So most of time, my mum and I just kind of did our thing, watched TV, it wasn't as, in like, we didn't notice it being different. (Paul, 19-22)

4.3.4.3 Mental health: *I feel like mental health has definitely gone on a decline (Declan, 19-22)*

The disruption of their usual activities and the inability to see friends, significantly impacted the mood of many YP, with some expressing anger, frustration, or boredom:

I'm not going to let this go – I'm not going to forget this. I know a lot of people probably have, but I'm not going to forget this. No effing way whatsoever. (David, 16-18)

Existing mental health difficulties worsened for some, with little support available in usual times and less during the restrictions. Mental health and mentoring support went online or via the telephone, which although was considered better than nothing, was very much second best. However, this support could be unhelpful, as many of the YP had communication difficulties, meaning phone use was not a good option for them:

Well, I have a support charity called Barnardo's and I've been with err one, one of the helpers, has helped me there since about 12 years now. I couldn't see her so I didn't have as support to understand, for example if I had to write an email or I had to write or to talk to this person about education and what I want to do. I had to kind of talk to her from the phone. So a lot of communication really hard to explain, oh, I need help with this, or how do I write this. (Paul, 16-18)

...when it comes to like, mental health side of things. I think that's like, face to face is like really important. (Peter, 23-25)

Declan felt his college placed insufficient emphasis on YP's mental health during the pandemic, as no one asked about his wellbeing while he was at home or on his return to college. This was reiterated by others who expressed concerns about the lack of support and guidance. Lisa also thought that teachers had minimised the impact of lockdown on them and had not tried to connect with their students enough during the lockdown:

So we got one phone call in the entirety of lockdown, one, and just checked that we were doing OK and had no concerns. So that was, you know, a nice effort from them. But obviously once is not really sufficient, I would say. (Lisa, 19 -22)

The YP did not think the loss of their social lives was appreciated by teachers, with the emphasis on education. Although the YP were concerned about maintaining their studies, there was also anxiety about the wellbeing of friends and family which was not addressed by schools. YP were tolerant of the fact that this was a new situation, but the impact on their lives did not appear to be dealt with holistically, creating anxiety. This was exacerbated by the TV news showing hospitals overwhelmed and the numbers of people diagnosed with COVID-19 on a daily basis.

In addition to concerns about physical illness, several YP mentioned family members or friends whose mental health had been affected during the pandemic which had worried them. Once college reopened, Charlie found it challenging to attend college due to the anxiety he experienced during the pandemic. Many others were honest about similar struggles with attendance, which highlighted a widespread issue post lockdown (Connolly, et al., 2023). However, discussion revealed that the effects of the pandemic were individual, and what was negative for one person, could be positive for another. The different impacts appeared to be related to the YP's personality traits, their specific impairment and the availability of support systems. This was conveyed by the way the YP spoke about the pandemic by relating aspects of the restrictions and their impacts to the kind of person they were. For example, Evan described himself as *"more of an indoors person"* so the restriction on going outside was not problematic for him. Others described being happy in their own company, and some, who found school or college challenging, the COVID-19 restrictions provided welcome relief:

I'm not really the biggest fan of college really, so... it felt like kind of a blessing really for me. (Harry, 19-22)

YP showed strong indications of resilience despite the difficulties. They showed the ability to adapt, for example some reported putting on a show despite the challenges of mask wearing, social distancing and limited rehearsal time. Most YP considered that by March to June 2023, when the interviews took place, society had generally returned to normal and the visible signs of the pandemic, such as wearing masks, had reduced. Some YP appeared to have put the lockdown experience in the past immediately normal life resumed, whereas for others it was taking longer, with issues of trust around the safety of returning quickly to normal:

I think it seems fairly normal, I don't know. If it becomes normal too quickly... if the illness is still about ... if people have decided too quickly to bring it back to normal. (Adam, 23-25)

4.3.5 Theme 5: Surviving or thriving: Independence is that much harder (Peter, 23-25)

With increasing maturity, most YP want greater control of their lives, to gain greater independence or autonomy. Additionally, part of experiencing satisfaction with one's life involves being part of a community and feeling you belong with other like-minded

individuals (Ryan & Deci, 2017). According to Ryan & Deci, (2017) these are considered fundamental psychological needs along with perceiving oneself as competent to achieve the things that matter to you and are important for thriving as opposed to just surviving in life. These three fundamental needs are discussed in turn, concerning how YP perceived their wellbeing.

4.3.5.1 Autonomy: *Having learning difficulties is hard (Peter, 23-25)*

Many YP stated they felt listened to at home and had some autonomy (albeit more limited in the pandemic). Those YP mostly reported they had coped and felt supported, once they had adapted to the initial shock. Many YP also reported they felt listened to mostly or sometimes at their school/college. However, this was more variable with some recounting difficult experiences of teachers not listening to their wishes, which appeared to result in lack of trust and confidence:

Harry: they didn't listen and so they just chucked me back in there.

JP: and what would you have liked to have said to them then or done?

Harry: saying anything to them is useless. (19-22)

The amount of autonomy that YP felt they had over their lives was mixed and also depended on the stage of their education. For example, secondary school appeared to be a more difficult phase for many YP, whereas better experiences were sometimes recounted of primary school. Additionally, many, but not all, were enjoying their post 16 education:

I enjoyed primary school and my first year in high school but then they made some changes, and I hated the last four years of high school. It gave me a lot of depression and I thought college might change that, but of course it has not. (Hamish, 16-18)

Peter considered that as a YP with a learning disability, it was harder for him to become an adult and find the balance between requiring support and becoming independent:

I think you're not always listened to, and some people make like assumptions, especially like, even leading up into adulthood. (Peter, 23-25)

4.3.5.2 Belonging: *I belong, but I'm different (Elias, 16-18)*

Most YP felt they were part of their educational community, with some commenting that the move to a post 16 placement had been beneficial in terms of independence and finding a

relatable peer group. Even some of those who found friendships at college challenging, still felt they belonged, as Elias states in the quote above.

Some YP had struggled with belonging in the past, and a minority still felt excluded at their post 16 setting. For a small number of YP who felt excluded either currently or at a previous placement, this appeared to be due to a misalliance of the YP's self-concept and how they had been labelled by professionals:

JP: So why don't you like coming to college very much?

Harry: Well I was in the special education thing and it was absolutely dreadful. (19-22).

4.3.5.3 Competence: I'm getting on really well (Bea, 16 -18)

To assess their feelings of competence, the YP were asked whether they enjoyed their course and if they believed they were doing well. Most felt they were achieving at least satisfactorily, with some like Bea, quoted above, expressing pride in their competence. However, support that was perceived as inappropriate reduced their feelings of competence. For example, LSAs doing too much for them or conversely, having insufficient support in the classroom. Beth said the LSAs at a previous placement were “*doing everything for me*” and had signed off work she knew she had not completed independently, which had angered her. In contrast, Frankie (16-18), felt unsupported at school and felt she was floundering:

I genuinely, like, struggled through a lot of my subjects. I didn't understand it and even like when the teachers like, were explaining to me exactly what was going on, I was still sitting there going like, I have no clue what the hell you're saying. (Frankie, 16-18)

Involvement in extracurricular activities or having a job or work placement appeared to increase feelings of competence for those involved in these activities. It could be argued that the more confident YP took part in these activities, but some YP acknowledged the activity itself had increased their confidence:

I thought I wasn't really academically skilled, it wasn't until, like I said, I joined the student executive I realised my true capabilities and potential. (Declan, 19-22)

There was variability in how competent the YP felt during home-learning in the lockdowns, with most saying they struggled, but a small number had felt more competent with home-learning than they did at school, as reported earlier in this chapter.

Most YP spoke with enthusiasm about their future hopes, with many having plans for work. It was evident this was an important part of the YP's vision, and that having a plan, even if it changed later, was important. They aspired to finding work in areas as diverse as the theatre, early years, mechanics, sports, science and hospitality. Two YP mentioned using personal experience of disability in their work choices. However, some understood that the lack of traditional paper qualifications or their communication difficulties could be a barrier to achieving their goals, with a discrepancy between what the YP could do practically and what they could show in an exam.

4.4 DISCUSSION

4.4.1 Summary of findings.

This part of the thesis aimed to hear directly from YP themselves about their experiences; a perspective that had not been previously explored in depth in-person in research due to the pandemic related restrictions. Moreover, only a few young people with SEND have been directly involved in research studies conducted so far, and even fewer of the age group involved in this study, as can be seen from the scoping review in Chapter 2, making this a particularly valuable contribution.

Even though COVID-19 measures intensified existing inequalities for YP with SEND in all aspects of their lives as reported in early research (Couper- Kenney & Riddell, 2021), most YP in this study showed resilience in adapting during the pandemic. However, the impact of the restrictions was not equal across the population of YP with SEND. The use of telephone contact by professionals, although better than nothing, was often unsuitable for these YP, particularly those with communication difficulties. Additionally, those in mainstream provision with SEND appeared to struggle more with home learning than those who attended specialist settings in this study. Furthermore, this study found that the subjects YP with SEND were studying were particularly challenging to adapt to online learning due to their practical nature. There was also an extra disadvantage for YP with SEND in missing a year of education, as it can take longer for them to catch up and not all were offered extra months to do this after the restrictions were removed. Friendships and family support were shown to be of great importance for YP with SEND and need to be considered as a priority in any future crisis. On return to their placements, the government emphasised academic education, but YP considered mental health, future opportunities and their relationships

with family and peers of equal importance. It was also found that even if the YP were well supported, some still faced challenges due to their specific needs and individual personalities.

These findings will now be discussed in more detail, in relation to COVID-19 measures and inequalities for YP with SEND; Relationships and relatedness; and Resilience.

4.4.2 COVID-19 measures intensified existing inequalities for YP with SEND.

4.4.2.1 Education

Although government guidance stated YP with EHCPs should be prioritised for school attendance during the lockdowns (DfE, 2020b), only 3 out of 42 (7%) YP with SEND in this study reported attending throughout this period. This figure chimes with national statistics, that reveal that an average of 8% of children with an EHCP or a social worker involvement attended school during the lockdowns, attributed to low uptake and a limited school offer (DfE, 2022a). Some families were reported in the Special educational needs co-ordinator (SENDCo) Policy Seminar in November 2020 (Skipp et al., 2021a) to have expressed concern about infection risk, while others, particularly those with children diagnosed with profound and multiple learning disabilities (PMLD), faced inadequate support or insufficient equipment to ensure safe attendance. PMLD refers to individuals with a severe learning disability combined with other impairments that affect communication and independence (NHS, 2022). These issues of fear of infection and lack of support and equipment were also highlighted by the British families in Lockdown study by Clayton et al. (2020) which was a research report submitted as written evidence to the UK Parliament Education Select Committee. However, even though the YP in this study did not have PLMD, they were still unable to attend during the lockdowns.

For many CYP with SEND, routines are an essential means for them to feel secure. Canning and Robinson (2021) reported that for families of younger CYP (5 -13-year-olds), the sudden cessation of school routines created stress for the whole family. A study by Vincent et al. (2023) focused on the parents' perspective and concurred with the Canning and Robinson view, but Study 1 of this thesis was the first to engage directly with older YP to find out how they experienced attending school/college during this time. It showed that for the small number who continued to attend, they appreciated the stability created and the

maintenance of in-person contact with friends and teachers, as found by Couper-Kenney and Riddell (2021). However, the one YP in Study 1 who remained at a residential school, found it distressing to be separated from her family for so long with limited contact, which was a new finding.

Ashworth and colleagues (2025) reported that educational professionals observed that CYP with SEND attending mainstream schools during the lockdowns enjoyed it more than usual. This was due to smaller classes, greater curriculum flexibility and increased individual support, but the YP in Study 1 who attended school did not comment on this. However, other YP expressed relief at not attending, as pre-COVID-19 they had found school stressful. Additionally, a small number of YP reported thriving by learning online during the pandemic, a finding which is consistent with early research finding a minority of students were doing better at home than at school (e.g. Canning & Robinson., 2021; Greenway & Eaton-Thomas, 2020).

Home-learning appeared to better meet the needs of some YP compared to traditional schooling. Studies such as McKorkell & Lobo (2021) found that CYP appreciated the opportunity to follow their interests at their own pace and take breaks as required. Building on these findings, some YP in this current study reported a preference for the more varied online resources available for home-learning, which they found more engaging than their typical school experience. This was reported by YP who enjoyed the online learning experience and could navigate the challenges or who had parents who were able to support their YP's education and research what was available. However, others found online learning challenging and the opposite was true. Study 1 discovered that online learning provided by mainstream schools was often based on listening, reading and writing, which are skills those with SEND find difficult. Consequently, online education was often perceived by YP who had inadequate support as dull and undifferentiated, whilst some YP did recognise it had been challenging for teachers to adapt to. There appeared to be little support for YP who would usually have relied on support from a LSA in class, leaving family to support them when possible. However, as noted in prior research (e.g., Greenway & Eaton-Thomas, 2021; McCorkell & Lobo, 2021) many families were unable to provide this. From the YP's perspective, the emphasis seemed to be on making the lessons available online, rather than differentiating them according to learning needs.

The findings of Study 1 therefore align with the findings of the scoping review in Chapter 2, which highlighted parental concerns about the lack of differentiation of work provided during the lockdowns. However, this study also suggests that the lack of differentiation was more pronounced for YP who had been in mainstream settings compared to those in specialist settings. YP attending a specialist setting reported better access to differentiated online educational sessions, supported by teachers familiar with their needs. One participant noted that small class sizes in the specialist setting facilitated a more manageable online learning environment, with fewer people on the screen and greater individual attention from the teacher.

Related to the lack of differentiation, another criticism from the YP, also reported by parents in studies by Canning and Robinson (2021) and Greenway and Eaton-Thomas (2020), was the excessive volume of work given by some mainstream schools. This study extends these findings to older YP, some of whom also reported feeling overwhelmed by the workload with the stress of managing it without support, causing some to completely disengage from home-learning. In several cases, parents intervened to protect their child's wellbeing by setting limits on workloads or allowed them to stop altogether. This parental intervention in response to excessive workloads among older YP had not been previously documented.

The National Development Team for Inclusion (n.d.) highlights four Preparation for Adulthood (PfA) outcomes that guide post-16 study programmes for young people with SEND: employment, independent living, community inclusion and health. Even those not following the PfA route, are often undertaking practical subjects, enabling them to work to their strengths. Study 1 discovered that YP were often enrolled on practical courses such as performing arts, motor mechanics, hair and beauty or catering, which were challenging to move online. YP had to contend with unreliable Wi-Fi, small screens and lack of support during the lockdowns. The YP watched a demonstration of an activity such as cooking or a hair technique and either followed synchronously or attempted it independently afterwards. YP with SEND struggle with executive functioning (Memisevic & Sinanovic, 2013) which is key for undertaking practical work. Therefore, guidance is usually required to be successful, which was problematic online. Access to a garage or salon was prohibited during the lockdowns, which resulted in a focus on theory which was both less interesting and more challenging for the YP to complete unaided. Additionally, at the specialist college, the YP

accessed supported internships in a workplace before COVID-19, with a job coach providing support. However, the work placements in this study ended abruptly at the first lockdown because they were in the hospitality industry which had to close.

This study discovered the subject choices of the YP with SEND post-16 put them at a greater disadvantage than their peers choosing academic courses. It is, for example, less problematic to study mathematics online than hair and beauty. Consequently, some YP felt their education was inadequate during lockdown. Furthermore, it was the more interactive elements of a course, even within an academic subject, that were removed from the curriculum due to difficulties with online delivery, such as science experiments. This has implications for the knowledge base and experience YP gained in their subjects during COVID-19, if parts of the syllabus were removed, unless these gaps can be remedied. However, the report of one YP about her experience on a science course at university showed this had not been addressed, as experiments post pandemic were still being shown as online demonstrations rather than students completing them personally.

The specialist college in study 1 had extended the course for another year in order to allow the final year students to make up the learning and workplace experience they had lost. However, the mainstream colleges, according to the YP, did not do this. The government authorised LAs to provide up to an extra year for students with an EHCP in year 13 if they had been severely affected by the pandemic (DfE, 2022b). This funding had to be applied for, but it is unclear how many took up this offer as this was not reported in the literature and anecdotally was not found to be common practice for mainstream providers. If YP passed their course, which during the pandemic was decided by the teachers (DfE, 2024e), they were not usually permitted to repeat that level course again. This was despite the YP not having had the full learning experience during the pandemic, thereby further disadvantaging all CYP in this COVID-19 cohort, with or without SEND. However, prior to the pandemic, the SEND education system was greatly stressed, creating an adversarial climate for parents to access support for their YP (Alghrani & Byrne, 2020). The difficulties experienced during the pandemic were amplified by their already disadvantaged state, meaning the YP with SEND experienced greater disadvantages than their peers without SEND.

Reliance on family for academic support exposed another area of inequality, as not all caregivers were able to provide this. Canning and Robinson (2021) discovered parents of the

younger children in their study felt they lacked skills for this role, and the YP's accounts in Study 1 corroborated this. Parents were not always able to support the older YP in this study, due to lack of knowledge, time pressures (for example, if they were working online themselves) or due to the YP's anxiety. YP reported that some caregivers advocated for them with teachers about the work and supported with home-learning, but it appeared that those without this support became more anxious about home-learning which subsequently affected their mental health.

Discussions about YP's sense of belonging and competence in their educational settings revealed preferences and challenges in their experiences. Enjoyment of education was strongly influenced by being on an appropriate course with correct support—an underexplored factor in previous research. YP expressed concerns about both too much support and insufficient support, both of which could hinder learning. Relationships with teachers and LSAs were critical, particularly in terms of feeling heard and involved in educational decision-making. Additionally, participation in extracurricular activities, such as drama, sports, or student union involvement, was associated with more positive educational experiences and higher confidence compared to peers who did not engage in these activities. While it is unclear whether participation increased confidence or confident individuals were more likely to participate, existing research suggests that extracurricular engagement enhances social skills and networks (Donnelly et al., 2019). Study 1 aligns with this finding, indicating similar benefits for YP with SEND.

4.4.2.2 Health

The majority of YP did not express much anxiety about becoming unwell themselves, but they were very concerned about family and friends. Several were worried about their parents or grandparents as they understood from TV bulletins that older people were more at risk. YP at greater risk themselves, such as those with Down Syndrome or pre-existing health conditions, were evidently more anxious about their health and were taking greater precautions than other participants. This aspect, however, was not emphasised in the interviews due to not wanting to distress or lead the YP.

Participants described the restriction of movement as a significant challenge during lockdown, as routines and social interactions abruptly ceased, negatively affecting their

physical and mental health. Most health services moved online which appeared to disproportionately disadvantage YP with SEND compared to their non-disabled peers, as also found by Ashworth et al. (2022c). An original finding in this study was that many YP found it difficult to express themselves over the phone, with some avoiding phone calls due to communication barriers. Participants in this study experienced expressive or receptive language difficulties, consistent with previous findings that people with ID frequently experience communication challenges (Smith et al., 2019). These challenges may have hindered communication during calls, leading professionals to engage more with caregivers than the YP directly, potentially resulting in missed opportunities to support the YP.

Additionally, Study 1 revealed a lack of mental health support during the lockdowns, and an absence of opportunities to discuss their experiences on their return to school/college. Some YP expressed gratitude for participating in the interview in this study, as they found it helpful to reflect on what had happened. While mental health support may have varied across settings, this study found that for the majority of those not attending school, no support was provided. Although there were reports nationally about the potential impact on a CYP's mental health during this time, such as from the Office for Health Improvement and Disparities (2022), there is a lack of information as to how this was addressed.

Anne Longfield, the Children's Commissioner, and the government advisor for post-COVID-19 recovery, Sir Kevan Collins, both recommended a child-centred approach with a focus on wellbeing to reintegrate YP back into education. However, Sir Kevan resigned over the much-reduced government offer which, against his advice, focussed on educational progress (Weale, 2021). The participants in this study admitted to experiencing challenges with attendance post-COVID-19, citing the reasons as anxiety or concern about COVID-19. The YP were not sure who to trust, in part due to information exposed about politicians' behaviour in the post-COVID-19 inquiry (Kettle, 2023), which showed that some were not following their own guidance. The issue of trust appeared throughout this study in various forms: when the news first broke, at which point there were worries about which media platform, news outlet or individual could be trusted, through to the end as the YP returned to school/college, querying if it was safe to do so. They were uncertain about who they could trust outside their families and expressed caution about believing any politician. This

disillusionment could potentially influence YP's behaviour in future health crises and may also undermine their views on democracy (Hussen, 2023).

For many, masks caused distress due to sensory issues or not being able to understand facial expressions, which was especially important for autistic YP (Clegg et al., 2024) and those with a hearing impairment (Young et al., 2024). However, experiences were variable, with this study exposing an interesting aspect of the YP's lives not reported in the early literature. A few YP had felt more relaxed behind the mask, and it appeared to reduce social anxiety for some YP. This aligns with findings by Clegg et al. (2024), who suggested that autistic YP may have experienced relief from autistic masking during this period. Masking is when a person alters their expression or behaviour to conform to societal norms. Additionally, adolescence is often marked by anxiety about personal appearance. A survey conducted by the Mental Health Foundation (2023) reported that 35% of YP aged 13–19 expressed body image concerns. This issue has become particularly pronounced in the era of social media (Papapanou et al., 2023) and so for some, the legitimate use of masks brought relief.

The disruption of routines impacted the YP's lives, with some reporting changes in their sleep patterns, aligning with the study by McCorkell and Lobo (2021) of seven YP aged 12–15, which found the YP often slept longer due to the lack of structure in their day. Study 1 extended these findings by exploring how older YP spent their time, and they mentioned listening to music, watching films, or using social media late into the evenings. Adolescents often naturally exhibit a delayed circadian rhythm, leading to later sleep and wake times, which can improve sleep quality and mood for those who prefer this pattern (Lang et al., 2022). Some YP favoured the absence of early starts and lengthy commutes during lockdown which suited their circadian rhythm. This shift may have enhanced their ability to learn, which is consistent with findings by Vidueira et al. (2023), and could partly explain why some YP performed better while learning at home.

Regarding physical activity, many YP found ways to keep active, such as daily walks which were permitted by the government (Johnson, 2020) or following the Joe Wicks workouts on YouTube. Wicks, known as 'The Body Coach', had previously provided weekly online workouts and on the first day of lockdown, he launched a daily 'PE with Joe' series of workouts for children, which continued until March 2021 (Wicks, 2020). However, some YP did far less physical activity during the lockdowns. This was evident among those who lacked

the motivation to exercise independently or had little family support to organise activities. This may have been in response to YP's low mood or boredom which has been found to affect motivation for exercise during the pandemic (Zhang et al., 2020). Additionally, some families faced increased stress due to the multiple roles forced on caregivers, as highlighted by Couper-Kenney & Riddell (2021) and Gillespie-Smith et al (2021). These findings expose the importance of support networks to facilitate physical activity, whether family, peers or external providers. Such support is important for promoting mental health and resilience, particularly during times of crisis (Andermo et al., 2020).

4.4.3 Relationships and relatedness (belonging)

Friendship was a key topic for many of the YP, showing its importance in their lives. YP with SEND commonly have smaller social networks compared with their peers, due to social and communication difficulties (Merrells et al., 2017). Furthermore, these networks are more likely to comprise of family, family friends and relatives rather than peer groups. Many of the YP in this study felt the lack of friendships intensely. The importance of friendships for the YP had not been conveyed in previous literature beyond reporting that YP missed seeing their friends during lockdowns. However, in this study, friendships were a vital factor for YP to feel they belonged in their educational setting, in addition to enhancing life satisfaction. Emerson et al. in their 2021 study found that "Loneliness was a particularly significant driver of poor wellbeing among people with disability" (Emerson et al., 2021 p.1) and certainly YP in Study 1 reported loneliness as a major factor in their pandemic experience. A further study by Emerson et al. (2023) compared young people and adults with and without disabilities in three waves from 2017 to 2020 and found those with disabilities were more likely to remain lonely than those without disabilities. ONS surveys during the pandemic found 40% of the disabled people responding reported feeling lonely at least sometimes, which was more than twice as many as non-disabled people (18%) (ONS, 2022a). In Study 1, YP also reported their loneliness was exacerbated when isolated from friends during special occasions.

Socialising with peers was important for most of the YP, despite it appearing superficial for some, in that interactions did not extend into time outside school/college hours. For some YP, social interactions at school were the only ones experienced outside their family, so when the schools closed, it was extremely isolating and had a wider impact than on their

education. Having acquaintances was seen as valuable, but YP still often strived towards what one participant called “proper friends”, which he described as someone you could phone up or have coffee with. Only a small number said they preferred to be alone, with some of those who faced friendship difficulties experiencing relief when remaining at home. Furthermore, there have been studies, such as that by Hutzell & Payne (2012) which demonstrated that bullying can lead to mental ill-health and isolation from peers, resulting in school avoidance. When this topic was explored in Study 1, avoidance of social situations and school anxiety did appear to be related to being bullied or a lack of friends and may partly explain why some YP preferred not to attend school.

Friendships were challenging for many of the YP to make, and they required support to gain and sustain them successfully, which was not always available. A 2021 study of adolescents in the Netherlands (Bernasco et al., 2021) looking at pre-COVID-19 supportive friendships found that they were a protective factor during the pandemic, but there was a decline in mutual friendship support as the pandemic progressed. Therefore, they surmised that long periods of isolation during lockdowns may well have had a negative impact on YP’s wellbeing, and friendship support should be a priority for any future crisis. As this was discovered to be true for non-disabled YP, it is potentially of even greater importance for those with SEND, with their greater social challenges. In Study 1, the data revealed that some YP believed teachers had not appreciated the impact on them of the loss of contact with their friends during lockdown. This was especially true for those who felt there was no closure at the end of year 11 when they were prevented from saying good-bye to their year group. The focus was on the academic, but this study showed that for the YP, their friends and families were equally as important to them for coping with the crisis. A strong connection to a community or peer group has been shown to be a protective factor against mental ill-health and Emotionally Based School Avoidance (EBSA) (Heyne et al., 2019), therefore friendships have significant implications post-COVID-19 for the health of YP and their ability to attend educational settings.

Caregivers are often the main source of support for YP with SEND in usual times and for longer than their non-disabled peers (Lippold & Burns, 2009). This was also found to be the case during the lockdowns, with greater reliance on family than friends for most of the YP as also found by Iovino et al. (2021). Therefore, caregivers are vital for this demographic, an

aspect that will be explored further in Chapter 5. Additionally, this has implications for those without supportive caregivers, as they need care via other channels. For this group of YP with little support at home, being told to remain at home was not an appropriate response.

YP reported both negative and positive impacts of the increased use of social media during lockdowns. For some, this expanded their worlds, connected them to others and allowed them to access learning in their preferred manner. This concurs with what Chadwick et al. (2023) found in their study of adults with LD and their digital use, but it was still considered second best to in-person activities. The participants in the Chadwick et al. (2023) study also mentioned barriers, such as not having enough ICT support, or the impact of their literacy or processing difficulties. Additionally, some YP in Study 1 felt digital use was a barrier to making face-to-face connections after the lockdowns, as they found it challenging to judge how to strike up an in-person conversation when people always appeared to be on their phone.

For a few YP in this study, however, nothing changed, as they were already living a socially excluded life due to their social communication difficulties or sensory needs (Broach et al, 2020). Furthermore, Wolstencroft et al. (2021) reported that some families believed they had already been undertaking social distancing with their YP with SEND before the pandemic, as they had to visit places at quiet times or could not visit at all due to accessibility issues.

4.4.4 Resilience and life satisfaction

The YP's resilience was evident in this study, despite the real difficulties around mental and physical health referred to in the scoping review (Paterson et al., 2023). It was clear some had found the pandemic immensely isolating, impacting their wellbeing, extending beyond the lockdowns. Resilience during the pandemic has been shown by studies of YP without disabilities but not to date for YP with SEND. This study found most of the participants were able to adapt, but with some finding it more challenging than others. As this study was completed in 2023, some time had passed since the lockdowns, allowing YP to report their experiences with hindsight. The disruption to the YP's lives came at a time when their brains were in a critical period of development (Larsen & Luna, 2018), when they were forming beliefs about themselves and how they fit into the world, with many seeking greater

independence just as the world closed down. Even though there were signs of YP adapting, for example, by using digital media, this closing down of their lives at a critical point in their development may still have unforeseen impacts in their futures (Crescentini et al., 2020). An example of this is the increase in EBSA reported in the UK post pandemic (Education Committee, 2023). School attendance issues, especially for YP with SEND, were increasing before COVID-19, however, they intensified during and post pandemic, with mental health often stated as the main reason for non-attendance. This problem is now of national concern (Education committee, 2023) and the government is responding by increasing mental health support in schools but also putting pressure on schools to fine parents of absent CYP (DfE, 2024b), with reports in the media of parents being fined despite evidence of SEND (Hall & Kersley, 2024). Absence is a multi-faceted issue, but non-attendance often indicates unmet needs of the YP (Connolly et al., 2023), therefore fining parents will not resolve this.

According to Deci and Ryan, meeting the three fundamental psychological needs of autonomy, competence, and relatedness facilitates self-determination, which promotes personal growth, learning and wellbeing. Feeling part of a community is a recognised protective factor that fosters resilience (Werner & Smith, 2001) and this thesis explored whether belonging or relatedness contributed to CYP's engagement with education and highlighted the potential interplay between community inclusion and resilience in shaping educational outcomes.

CYP have been shown to need a sense of belonging to their school/college to feel they are included and it is relevant to them (Osterman, 2000). They need to trust the staff and other students and know that they will be safe, and their needs met (Furman, 1998). When school does not meet the CYP's needs, an Alternative Provision (AP) placement is sometimes arranged, and these education providers focus on cultivating a sense of acceptance and belonging in order to give the CYP another chance at their education (Halse, 2018).

Belonging has a rather vague definition however, with CYP possibly interpreting it differently to adults around them (Allen & Kern, 2017). However, belonging always involves a relationship to others and a connection to them through a shared culture, language, activity or place (Halse, 2018). Therefore, the relatedness aspect of Deci and Ryan's self-determination theory overlaps with the idea of belonging in implying a connection to the people and place of the educational setting.

Deci and Ryan (1985) state that to satisfy people's basic psychological needs, they need to feel they have autonomy, a sense of belonging and feel competent. This is considered to be part of the broader concept of thriving rather than just surviving (Šakan, Žuljević, & Rokvić, 2020). However, a pandemic and national lockdown is likely to challenge the possibility of meeting basic needs due to government restrictions which purposely limit autonomy, could potentially fracture family and community units and make most people feel incompetent due to lack of knowledge. This study investigated whether the YP's belief about their life satisfaction had an impact on their sense of wellbeing and whether it was a protective factor during this crisis. A study conducted early in the pandemic by Vermote et al. (2021) with non-disabled adults, found that meeting these universal needs of autonomy, belonging and competence remained important for wellbeing during the pandemic. Research by Tay and Diener (2011) had looked at whether more basic concerns for safety and security would surpass those for SDT in a stressful situation and found this was not so. Basic security concerns of health, finances and environmental safety are linked to poor mental health if they are not met (Frankham et al., 2020) and are likely to have impacted people's resilience during the pandemic. However, Vermote et al. found that even when security needs were particularly threatened at the start of the pandemic, self-determination theory need satisfaction was positively correlated with life satisfaction and negatively associated with depressive symptoms, and also that need frustration showed the opposite connection. There was an indication in Study 1, that those who felt they had their basic needs met prior to and during the lockdowns had a less problematic journey through the pandemic and recovered more quickly afterwards, however further research is needed to investigate this link.

Well supported YP might be predicted to be resilient, but the data did not always support this. Resilience also depends on additional factors such as flexibility of thought, communication skills and independence (Werner, 2000), which YP with SEND can find challenging (Fidler & Lanfranchi, 2022). Additionally, some YP who usually embraced social interactions, found the removal of these particularly difficult, even with good support. Development of resilience also depended on the YP's type of impairment, support networks and personality as Yusuf et al. (2022) also found in their study of children with disabilities in Canada during the pandemic.

Autonomy is defined as having control over personal decisions and frustration of autonomy occurs when compliance is imposed rather than chosen (Vermote et al., 2021). It was good to hear that most YP did feel listened to at home and many also felt listened to within education, expressing they had some autonomy in their lives. However, although valuing the support they received, some YP reported they did not always feel involved enough in decisions made about them by professionals. Shogren and Shaw (2016) found that developing autonomy in adolescence plays an important role in outcomes into adulthood for disabled YP. They stated that early adulthood may be a critical time to develop autonomy, with choices being made about work, education and living arrangements. Clearly this is also true for non-disabled YP, but the path to adulthood for YP without disabilities has usually been more straightforward, as they experience fewer barriers to independence than those with disabilities and have more opportunities to experience autonomy (Jingree & Finlay, 2013). The experience of YP with disabilities once they leave education or turn 18, is a reduction in available support services, resulting in the barriers becoming more challenging (Young-Southward et al., 2017). However, as transitions now happen later for all YP, the difference between young adults with and without disabilities may be less clear until both groups are older than 18 (Salt & Jahoda, 2020).

Belonging, or relatedness, is the development of relationships which create a mutual connection with others and enable the individual to feel valued (Koole et al., 2018). Many YP felt they belonged in their previous or current settings, sometimes despite difficult experiences. Those who did not feel they belonged said it was due to lack of friends, being bullied, being on the wrong course or not having appropriate support. Lack of belonging can lead to feelings of loneliness which can then result in poorer wellbeing into adulthood (Emerson et al., 2023). Study 1 indicated that the sense of belonging for YP with SEND was often fragile and that the feeling of connection to educational settings and peers lessened for most if they did not attend school or college during the pandemic.

Competence is the third strand of Self Determination Theory (Deci & Ryan, 1985) and reflects the need to have just sufficient challenge and confidence in one's ability to meet that challenge to bring about growth (Vermote et al., 2021). Almost all YP felt less competent when asked to work online during the lockdown, however, their feelings of competence appeared to strengthen once they were back to in-person education, with more

personalised support, but only if they enjoyed their course. Study 1 also agreed with research completed by Webster (2022) which showed the right level of support was required for YP to feel competent in class. Webster found that if LSAs did too much or not enough for students, it could undermine the YP's confidence and beliefs about their competence which was reiterated by findings in Study 1.

4.5 LIMITATIONS

As with all qualitative studies, the findings of this study do not aim to be generalisable but to give an overview of the experiences of YP with SEND in the settings accessed, during the pandemic. Participants came mainly from only two settings with a further three who came from other settings who participated online. Only YP able to communicate for themselves were included in this study, which was a decision made to enable the YP's views to be heard directly. However, it also had the effect of screening out those only able to express themselves with support from adults, possibly because caregivers did not think the YP would be able to understand the purpose of the research. There already exists some research which has taken place with carers of people with PMLD during the pandemic, such as Bradshaw et al. (2023) who reported on the wellbeing of both people with PMLD and their carers. However, that research did not specify the experience of those still in education, leaving a gap for further research about the population of those with PMLD who were in education during the pandemic.

Most of the YP in Study 1 were interviewed at the college they currently attended, but there is the possibility that if they had been interviewed outside that setting, they may have been more forthcoming about their experience. However, it appeared they were relaxed in the familiar setting and welcomed the opportunity to express their views. There is also the issue of fading memories as the research took place after the crisis had passed. However, although some detail may not have been recalled, such as exact dates, most YP had clear memories of what happened and how it had affected them. It was difficult to get accurate responses to the type of education they had been attending during COVID. The researcher was conscious that it would have taken too much of a busy professional's time to have looked this up for every student prior to the researcher's visit and may not have been agreed by the setting's data protection policy. Although this information was sometimes given during the data collection it was not requested formally after it was clear that it was a confusing question for

the participants. YP did not always know what kind of setting they had attended and became confused when much of it recently had been home-learning. However, those interviewed online did know and provided this information.

Additionally, most of the participants in this study were of white British ethnicity, despite attempts at contacting areas where there would be a greater ethnic mix and advertising separately for participants of different ethnicities. According to Government statistics (ONS, 2022b), 82% of people in England and Wales are white, and 18% belong to a black, Asian, mixed or other ethnic group. Therefore, the participants do not fit the national profile, with 6.5% of Study 1 participants being of black, Asian or mixed heritage and 6.5% of other white heritage. Therefore further research is required to discover what the experience was like during the pandemic for those of different heritage.

4.6 CONCLUSIONS

4.6.1 COVID-19 measures exacerbated existing inequalities for YP with SEND

It is clear the educational provision during the pandemic for YP with SEND was not only not as good as usual, but also not as appropriate for them as for YP without SEND, partly due to the speed with which the measures were introduced. However, even after feedback and adaptations, the situation remained inequitable. Additionally, although it appeared appropriate to move therapeutic support online or by phone, it then became inaccessible to some vulnerable YP. There appeared to be little thought by leaders of how YP and their families were impacted due to their varying social and economic status, with negligible consideration given to those with SEND.

However, it is notable that a small minority of YP benefitted from some of the changes. A few preferred learning online, found it more interesting and were able to learn more with family support. Some benefitted from the reduction in stress due to not having to attend school/college, which is important, as this group finds attendance challenging which can result in poorer mental health.

4.6.2 Relationships and relatedness

The relationships of YP were key during the pandemic and this study highlighted that this appeared to be considered last, if at all, by those responsible for pandemic guidance. The YP would benefit from relationships and support being considered a priority, as other aspects of

wellbeing emerge from this foundation. The importance of relationships and belonging was acknowledged post pandemic, when in her speech at the Confederation of School Trusts Conference, Bridget Philipson the Education Secretary, said:

If we want to transform the outcomes of all young people with SEND, children need to feel that they belong in school. (Nov 7th, 2024)

4.6.3 Resilience

At the time of the interviews, some YP were living fulfilling lives, felt part of their educational community and were enjoying their course. They were taking part in extra-curricular activities, had friends and were supported by family. However, others were hampered by poor mental health, attendance issues, relationship difficulties and lack of opportunities, all of which impacted their resilience. The most significant factors for adjustment during the pandemic were caregiver support, friendships and whether their needs were met. The impact of their individual needs and personalities on their coping mechanisms was clear, making it imperative to appreciate there will not be one solution for all, and the perspectives of all parties need to be heard.

This study's aim was to hear the YP's voices, but it is also important to hear from those who care for the YP, either personally or professionally, which is the purpose of the next two studies.

Chapter 5: Parent perspectives of the challenges faced by families with a YP with SEND during the COVID-19 pandemic.

5.1 INTRODUCTION

The next phase of this thesis was to investigate the experiences and views of parent/carers of YP with SEND. As only parents rather than the broader category of carers were involved in this study, 'parents' is the term that will be used for the participants. This information was then used to establish greater understanding of how the pandemic was experienced for YP with SEND and those caring for them and to triangulate the data gained from the YP.

Parents are more involved and for longer with YP with SEND, due to the YP taking longer to mature and having to navigate greater difficulties throughout life (Jingree & Finlay, 2013). Therefore, although some of the YP would be considered adults, parents are still supporting and mediating for them to a greater extent than their non-disabled peers and they would be likely to know how the pandemic affected them. However, it is also possible that a parent may not know everything about a YP of this age, as they may not necessarily confide in them (Raw et al., 2021). Study 2's purpose was to add to the breadth of understanding of the YP's experience and to consider how the whole support network of family was impacted, as this would affect the YP too.

5.1.1 Research concerns

All four of the overarching research concerns for this thesis are again shown below and are addressed in this study but from the parents' viewpoint (exact questions for the interview are given under Procedure). In addition to finding out about their family's pandemic experiences, the author also wanted to find out how the parents had experienced their YP's educational journey. This was in order to explore their views on their YP's sense of belonging to the educational community and what impact that may have had on their resilience during the pandemic restrictions. It was also to triangulate the information gained from the YP during their interviews about their educational experiences. Question three in this study focused on parents' perspectives regarding young people's belonging and their perceived autonomy during the transition to adulthood.

The questions regarding the concerns for the whole thesis are below:

- How did YP with SEND experience the pandemic?
- Did the YP receive appropriate support and information?
- In what ways did young people's pre-pandemic experiences of autonomy, competence, and belonging shape their lived experiences during the pandemic?
- Were the families and organisations who delivered services and care to YP with SEND given the resources to enable them to cope with the pandemic?

5.2 METHOD

5.2.1 Participants

Eleven parents of YP with SEND were initially interviewed, but one parent was withdrawn before data analysis, leaving ten parents to take part in Study 2. This involved the parents discussing 12 YP who were recruited based on the following inclusion criteria:

- Parents of a YP with SEND between the ages of 14 and 25 during the pandemic
- The YP were on roll at an educational setting for at least some of 2020-2022

Parents of young people who participated in Study 1 were eligible to join this study and flyers were displayed in the settings the YP had attended. Two parent participants were parents of YP interviewed during the previous study. One heard about the study independently not knowing the two studies were linked and one parent responded after her YP informed her of the opportunity. Two of the ten parents (Referenced as Parent A and B) each had two YP with SEND who met the criteria for inclusion in the study, and it was difficult for them to separate out the family's experiences to just one YP, so the participants spoke about both their YP in the interviews and gave demographic information for both.

See Table 15 for information regarding the parent participants and their YP. Abbreviations in the table are as follows: AFAB stands for assigned female at birth; ADHD for attention deficit hyperactivity disorder; ASC stands for autism; LD, the abbreviation for learning disability, was used rather than intellectual disability as this is the term used within education in the UK and one the parents would be familiar with; SEMH for social, emotional and mental health; SLCD for speech, language and communication disorder and WB for white British. Additionally, MS indicates a mainstream placement and SSU a Special Support Unit at a mainstream setting.

Table 15. *Parent Participants and their YP Demographic Information*

Ref	Area of UK	Gender of carer	No of children in family	No of children with SEND	Gender of YP with SEND	Age of YP with SEND March 2020	Diagnosis of YPC	Where on roll during Covid	Ethnicity of YP	Duration of interview in mins
A	W	F	2	2	1.F non-binary 2. Trans Male, AFAB	1.16-18 2.14-16	1.SEMH & ADHD 2. ASC, ADHD & SEMH	1.MS college 2.School MS College MS	1.WB 2.WB	74
B	E	F	5	2	1.M 2.M	1.19-22 2.19-22	1. Severe LD, ASC, SLCD 2. Severe LD, SLCD	1.SSU at a MS college then supported internship at special needs college 2. MS College then gap year, then supported internship at special needs college	1.WB 2.WB	69
C	SE	F	2	1	F	16-18	Severe LD, ASC, Physical disability, medical condition	6 th form at special school.	Mixed Black ethnicity.	63
D	SE	F	2	1	F	16-18	Dyslexia	Private MS	WB	61
E	SE	F	2	1	M	16-18	ASC, severe LD, SLCD, sensory processing	Special college	WB	54
F*	SE	F	1	1	M	16-18	ASC	Special school	WB	66 (inclusive of questions as part of the professionals' study)
G	N	M	2	1	M	23-25	ASC	University	WB	60
H	SE	F	2	1	M	16 -18	ASC	SSU at MS school	WB	53

J*	SE	F	1	1	M	19-22	ASC	Other, specialist provision	WB	79 (inclusive of questions as part of the professionals' study)
**K										
L	N	F	1	1	M	14-16	ASC	MS school	Mix British and Latin American	75

* Parent F also takes part in the Professionals' study as Professional J and Parent J also takes part in the Professionals' study as Professional M

**Parent K was removed from the study before analysis so is not included in any of the statistics or findings

5.2.2 Measures

Online semi-structured interviews were chosen as the appropriate measure to use for the parent interviews. This type of interview, as stated in Chapter 4, allows for some structure around the questions asked, but also for flexibility.

The first interview was used as the pilot study and any issues with the questions or platform were noted. This interview was also included in the final analysis. However, later there were sometimes difficulties with the online method of the interviews, due to the multiple ways digital connections could malfunction, and it was not always possible to foresee these. There were occasions when initially the sound or camera was not working for a participant, which meant re-starting the platform several times. All were successful eventually and the parents were stoic in the face of these setbacks. It gave an indication of what they may have endured during the pandemic.

5.2.2.1 Interview questions

The questions asked of the parent participants are shown in Table 16. A more detailed list is given in Appendix L which also shows the prompt questions used if that was necessary.

There was some knowledge discovered through the scoping review of how parents had felt during the pandemic. However, the author also used the findings from the YP study to formulate questions asked of the parents, which to the author's knowledge had not been done before regarding the pandemic.

Table 16. Interview Questions for Parent Participants

Interview question for Parent/carers of YP with SEND.
1. How did you and your family manage during the pandemic?
2. How did you and your YP find out what was going on during the pandemic?
3. Did your YP continue to attend school/college?
4. How was school or home learning for you and your YP?
5. How much support was there from school or other professionals during the lockdowns?
6. How did the YP react to the restrictions and guidelines the government put in place?
7. Did any services you usually use stop or change?
8. How was returning to school/college?
9. Did they go to a new placement during the pandemic?
10. What do you think was the impact of the pandemic on the YP's learning?
11. Did you think your YP was vulnerable or at risk during the pandemic?
12. How savvy re social media is your YP now and did this change over the pandemic?
13. How important do you think friendships are for your YP?
14. Were there any difficult situations to deal with during the pandemic, like dealing with a death or illness?
15. Did they miss any special occasions during the pandemic?
16. How has the educational journey generally been for your YP?
17. Would you describe your YP as happy and thriving?
18. Is there anything else you would like to tell me about your experience with your YP during the pandemic?

Discussions with the parents purposively encompassed their own experiences as well as that of their YP and emerged spontaneously as the parents' experiences were bound up together with their families and would have been difficult to separate. A parent has a major influence on their YP in usual times; this is especially pronounced for YP with SEND, for whom consistent parental engagement and home-based support are vital for emotional stability and educational achievement (Lamb, 2009). Additionally, anything that impacts a parent will also have an impact on the whole family (Bronfenbrenner, (1979). This impact was potentially heightened during the pandemic due to compulsory familial proximity combined with increased role demands and it was important to investigate this in order to appreciate any influence on the YP during and post COVID-19.

5.2.3 Procedure.

5.2.3.1 Ethics

Ethical issues are present with any qualitative study and a submission for ethical approval was made and gained for this study from the Tizard Centre ethics committee at the University of Kent on 24.07.2024. (The letter of approval can be seen in Appendix M). The ethics committee also endorsed the materials which were subsequently used to advertise the study, inform the participants and gain consent.

Confidentiality was assured to the parents, apart from in the unlikely circumstance that the participant told the researcher they were either at risk of harm themselves or to others, or that their YP was at risk, when the participant's Local Authority Safeguarding Lead would need to be informed. They were also informed of their right to withdraw from the study up to the analysis of the data. One participant was removed from the data before analysis. This parent asked to see the transcript after the interview to check what they had said and the parent expressed reservations. The concern was not with the accuracy but about the candour they had displayed during the interview. The parent was reminded they could withdraw from the study at that point, but no response was received regarding this. Alternative options were suggested that they could remove the parts of the interview they were concerned about, or they could remove consent for quotes to be used, or both. However, despite reassuring the parent, eventually their data was removed due to receiving no response as to how they wished to proceed, as it would have been unethical to proceed in these circumstances when reservations had been expressed, despite not formally withdrawing from the study.

None of the parents had been individuals the author had worked with as part of their role as a Special Needs Information, Advice and Support Advisor for a Local Authority as this could have created an imbalance of power within the interview dynamic (Anyan, 2013).

5.2.3.2 Recruitment

Potential participants were initially contacted via connections made with schools and colleges during the previous YP study and by word of mouth or snowballing. These contacts were important as parents understandably had concerns around trust and confidentiality, and these more personal contacts could be seen as a trustworthy source. Charities and

organisations who supported families with CYP with SEND and Parent/carer Forums were also contacted. Lastly, closed online parent support groups were contacted, although this did not prove fruitful. Although many gatekeepers, for example college learning support managers or principals, were enthusiastic about the research, and advertised it via their newsletters or by displaying flyers, few participants came forward in this manner. Some managers were apologetic about this lack of response but explained that their parents just wanted to forget that time and move on, and some who inquired about the study did not follow through as they were concerned about emotive issues that may arise and were unwilling to return to that time. Some parents said the story was not just theirs to tell and they would need to seek their YP's permission which resulted in YP being aware of the interviews but also resulted in a small number of potential participants not following up. It was not then known if that was a result of the parent's concern or if their YP had vetoed involvement.

A flyer was developed to advertise the study at colleges and to publish in parent carer forum newsletters (See Appendix N). An information sheet was then sent to any interested participants who requested further information about the study (See Appendix O) with the opportunity to contact the researcher for more details. The information sheet explained the purpose of the study, together with its risks and benefits and what the participant would be asked to do. Information about how the data would be stored was given and that data would be made anonymous at the transcription stage and the recordings then deleted. A consent form and demographic form was then completed if they wished to participate (see Appendices P and Q).

Once the participant had offered to take part, a date and time convenient to both parties was agreed and a consent and demographic form were sent, to be returned before the interview date. These forms were either emailed or a link sent via Google Forms to the participants, depending on which format they preferred. The consent form was to ensure that any questions from the participants had been answered, that they understood the purpose of the study and that they were freely offering to take part. There was an opportunity on this form to agree to take part but to not agree for their words be quoted, which one participant opted for.

A debriefing session was available if any parent wished to talk further about the issues raised during the interview, and resources were offered should they require further support or information afterwards (Appendix R). A follow up email thanking them for their participation and a form for giving feedback were also sent (Appendix d(i)). Time was allocated at the end of the interview for a short off the record conversation, to allow for any further comments or questions.

5.2.3.3 Data collection

Data collection for both the parents' and professionals' studies spanned September 2024 to July 2025. This timeline was extended due to participant engagement challenges and university institutional delays. An online interview was chosen as a convenient method for both parties. During COVID-19 using online methods to connect with others became more commonplace and subsequently a broader range of people were familiar with it. It was felt this would be a suitable way to connect with busy parents at a time of their choosing as well as to increase the geographical reach of the study. This indeed proved helpful, with participants from a wide area in the UK taking part. Microsoft Teams was chosen as the platform for the interviews as this was considered secure by the ethics committee. The interviews were recorded via the integral recording software on the Teams platform which included both video and sound. This made transcribing the interviews easier than those completed via the voice recording device used for the YP in-person interviews. Additionally, the parents did not have speech difficulties which had made the YP interviews more difficult to transcribe, but accents could sometimes present issues for the accuracy of the software but were able to be overcome by careful listening to the recording together with watching the video.

5.2.4 Analysis

Braun and Clarke's (2019) six phase reflexive thematic analysis was used for data analysis, which has been explained in more detail in Chapter 4. All data was transcribed, anonymised and uploaded to NVIVO where line by line coding took place. Codes were then collated into potential themes, reviewed and named. There is more than one way to code or name themes even within one dataset, but the codes and themes finally chosen reflect the

purpose of the study and the connection between the two studies while also giving space for new themes to be recognised.

5.2.5 Reflexivity

As a parent of YP with SEND, and as a professional working with families of YP with SEND, the researcher acknowledged that any prior knowledge or assumptions could influence code selection. Again, a reflexive journal was used to document the researcher's emotional responses, and those of the participants, which included the challenges of listening to distressing accounts from distressed parents at times. However, far from compromising objectivity, the researcher's empathy and compassion supported the interviews and enabled deeper engagement with the participants than might otherwise have been possible.

5.3 FINDINGS

Four main themes were derived from the analysis of the data. These were Personal and Home life, Education, Wellbeing and Post COVID-19. The diagram below shows how the themes are arranged together with the sub-themes.

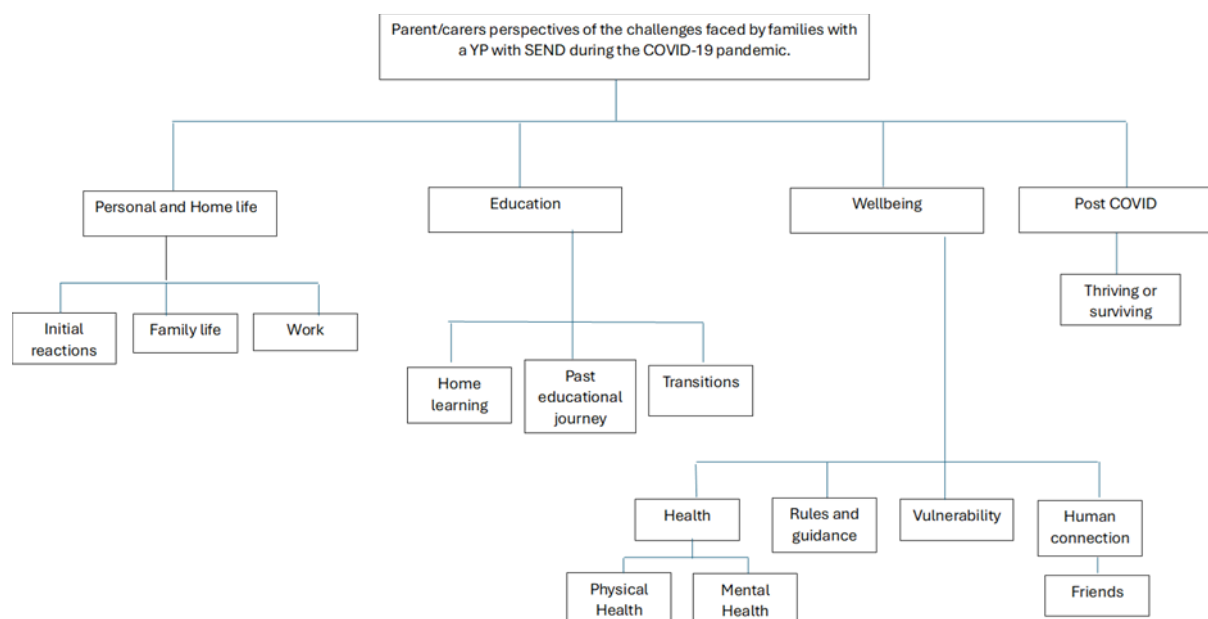


Figure 5. *Diagram of Themes and Sub-themes for Parent Study*

5.3.1 Theme 1: Personal and home life: *The impact was huge on us as a family. (Parent C)*

Many parents depicted their family life during interviews, describing how difficult it was in usual times to meet their family's needs, juggling work, siblings, older parents and their disabled YP's needs. They talked about the sacrifices that had been made along the way in order for their YP with SEND to succeed. These included one parent moving to another county during the school week to find appropriate education for her children and other parents had to change their work patterns:

I mean, it's not, not any more than I juggle them already. It's been that way for a while since he was little that we made a decision to operate in that way - that I went full time, and he (husband) stepped back. (Parent F)

Most parents advocate for their children, but these parents appreciated there was a greater necessity for this group than for typically developing children, as advocacy was required for longer, even when the child has reached adulthood. They highlighted how isolating that experience could be and the impact it had on siblings:

I can look back now and see that, you know, so much of my time and energy and effort was sucked into the boys (with SEND) that he (son without SEND),....yeah, he definitely missed out. And I think that is having an effect now. Or has done, he struggles with his mental health. (Parent B)

When the pandemic started these families were therefore already under considerable stress:

And I think you know, as a parent of a disabled child, who works, as I said, you're always juggling things as a parent anyway. You're juggling things. And I suppose, you know the onset of COVID and going into lockdown just exploded that out of the water. Bigger than anyone could have imagined. So it exaggerated all the challenges that you had anyway, with keeping all the plates spinning, it was suddenly made much worse by COVID and exacerbated everything you were trying to do in your normal daily life. (Parent E)

5.3.1.1 Early days: *I think mentally it was hard for them to think, when will it ever end? (Parent D)*

The details of exact timings were no longer recalled easily by parents in late 2024/early 2025, but the overall impact on them was clearly recalled and reported as “stressful” or “shocking”:

If you look back to the very first lockdown in March 2020, you know, I remember back then that we were genuinely worried that the virus would kill us. You know, there was

that kind of feeling at the beginning that if you caught it, there was a good chance that you were gonna die. (Parent B)

For parents of YP with profound disabilities, changes occurred to their support systems very suddenly:

I can't remember how we found out, to be honest with you, I really can't remember. But I do remember realising that that Friday there was going to be no school for her. There was going to be no respite care. She was going two nights a week at that time. There was going to be no carers available to her that she was going to be literally 24/7 with us from that Friday evening. (Parent C)

Trying to explain this new phenomenon to YP with significant difficulties was challenging but parents found different approaches to convey the seriousness to their YP in a way that was appropriate to their level of understanding, using simplified language and the picture of the virus on television. Some avoided watching the TV bulletins about the pandemic with all the numbers being shown of those sick or having died and instead relayed the information they thought necessary to their YP. Other families watched the bulletins together every day and it became a ritual to alleviate the uncertainty:

Whether that was a good thing or not for the kids, I don't know, whether that looking at that maybe that wasn't necessarily helpful for them to hear the data, I don't know, but it just became a way to punctuate each day, because otherwise the days - it was important to have structure. (Parent D)

There was no universal experience of families during COVID-19, and some participants were very aware that their living situation meant the experience, however difficult, was better than for others. Parents expressed gratitude for having a garden or space in their homes, especially if they knew friends or family who lived in more cramped conditions. One parent experienced difficulties connected to the cramped living space in their flat when they needed privacy for work and their YP was learning from home. She felt her YP spent too much time in a single room with the door closed which she felt was not good for the YP to isolate himself further. Some parents purchased resources during lockdown with their own money and one redirected funds from a social care budget originally given for respite care, which was unavailable during the pandemic, to purchase items to support their YP:

Yeah, she had a personal budget, and of course I couldn't use the budget for anything, so I just bought loads of things off Amazon.... for example, I bought a whole lot of paints..... I said that was the only way that I could, you know, keep her busy was doing loads and loads and loads of arts and crafts with her. (Parent C)

5.3.1.2 Family Life: *It was a very mixed bag. (Parent A)*

Parents described a wide range of experiences, from the extremely challenging to those who had managed well. Even within one family, the experiences of siblings often differed due to the different needs of each. However, some parents of YP with greater difficulties experienced huge challenges in their home life:

We'd had four months of extreme, extreme behaviour from her because she was so confused about everything because literally everything stopped overnight. She, and this is where the trauma comes in, she broke everything inside. She (parent breaks down in tears), she smashed everything up. She broke every, every chair at our house. She smashed the TV and then, you can't blame her, she had no idea what was going on. Sorry, I didn't realise it would affect me this much. I mean, she literally, she literally broke everything inside because she had nowhere to go with this. (Parent C)

This behaviour then had a big impact on the rest of the family:

My son was so traumatised by YP's behaviour he wouldn't even come out the room anymore (parent breaks down). He saw the impact on us. He saw how I had to do everything for YP. Some ways he sort of says, oh, you, you know, you ...I was always for YP and I wasn't there for him. I wasn't there for him. I couldn't be there for him. You know, I mean, my son, my husband was, but I couldn't be there for him. I couldn't leave YP out of my sight because I just didn't know what she could do next, you know. So there was a huge impact on our relationship, on everything. (Parent C)

Other parents also reported difficulties with their YP's behaviour which included feeling angry, bored or frustrated. Some parents said this was due to a lack of understanding of the situation or as a result of being unable to continue their routine. Some YP re-directed their feelings into productive activities, especially if parents had the resources and time to support them, but this was not possible for all, due to the YP's personality or disability. Trying to create variety in the YP's life was difficult for some parents due to the YP's behaviour:

I then eventually didn't take her anywhere because I was too afraid to, because if she melted down somewhere where I couldn't get out of somewhere and then people were still pretty judgmental. I mean, I only took her to places where we could just go for a walk, you know, where we could just go, you know, to the beach. Yeah. But that was really hard. (Parent C)

Parents became the educators, leisure coordinators, cooks and conductors of family life in an even greater capacity than usual which was sometimes further heightened by location:

It was a very, very narrow life and it was completely dependent on me. I had to take him to everything wherever he went because, because geographically we live in the middle of nowhere, so there's no buses. (Parent B).

Tensions occurred at times between YP and their parents, in reaction to the constraints and uncertainty. If a YP was able to go out independently, this also brought difficulties due to different interpretations or adherence to the guidance, especially if they lived near a county or country border where the guidance was different:

But as time went on, they quickly saw other people sort of meeting up, you know, limiting to six and all that sort of thing. Whereas we were saying, well, that's not what our advice is here. We're not supposed to be seeing anybody outside of our, who lives in this house. So it caused a lot of difficulties within the family. (Parent A)

This meant parents then felt unable to see other more vulnerable family members if their YP had been mixing outside their immediate family due to the risk of infection, especially at the start of the pandemic when the virus was unpredictable. However, many families were stoic. They may not have liked the constraints, but they made the best of the situation:

We just kept home a safe place. We looked after each other. (Parent F)

There were also significant changes and difficulties at home due to education moving into the home, but more will be discussed about this under Theme 2 Education.

For some families, there were definite benefits of the lockdowns, giving more time to spend together. It also gave time to pause with some unexpected outcomes, as these parents reflect:

But my youngest at the time was coming up to 16 when the first lockdown happened and it was an absolute godsend at the time that it came, because it just took away the daily intense pressure that he was under and allowed him to reset. (Parent A)

He stopped taking his ADHD medication, and we didn't force it because he wasn't at school. He only ever taken it in school term times and he'd always been very small for his age so he was under growth specialists at the hospital. [...] And actually, he grew 6 centimetres in lockdown! (Parent F)

Those who had access to the outdoors, or had hobbies particularly benefited, as more time was available for these activities. For some, the time at home was a chance to develop new skills such as cycling independently or making videos to send to grandparents.

A key moment in a YP's educational life is the end of year celebration or prom, which was cancelled for at least one year. There was no opportunity for year groups to say goodbye to each other which was particularly hard if they were leaving that placement:

So they never had closure on year 11. And that was quite sad. I think that took quite an emotional toll on them, actually. (Parent D)

There were also milestone birthdays and family celebrations that had to be adapted, with some settings and parents showing great creativity, with personal doorstep deliveries or outside entertainment. However, for some families it was a relief not to feel they had to celebrate, especially if their YP did not enjoy it, and they were able to just have a takeaway at home.

5.3.1.3 Work: *We all had to kind of adapt, didn't we, to a different way of working (Parent J)*

All parents' work lives were disrupted, but some were more affected than others. If parents were already used to working from home, they were prepared to some extent, but not necessarily for full time working from home. However, for most, anything that was usually in person went online, requiring adaptation to unfamiliar digital platforms. Additionally, one parent was made redundant during the lockdowns, and one was furloughed. Working online was seen as efficient, but was also more intense with more meetings with less time between them:

And whereas I've been used to going out to schools and various other places for meetings and things like that, I was then all of a sudden, I was in at home just doing all of these meetings like this. You know, literally finishing one conversation and then jumping onto another meeting and then jumping on to another meeting. (Parent J).

Those parents who worked in education or with children and young people were particularly impacted due to coping with the high stress levels of their work alongside their now full time caring and educational responsibilities for their YP. If both parents were working from home, this created additional difficulties:

Yeah, so stressful would be the first thing I would say. Both I and my husband were working flat out full time in jobs in higher education. I was also director of student experience, so I also had all the stress of our university students going through what they were going through. So, I had a very emotionally demanding role as well as the work of being a lecturer and academic. (Parent E)

If other family members were available to help support the YP, this eased the challenges:

My daughter picked up some of that, in terms of just being able to be with my son and do some activities with him and things like that. So, if she hadn't been home, or if we didn't have another child involved, it would have been even harder. (Parent E)

Parents described how difficult working was in usual times and they felt that the supreme efforts they made to work normally was not recognised. If a parent sought support from their workplace to try to ease the pressure, this was not always responded to positively, due to the lack of understanding of their situation:

I did ask for help from work to say, you know, this is difficult, and I had no help. I had no support and that, that was quite shocking. Nobody ever checked in with me to see how I was doing. (Parent E)

Boundaries between home and work life were blurred due to working from home while their YP were present, which would not usually have happened when their YP had been at school. This created anxiety about their YP overhearing distressing conversations:

I remember sitting like this with headphones on and having conversations with people and being so aware that he was literally 100 yards, less, 50, 20 yards away and he could hear what I was saying or just the, just the worry that it would seep into the house. (Parent F)

For some, financial difficulties resulted from not being able to claim through the Government furlough scheme. Additionally, the nature of some work meant working from home was not possible and some work closed entirely, suddenly leaving people without any income:

The impact financially on us was really hard [...] So of course, in this, in all those months, filming and general aviation completely shut down, there was nothing, nothing at all. [...] Everything shut down and he [husband] never really recovered from it afterwards financially. (Parent C)

5.3.2 Theme 2: Education: *He was just left to his own devices, really. (Parent J)*

When the lockdowns began, most schools attended by the participants' children closed to the majority, despite eight of the twelve YP having an EHCP. Initially only one of the participants' children remained at school despite the government saying that YPs with an EHCP could attend:

And he was then home full time and although many people said to me, oh, you're fine because children with special needs can go into school, no they can't in a special school because everyone has special needs and they haven't got, staff have to deal

with their own, you know, things going on. And there weren't enough staff to have children in school. (Parent E)

Parents understood this decision had been made as a result of the staff themselves having children who were at home and issues of risk due to their YP not being able to socially distance. This resulted in only a few children whose parents were frontline workers such as doctors or nurses being accepted initially. The parent of the one YP who was permitted to attend school from the start decided not to send him, due to his younger sibling not being allowed to attend as she felt it would be unfair to send just him and he was not keen on school anyway.

The communication from settings varied considerably, with some parents having regular contact and others feeling abandoned. Parents who had contact from school found it reassuring to talk about their situation and felt the school was monitoring how the family and YP was doing, especially as this was often the only contact with any service they had during the lockdowns:

I knew I could ring up his class teacher and just, you know, talk about what was happening for him and how difficult it was. So I felt like there was positive support coming from there and we could reach people. (Parent E)

As a result of this contact, some YP were then allowed back into school if the school felt they were not engaging or the family was not coping. However, some parents whose YP had not been offered a place but knew their YP was eligible and needed to attend, often had to battle for this, either via their social worker or with the school itself, which was stressful. Additionally, the definition of a critical or key worker, which during the restrictions were those whose jobs were essential to the pandemic response and the functioning of society (DfE & Cabinet Office, 2020), was problematic, as some found themselves arbitrarily on the wrong side of the line despite their YP's level of need and the demands of their job:

And then gradually, obviously some people who had protected jobs, their children could go in. But while teachers' jobs were protected, university lecturers' jobs weren't. (Parent E)

Initially, parents and YP struggled to create a new routine without any opportunities outside the home, but in time this was achieved. Some used visual timetables to reduce uncertainty by showing the YP the day's plan. However, this was easier for parents who did not have demanding work commitments or who had greater educational knowledge. If the YP's

education was going well before the pandemic, the parents were upset that the enforced break meant the YP lost the continuity and motivation they had prior to the lockdowns, which they did not always regain. This disillusionment appeared enhanced if the setting did not contact the YP or provide appropriate work or activities:

He was very much left high and dry as well in terms of what, what he was trying to do. He [had] really enjoyed it. So it was a real shame that that sort of completely stopped. So there was nothing, they weren't able to really produce anything remotely, it just sort of shut down. (Parent B)

5.3.2.1 Home-learning: *To be doing learning at home instead of at school was very challenging. (Parent E)*

When the lockdowns began, education settings were expected to provide learning at home. There was great variability of the quantity and mode of delivery settings provided, with some taking time to develop a suitable offer, if they ever did, whereas others were able to start immediately the lockdown started, which included both private and mainstream settings:

That first day of being locked down was straight away. "Don't worry everyone. We're going on to real time remote learning", so I think that's the thing, because obviously up at (school), they are advanced with the technology, and they've all got Chromebooks because it's like part of the uniform. You have to buy them one. (Parent H, SSU mainstream)

Some special schools rapidly provided work for the YP to do at home, whereas others provided very little or nothing for the whole duration of the pandemic:

There was nothing, absolutely nothing. All we got, I think at one point, a (short breaks charity), I think, delivered a little like package of colouring in and things somewhere along the line, in the four months we got this little package of, you know activities but not from the school. (Parent C)

Additionally, less traditional settings, such as the educational offer at a local football club, were far slower to move to online learning, mainly because many staff on that programme were redeployed in the community, making it impossible for them to spend time creating a replacement curriculum:

It was kind of like radio silence for ages and I must admit, I was really quite disappointed because, you know, because of the fact that, it was the football club,

and obviously they, you know, YP had an EHCP, so he was classed as a, you know, a child that was quite vulnerable. (Parent J)

The participants all managed to create space for home-learning, even though it was not always ideal, and the YP were often initially in shared spaces so the parents could see what they were doing and support them. However, some realised that this was not practical longer term and allowed the YP to study in their bedrooms if they were able to do so independently but with regular checks. One parent mentioned it was difficult to monitor what her YP was doing behind the door and knew he was spending too long on the work and becoming overwhelmed. Some YP were not able to engage with home-learning at all however, and struggled with the concept of school invading their home and their parent becoming the teacher figure:

School is school, and home is home. Always has been, never, never did homework, and they never set homework. (Parent F)

I suppose YP kind of, oh no, instead of mum being like mum and there to support, now she's suddenly, oh, gosh, she's moaning at me. She's become the teacher! (Parent H)

Additionally, within the home environment there were more distractions to contend with which were difficult for parents to monitor, creating tension:

Mum, you're getting really annoying. Can you just leave my room now? You know, I'm trying to do this, you know? And I'm like, are you doing it? You know, because there's too many distractions at home. You know, when you're not set up for that, you're set up for doing a bit of homework, not actual full thingy you know. [...] So he'd be connecting up a circuit board, and then I'll be like, going in at YP, what are you doing? This isn't your lesson, you know. Oh, I'm just fixing this, you know? So it's quite hard. (Parent H).

The participants' YP had access to a device to learn on and parents were aware their schools provided for those without devices or internet access. However, one family who lived remotely, found their Wi-Fi was not sufficient for the whole family to be online, resulting in the need to move around the house to find enough signal or take turns to use the computer.

It took time for providers to work out how to deliver home-learning successfully as most had never used online learning platforms before. Meanwhile, parents spoke of physical packages of work being delivered to their homes or using videoconferencing to keep in touch with YP. This was helpful for some, and particularly so if the online groups were small and the YP had

the chance to interact. If the groups were large, parents said the YP rarely unmuted or asked any questions and just received the lesson passively or refused to take part. However, sometimes the use of videoconferencing was a barrier to inclusion for the YP:

I think she joined in once, but she was very confused by it all. She had nothing to contribute. So, because she can't speak. So, I found that when we were online with the rest of the class, those that could talk were just taking over everything. And they never checked in on YP, so eventually I didn't even let her go online eventually because she was sitting there trying to go aah, aah, she was trying to communicate, and they just ignored her. They just muted her and that upset me a lot. (Parent C)

Participants mentioned ways the schools supported them as being helpful for some but not all. In one school a TA contacted the YP every school day to check on him and see if he understood the work and was engaged with it. However, this support was via messages within the online learning platform which was difficult to navigate and the YP needed reminders every day to look at it. Receiving a phone call to check on their welfare was also not always appreciated due to YP's communication needs and aversion to speaking on the phone. Parents said if the school rang to speak to the YP, the YP did not always want to speak to them.

As mentioned, the mode of home-learning varied. Some placed work on the school intranet to be completed and emailed back to school. Others pre-recorded presentations by the teachers to be watched online with homework linked to this. Another method was a live lesson which sometimes was interactive, with the chance to take part as the lesson progressed. For some schools, the work was set and could be done whenever the YP wanted to complete it, allowing them to create a personal timetable whereas others expected them to be online at a certain time each day for a fixed period. Additionally, there were schools who ran the school day online as though the YP were still present in person, which was a much more intense experience than usual. The methods also changed over time as schools became accustomed to teaching online, but both parents and YP found the platforms complicated to navigate:

They then tried doing Teams where people would log on and the teacher would be there and it didn't work. There was all, it was, it was all in like documents at the side. So, I mean, I couldn't work it out. I had no clue what was going on. So how he, had no patience for any of it. So he just wouldn't... He would just sit there and not say anything. (Parent F)

Additionally, the intensity of online education created difficulties which were expressed in the YP's behaviour, with frustration building up by the evening. One YP became very obsessed with completing everything perfectly and would not send work in unless it was flawless, resulting in too many hours spent trying to finish work which was often never sent in as he never deemed it perfect enough.

One YP attending a Special Support Unit in a mainstream school was still expected to complete the same work as everyone else, whereas if he had been in school this was not expected and his parent was unsure how much work was realistic for him to complete:

Would he be having a bit of a brain break now, would he not? [...] But would he normally be doing that amount of work bearing in mind quite often he'd be in the unit? (Parent H)

For more academically able YP, having work online meant it became less accessible, as it became all about reading, making notes and listening with no practical sessions. These were all skills with which many of the YP struggled. There was also little opportunity to talk to teachers and ask questions. There were some YP who had very little home-learning in the first lockdown in spring 2020, because if they were in years 11 or 13, the external exam years, they were sent home with nothing particular to do, with the uncertainty of whether exams would run or not. Eventually it was decided to replace exams with teacher assessments, but this meant that their education then ended abruptly:

They were year 11 and year 13. So in both cases online learning for us as a family was very, very short lived - well they both did online learning subsequently, but at the at that original stage, their, basically, their schooling stopped. (Parent A).

Later on, when these cohorts then sat external exams for the first time, they felt unprepared and anxious. Some parents mentioned their YP had done better in the teacher assessments and some commented they had performed worse than they had in exams. However, teacher assessments were a less stressful experience for some, whereas others who preferred to leave study to the last minute did not do so well, as assessments were based on work completed earlier in the year.

For those with more complex difficulties, online education was not feasible at all, because they needed more support than the family were able to provide, they lacked engagement with it or as a result of behavioural difficulties within the home:

And then towards June, I called the social worker, and I said she's got to go back to school. Is there any way she can go to school and the head teacher said no, she couldn't go back. Not even for a day she couldn't go back. And I just said to this, the social worker I said, well, it's reaching a point we have to do something because we're not managing at all. She's just trashed our entire house. You know, we're not managing, we have to do something. And she eventually got her into school in July. (Parent C)

However, the days that were then offered were not consistent, which created difficulties due to the unpredictability of the offer and lack of routine. Other schools, who had more contact with parents, could see the challenges families faced and were proactive:

He really just withdrew. [...] He was allowed back under the keyworker scheme because they recognised that he wasn't engaging, he wasn't thriving. There was a worry about him, and I was worried about him. (Parent F)

Parents with more than one CYP undertaking home-learning found it more challenging, even if they were not working themselves and even if the siblings did not all have SEND. This was due to different methods at different schools for home-learning, with diverse devices and online platforms being used, making it more onerous to navigate:

I had to be at home anyway because obviously the salons being shut, but it was very tricky because obviously (sibling's) work was all set in the morning and you had till the end of school day to complete it. So that could be done whatever time you know, we just obviously got on with it but it wasn't so pressurised, whereas obviously YP's been exactly like a school day. So it was a lot more pressurised, doing it for the two of them. Obviously, it would have been easier if it was just one of them. (Parent H).

5.3.2.2 Past educational journey: *It was an absolute struggle and fight every step of the way. (Parent B)*

The exploration of YP's educational journeys offered context for coping with disrupted schooling and belonging. Parents reported diverse experiences but those of autistic YP reported the greatest difficulties in finding suitable settings, though most families faced challenges. Choosing the right school was vital to the child's success, not just academically but also socially and emotionally. Parents often chose schools, especially initially, on what was considered a 'good' school, but a good school did not always mean a good school for their child with SEND:

Because the local school is known to be the best in the area, but of course the best in the area is what churns out the best exam results and we now know that it was not the best environment for either of our kids. (Parent A)

Furthermore, finding appropriate education meant that the YP often had to change schools more often than their peers, with Parent J stating that “*by the age of seven, he'd had five schools*”. This was sometimes due to the parent removing their child from an ineffective provision, but sometimes because the child had been excluded or asked to leave by the school. CYP had often started in a mainstream class with a TA, then moved to a Special Support unit and then to a special school, sometimes with home education or no education in between, resulting in a fragmented education. Some parents had considered home education but had reservations about the benefits or due to their own work commitments.

For many of the YP their education had not been enjoyable and even in this small group of participants, there were accounts of YP having some parts of their education alone, as needs were not met in a mainstream classroom:

He would be outside in the corridor all the time, so just him and 1:1. And he had a desk in the corridor. Just him and the 1:1. And he spent a lot of time under the desk, sitting under there. (Parent H)

These challenging educational experiences meant that more input was required of parents to enable their YP to achieve academically. Nine of the 10 parents mentioned significant impacts on their home life of supporting their YP's education, varying from helping with homework to moving the family across the country to access the right school. Parents reported spending many hours supporting YP, finding appropriate placements or trying to get adequate support in place, adding to the stress of parenting a YP with SEND.

However, the parents were also quick to acknowledge when an educational setting or professional had met their YP's needs:

My fear of special school was that they would just be sort of patted on the head and, you know, sat down. But they are absolutely on it with moving them forward, ensuring they can be independent. So, I feel very fortunate that he's been in that place and I know that's not a general experience, so you know. (Parent E)

However, some mainstream schools were felt to have a lack of knowledge of SEND, especially if the YP were not causing trouble:

I think there was an incredible lack of knowledge in both school ...primary school and secondary school of neurodiversity and mental health challenges. And it makes me quite cross, to be honest, because I now know that the knowledge was there. I didn't have the knowledge, but I was just a mum. (Parent A)

5.3.2.3 Transitions during COVID-19: *It was more of a rota of different children on different days. But I think he still preferred it to being at home full time. (Parent E)*

All YP experienced transitions during the pandemic which included moving up an academic year, starting a new placement, leaving education or finding work. They also experienced the transition back to in-person education or to respite care. For some, the return to school was welcomed as the YP had missed the routine, their peer groups and teachers. However, initially the return was not a return to customary schooling as only some children returned on a rota basis before the full opening of schools. This could be problematic due to changed class groups and attendance days, resulting in the YP not comprehending what was happening. However, some YP did well with the smaller classes when the schools were not fully open and developed stronger relationships with the teachers and other children attending. For others, returning to school or respite care was challenging because they had not left their family for a long time, resulting in behavioural difficulties possibly caused by separation anxiety which developed after the restrictions ceased:

She wouldn't go to respite care. She got to the point where every time she got in the car with me as I was taking her to respite care for example, she would then pinch me, hit me, grab the steering wheel, pull my hair..... because possibly she didn't want to leave us. (Parent C)

There were also social difficulties once back in school, as parents reported that some YP were out of practice at being around large groups of people, which took time to become accustomed to again, resulting in anxiety and agitation. Parents themselves also found the transition back to a more normal life challenging and said it had taken time to trust that it would be safe.

Although education for those with an EHCP may continue until age 25, if appropriate, the transition from children's services to adult services in social or health care occurs at the age of 18 which resulted in further disruption for some families:

Just before lockdown, she was she was going to go (to respite care) for three days. But by the time they sorted it back out again, she could never go back for three days. She went back for one day, I think. And then I think they certainly agreed to two again. And then she turned 18 in January. So that was it. She was out. So then she had nothing. (Parent C)

On return to school, one parent noted there were changes in staffing and attitudes of staff, resulting in a decline in their YPs attitude towards attendance. Parents reported some staff had left or had long periods of absence, which if they were a key person for the YP, disrupted their ability to re-engage, especially if the YP was already a reluctant school attender:

Well, so he knew like something happens, he gets sent home, so then they get to the point where if they won't send him home, he'll try and act up it a little bit because he knew they just kept ringing me to get him home. (Parent H)

Some YP made some major moves away from home during the pandemic, which proved to be problematic due to the guidance still in place or due to repeated lockdowns:

So he went down to live in (Town X) to do the course, but there was, nothing was really open. So it was quite lonely for him. And then if you remember the next sort of lockdown happened in November. He just came home at that point. He said I can't actually do this anymore. (Parent B)

Additionally, those starting at university had a difficult start, with Parent A describing their YP as being “literally imprisoned in their in their uni building”. YP at university during the pandemic had a much-reduced offer which did not include the full academic or social experience. Learning was online with no in-person lectures and the YP were not able to mix outside their accommodation or have freshers’ events. Furthermore, it particularly impacted practical courses which could not be readily transferred online, such as music, which meant collaboration was challenging and performance ceased.

5.3.3 Theme 3: Wellbeing: *It was traumatic. There's no other word for it. It was probably the worst time of our lives. (Parent C)*

The theme of wellbeing is explored in holistic terms encompassing physical and mental health and the elements that may impact these such as adherence to pandemic guidance

and perceptions of vulnerability. Social connections between family and friends are also examined as key drivers of wellbeing.

5.3.3.1 Physical health: *I think people forget that really, that we were genuinely terrified of the virus. (Parent B)*

Some YP's wellbeing increased due to not having to attend school, or due to attending smaller classes, but it was mostly a mixed experience, as they often missed their peers or usual activities. Although many YP continued with their same eating and sleeping routine during the pandemic, there were some whose sleep/wake cycle was disrupted by the change in their daily rhythm:

During the pandemic he has started to get very, very late in the evening and have all these friends on the internet and also others like playing FIFA or playing different things and then it need to be after you finish the homework. So it was two or three in the morning and sometimes we wake up and he was there in the internet. (Parent L)

Parents reported that some YP were concerned about COVID-19 itself, especially if they had additional health needs such as asthma, but many YP were reported as being more concerned about their families than themselves. The fact that they were following the guidance and not mixing with others reassured most YP. Parents were often concerned about what they would do if they or the YP caught it and were seriously unwell:

I mean, there's no way we could isolate from him if he got it, we would have to attend to him. But I was worried how ill he might be because obviously in that first wave people were very ill. And how he would cope with that. And also how we would cope with it if we became ill and I'm, I'm a bit asthmatic, so I was worried about me getting it and becoming very ill as we all had some fear of that. (Parent E)

Most had experienced COVID-19 within their family by the time of the interviews, but none had been seriously unwell with it. They were keen to protect elderly relatives who they saw as more vulnerable to the virus, although many reported their parents had either not tested positive for COVID-19 or had only had it mildly. There had been some family deaths during the pandemic but not directly connected to COVID-19. Deaths were sometimes complicated by the pandemic, such as a grandmother going to hospital unwell and then catching COVID-19 whilst there which caused her death. Arrangements for visiting relatives in hospital were

restricted during the pandemic, with no visitors possible at some points and limited access for a long time after the lockdowns. This resulted in parents and their YP not being able to visit family members before they died and YP had sometimes not seen their grandparents for some time due to the guidance. Funerals were also restricted in how many could attend and were socially distanced events where masks had to be worn, compounding the strangeness and grief.

Participants reported that medical appointments moved online and were less frequent than usual. Parents were asked to send in health information and then a review was held via phone or online. Appointments that should have been annual were delayed, often by a year, leaving a YP without the regular checks they usually had for medication. This delay may have been further complicated by the transfer to adult healthcare which occurred during this period for some. Parents acknowledged they may have been able to call someone if they were concerned, but they did not do this, mindful of the pressure on NHS services.

Parents knew that exercise was helpful for both physical and mental health and it was encouraged by the Government allowing a daily walk outside. Some YP took up running and others walked with their parents. As the walk was one of the few things which was a permitted reason to be outside the home, one parent with a more challenging YP took her out more than once a day:

I mean, I took her out for a walk in the morning. I took her out the walk in the afternoon. I didn't care what anybody said by then. Don't even challenge me because, but luckily we live in a bit of an estate, so nobody was going to mind us going out for a walk twice a day. (Parent C)

Not all YP were enthusiasts of walking however and some missed their usual sports. A few parents mentioned their YP usually used video games to exercise, which increased during the pandemic. Gradually some activities could be booked ahead in order to ensure reduced numbers and social distancing, but this was not successful for those with significant difficulties as not enough time was allowed:

To go swimming, you have to book, now with a child like YP or in a child with autism or ADHD it's really hard. So they were very strict at the beginning. So you could only go for between 2:00 and 3:00. Well you try getting firstly, YP there properly by 2:00

getting her dressed and then you get to in the swimming pool and then you have to get her out by three! (Parent C)

5.3.3.2 Mental health: *He still struggles with his mental health. He still struggles. He still goes into dark places. (Parent C)*

The anxieties that everyone faced during the pandemic were amplified for most of the participants due to their YPs disabilities. Some mentioned they were trying to forget what had happened now the crisis had passed, and others had found it totally traumatic and felt unable to move on.

As mentioned in the section on Family Life, behavioural difficulties of the YP resulting from frustration, boredom and lack of understanding had a major impact on all family members. One parent considered the pandemic had more of a lasting impact on the sibling of the YP with SEND than the YP themselves. They thought this was due to witnessing the extreme behaviour of the YP during the lockdowns, which led to the sibling's increased mental health difficulties which continued after the pandemic.

Some YP experienced a lessening of mental health symptoms, which parents thought was because the usual stresses of socialising and attending school had ceased. However, other YP found the lockdowns particularly challenging and their anxieties increased. One parent mentioned trying to access mental health support during the pandemic due to her YP's potential paranoia as completely inadequate, resulting in her eventually privately funding online counselling from her home country.

Although the YPs experiences of anxiety were varied, the parents all experienced an increase in their stress levels. Some of the stress came from the uncertainty of the situation which was exacerbated by the practicalities of having to juggle so many responsibilities and roles at once with less support than usual. Parents felt responsible for relatives who needed more support, as well as acquiring the role of educator for their children whilst many were also working full time. The uncertainty of interpreting guidance that did not appreciate the reality of their lives and the closure of many schools, often together with the lack of support from workplaces and education settings, meant the parents could feel isolated.

Furthermore, if you were a family who was experiencing multiple challenges, even when some services resumed, there could be an extreme reaction to the release of pressure:

But I remember when she went the very first time, she went from school to respite care, it was the first time we didn't have her at all. I took two days off work. I couldn't move (voice trembling and tearful at the memory). I remember sitting on my bed. I couldn't move for two days. I was completely, absolutely a shell and I only realised afterwards how traumatised we all were. (Parent C)

However, there were some participants who experienced relative harmony at home who were aware of how difficult it was for others, appreciated their own experience and were able to develop a resilient perspective:

He's alive. He's safe. He's in his bed. You know, school's never been his favourite thing. He's, academically, he's always struggled. What on earth makes us think that this is going to make it any easier? (Parent F)

5.3.3.3 Rules and guidance: *She didn't understand, you know, the touching thing she didn't understand. (Parent C)*

Many of the YP were reported to either not understand why they had to follow the new rules or only had a basic understanding. The changes in acceptable public behaviour were especially challenging for families with a YP with more complex needs:

You have to wait for somebody to come out (of the shop) before you could go in. She didn't understand the waiting bit then she didn't understand when she was in, we had to then get out because you all are having to go. So that was really, really hard. I mean, you cannot believe how everything became so much more difficult because she didn't understand and you can't push her. You can't tell her. You can't reason with her. (Parent C).

Most families reported adhering to the guidance given, at least initially, reporting the protection of others as well as themselves as the motivating factor:

I finished my treatment in 2018, so even though I was what, maybe 18 months post, my treatment carries on now and still in terms of the chemotherapy and everything else, I wasn't as immunosuppressed as I had been. But I think we were all still aware of that vulnerability. So, I think that abiding by the rules was something that

everyone was conscious of, particularly having elderly grandparents and myself as well. (Parent D)

Some parents reported that their YP would challenge them if they felt they were not abiding by the rules, warning them to wear a mask or not to go out more than once a day. However, as time passed, some parents reported changes in their approach, either because their YP could not adhere to the guidance, or there were other struggles at home that were more pressing, resulting in the need to prioritise family members wellbeing:

I mean, I know the impact, but on us personally, it was massive. We all reached the point we didn't care anymore. We just didn't care anymore. We never followed the guidelines by the January, February of the following year. By then, YP was stripped of everything because she was 18. So there was no respite care for her anyway. You know, we were still trying to figure out what she was going to do after school, so you know, we were already ... it's such a state of change. That we didn't care about COVID by then, we just didn't care. (Parent C)

People with disabilities were allowed to go out more than once a day from early in the lockdown, and parents mentioned they had a letter to carry with them to explain the reason if they were challenged by the police. However, this was not always understood by the community:

Well, the neighbour did say to me, haven't you been out once already today? And I wasn't sure if that was a kind of friendly comment or if I was going to be reported to the police. Nothing came of it. (Parent E)

Parents at times continued adhering to the guidance as their YP liked to socially distance or wear a mask, although some also felt with hindsight they had been too compliant:

Yeah. Stuck with it. We obviously all did, but we would say now, like we'd say, we took it bit too, too seriously and too extreme really, because we literally all just stayed at home and didn't go anywhere. (Parent H)

Sometimes it was grandparents who were not following the guidance, which was challenging to manage. Some parents mentioned that at the age their parents were, they preferred to

risk infection rather than become isolated. Additionally, some of the older generation had dementia or roles caring for a less able partner, which meant they found adherence to the guidelines difficult:

We couldn't visit her (grandmother) and she, we couldn't see her or she couldn't come to us. She's just going into the bus and she didn't understand what is happening. (Parent L)

Some YP were compliant with wearing masks when required, others did not venture out in public so did not have to wear them and some continued to struggle with them:

I'm not sure he really understood why he had to do some of these things, but we did. We occasionally were able to get him to wear a mask, but you know, he would just take it off. We did use the sunflower lanyard that became suddenly, you know, been around for ages, but suddenly became more acceptable. (Parent E)

The sunflower lanyard signifies that the wearer has chosen to indicate that they have a disability that may not be immediately discernible. It was used more widely during the pandemic to show that the wearer may be exempt from wearing a mask. Once mask wearing was no longer mandatory, some YP continue to wear one in public:

So like at school, he still wore his mask in every day, even though other people weren't. And I said to him, you don't have to wear it anymore, he said - I want to. (Parent H)

YP with little understanding of the reasons for masks struggled with wearing them causing additional stress for parents when out with their YP, as not all used the sunflower lanyard. Furthermore, some parents felt judged by others when their YP did not wear a mask. Masks also continued in medical settings for some time after the lockdowns so in-person appointments would require a patient to wear one.

The topic of vaccinations also arose, with the majority of people who mentioned them being in favour of the vaccine as a route back to a more normal life. Even a parent who had strong views about some other vaccines, considered having this vaccine better than the possibility

of a longer pandemic with further deaths. However, there were criticisms about access to vaccinations for YP with complex needs:

They should have had a basic visual story that could easily have been put together and distributed to people. Of what this is, what it's for and why it's important and also more accommodation locally of, you know in in GP surgeries or wherever or going to people's homes to do it. [...] If we're serious about inoculating the learning disability population, then, we should have done a lot more to put that in place.
(Parent E)

Additionally, there was mention of side effects of the vaccinations which included an acute unexplained collapse resulting in hospitalisation for one parent's partner and a rapid deterioration in an older relative's health which they thought was instrumental in their later death.

5.3.3.4 Vulnerability: *She's always going to be vulnerable (Parent C)*

When asked if the parents considered their YP vulnerable, this was interpreted in different ways. Some did not see their YP as being any more vulnerable to the COVID-19 virus than any other YP during the pandemic, unless they had a pre-existing condition such as asthma. Parents were more likely to consider their own parents as vulnerable due to age, or themselves if they were immunosuppressed or had a health condition. However, they also considered whether they thought their YP was vulnerable in a more general sense in their everyday life, and most thought they were, due to their disability. This vulnerability was felt to have increased as they matured and were then not always with their parents. The vulnerability was also present across a range of disabilities, with some more able YP being considered vulnerable as much as those with more complex learning disabilities, due to not appearing disabled. There was a particular kind of vulnerability mentioned due to being non-verbal or having other communication difficulties:

I mean, he's vulnerable in terms of, you know not having any sense of danger, of not having strong friendships. And so he's not got a peer group he can be with. He's vulnerable to being out and about and responding to people in different ways or them responding to him. (Parent E)

Additionally, there was vulnerability due to not being able to remain as healthy during the restrictions. One parent considered the reduced ability to socialise and exercise meant that YP were unable to stay healthy. Furthermore, a parent said that she felt her whole family was vulnerable during the pandemic due to the YP's challenging behaviour and the stress that caused. Challenging behaviours are those displayed by people whose needs are not being met, and who often have ID or communication issues. These behaviours can threaten their or others' safety and can also hinder a person's quality of life. Examples would be aggression towards others or themselves or general disruption:

I think we were all vulnerable. I think she was vulnerable to the point that, if we, we could have lost our absolute marbles with her because she pushed us to the limit. She pushed us to the absolute limit. We, you know, we were mentally, physically, psychologically pushed the limit by her. We could have harmed her. I'm just being brutally honest. We could have because there was nowhere else for us to go. There was no other outlet for us. (Parent C)

The isolation felt by some parents added to their vulnerability, as there was sometimes little support or understanding of their situations from the local community:

They must have heard YP shrieking and stressing things around. They must have heard that. Not one neighbour came and offered any kind of support at all. Nothing. Nobody. None of the neighbours checked in, they must have realised we were struggling. (Parent C)

Additionally, there was heightened digital vulnerability during the pandemic, due to the increased time at home and use of digital devices. A parent mentioned a time when links were sent by peers to a YP encouraging him to explore gender diversity issues. The parent felt he had been picked out by other YP at school for this, although he had no interest in it. The parent had only seen one link and felt it was sent by a group trying to "indoctrinate" (Parent L) him. However, her son responded because he thought they wanted to be friends with him, rather than any interest or understanding in the message they were delivering.

5.3.3.5 Human connection: *It's a very large cohort who are very supportive. (Parent B)*

All participants mentioned their YP had missed social interactions. Parents stated that the support of family had always been important, and some YP did not understand why they could not now see their relatives. The contact by phone or via digital means was valued for both checking on relatives and for their own connection with others. Using the telephone was common if relatives were older, but many also used digital means. One family supported their YP to make videos to send to their grandparents to entertain them while they were confined at home which *"was a way of creating something that we could share with them and have a laugh and, you know, kind of spread a bit of joy"* (Parent B).

Maintaining contact with peers was challenging, especially for YP whose main social activity was sport, as most sports sessions closed, meaning they lost any interaction with others together with the physical and mental health benefits.

It was of note that many anxieties appeared to be directed towards grandparents rather than the YP. Life was often stressful at home, but at least they knew where everyone was. The grandparents who caused most concern were those for whom the parent had been a frequent visitor or when the grandparent suffered from ill health, especially dementia. They were aware that all social and support groups had ceased, making life challenging if one grandparent was caring for the other. It was much easier to manage if the grandparents lived locally, as driving any distance was not allowed at various stages of the pandemic. If local, they could undertake a distanced visit, take shopping and check on them.

Other family members who unexpectedly came home during the pandemic became a vital source of support:

And actually, because my daughter came home as well and she's very good with my son, it would have been even worse if she hadn't been there because she was able to, you know, at least keep an eye on him at times and you know, help us out. (Parent E)

Some mentioned that their local community, family and friends could not fully understand their experience parenting a disabled child in normal life, not to mention during a pandemic, which impacted their wellbeing negatively:

Nobody reached out to us. Nobody. She had quite a lot of meltdowns on the, when we were going out for walks. Nobody reached out. They all just looked at, scurried

past us. They just left us. You know, and I suppose I realised nobody cares, as hard as it is, nobody cares, you know. (Parent C)

Those with a social worker or the involvement of therapists said they eventually had contact with them, but the format or frequency changed. Parents were initially sceptical about online interventions but later appreciated it, providing the YP was able to adapt to the new method. *“All the therapists kind of fell away”* (Parent E) at the start, but one YP later received one-to-one speech and language therapy online which was considered superior to his usual in-person group. The online therapy was provided by a professional speech and language therapist, whereas in-person it was given by a TA in the school who had been trained by the therapist. One parent reported that a long-awaited autism assessment was also completed online during the pandemic resulting in a diagnosis and she expressed satisfaction with this method. Others mentioned an online care assessment and a PIP (Personal Independence Payment) renewal on the phone, which they found convenient.

For some YP the interaction with peers at school, teachers and carers was the main social contact they normally experienced beyond their family, so when this ceased, they felt the loss of acutely:

She's quite a social being. She had a life full of carers [...] and you know, activities. She was always out and about doing stuff, and that stopped overnight. (Parent C)

However, parents gradually found ways to reintroduce carers as time went on, usually meeting for an outside activity.

5.3.3.5.1 Friends: *I think they really deserve to have loyal kind friends (Parent A)*

Parents reported that friendships and socialising were important to the YP even if the friendships were not conventional ones, with Parent H describing them as *“more like associates”*. Many YP enjoyed the presence of their peers but did not have friends they independently linked with:

He doesn't have typical friendships that we might recognise, but he definitely has been with some of those young people for quite a long time, so he definitely missed them and enjoys connecting with them when he does see them, and the staff. (Parent E)

Some parents had worked hard over the years to encourage and support independent friendships but were still acting as “social secretary” (Parent F) to enable this to happen well into young adulthood.

However, some of the YP had traditional friendship groups and the unexpectedness of the closure of schools resulted in them not being able to say goodbye to their peer group, which was upsetting. Most of the YP had reacted positively once schools re-opened and activities resumed, so they could see peers and staff in-person again.

Friendships could be problematic at times for the YP, and some found it difficult to choose trustworthy friends or to maintain friendships, but they were still rated as important. During the pandemic, gaming became more important for some as a way to connect with others remotely with a shared activity without social pressure. Parents also allowed YP more time for gaming online, as it was seen as something to do and a connection with peers. Some parents thought that socialising via digital means was easier for their YP but that it did not encourage the development of in-person social skills. Additionally, there was a concern about who a YP may be contacting online, as although sometimes they were other YP the parents knew, this was not always the case. This concerned them as these contacts could be anywhere in the world. One parent promoted the use of a creative software as an alternative to gaming for their YP, which they hoped had helped divert them away from the gaming world. Some online activities occurred in shared family spaces, so the parent was aware of who the YP had engaged with, but other interactions were behind closed doors as the parent needed privacy to work, and the closed doors concerned them. The infinite nature of the online world worried some parents, and although some mentioned they set time limits, they could not police the activity 24/7. Conversely, there were some YP who did not connect with others online who found the pandemic a lonely time. However, some parents felt their YP did not mind as they were reliant on their family for activities:

He doesn't have a like a friendship circle. He doesn't tend to go out a lot. So you know, if he goes out, he'll either be going out to work or college or whatever or go out the house with myself, my husband or my mum. (Parent J)

Family members were also seen as a ready-made social group for some YP, especially if there were relatives around the same age. A parent mentioned that a sibling who had left

home regularly invited the YP with SEND to meet up for a drink as did their cousins who made efforts to meet up for celebrations. Siblings also brought non-disabled YP into the YP's home which parents found beneficial, as they lamented the fact that YP who attended special school did not have friendships outside that world:

When he's with my daughter and you know, sometimes her friends have been here and he comes alive when there are other young people in the room, he really enjoys it and likes interacting with them. I still think there's a missing bit between.....if you're in a special school environment or alongside disabled people all the time, it's still hard to access the wider world and be properly included alongside your non-disabled peers, so I still think that's an ongoing challenge. (Parent E)

5.3.4 Theme 4: Post COVID-19: And we're still reeling from it five years later (Parent C).

By the time of the interviews in late 2024/early 2025, some aspects of life remained impacted, and some families had reassessed their lives and made changes as a result:

As the parent of a disabled child, who worked, you do a lot to keep everything going. You work hard, you kind of overcompensate sometimes and working really hard to make sure that I always was doing my job to a good standard and my parenting. And then when it came to that, you know, unique and, you know, catastrophic situation, you know, for everybody suddenly go into lockdown. When I needed support, I felt it wasn't there and I found that quite shocking. So that was certainly part of how I was re-evaluating my experience as an employee, so I left that job at that time or soon after that time, so it was definitely connected. (Parent E)

Probably the most affected participant during the crisis made the most extreme change to their family's life as they were preparing to emigrate soon after the interview took place. This was for both the practical reason of finding work which had been badly impacted by the restrictions, but also as a result of the emotional toll:

So now we were just existing literally, since COVID, we were just existing as a family, you know, no real joy in anything, no friends because we, because we'd got so out of the, because YP's behaviour had been so extreme. We just literally dropped off the edge of the earth if you can say that and we've never picked up again. As much as I like England, what are we doing here? They don't care about us. They don't really, don't care about us, you know? It was really hard to come to that realisation that nobody really cared. (Parent C)

Family relationships had also been affected by the lockdowns and needed time to recover due to the stress of being confined to the home for so long and because parents became teachers, upsetting the usual norms. Although some challenging behaviours declined once restrictions were relaxed, they had not disappeared. However, parents could not say with any certainty whether that was to be expected at the stage their YP was or whether it was purely as a result of the pandemic. However, some mentioned separation anxiety which developed after the restrictions ceased and were directly attributed to not leaving the family during the pandemic. Additionally, some parents felt the YP had lost skills such as social and communication skills. They also mentioned they still lacked the confidence to travel independently which some families had worked hard to develop prior to the pandemic. A few parents described the loss they felt their YP had experienced in terms of the loss of opportunity and the YP's general development having stalled or gone backwards during lockdowns.

During the pandemic, the use of devices to for home-learning or work became more common. This mostly reverted to in-person teaching in schools and colleges, however at the university level this took some time to return. One parent whose YP went to university after the restrictions eased, found that his learning support was all online, even though in-person lectures had resumed. This parent was concerned about the lack of oversight for support offered in this way, as her YP was struggling but he was able to hide this as the camera could be off or the background blurred. Additionally, some parents themselves did not like working online after the pandemic and missed the social interaction that happens naturally in an office. Others felt their job was not the same or more difficult to do from home.

All the YP in this study returned to education after the pandemic, but parents were aware of friends whose children found it difficult or impossible to return. Some courses were no longer available post pandemic and there were also changes in staffing which was unsettling for the YP. The emphasis within education was on CYP catching up academically after the lockdowns, however one parent commented:

My position is catch up with what? Catch up with who? Who decided where the bulk, who decides where that line is? And that line is based on children who haven't been through an international crisis. So, I, I don't like that idea of catching up. (Parent F)

With hindsight, a few parents expressed the view that pandemic measures had been draconian and unnecessary, whereas others reasoned it could have been much worse if those measures were not taken, but appreciated that we may never know with any certainty. What they were certain about was that *"I know I never want to go back there again"* (Parent F).

5.3.4.1 Thriving or surviving: *Our eldest is still waiting for appropriate support really. (Parent A).*

The interviews explored how parents perceived their young person's sense of belonging and identity formation and the extent to which they felt they were part of their community post-COVID-19. Some parents said that despite difficult times during the pandemic and a two-year delay in their education in many cases, their YP were progressing well. However, even within this group, parents acknowledged that social opportunities had diminished and as reported above, some skills and confidence had not yet returned.

Parents considered that some YP had not felt they belonged in their education settings before or during the pandemic if their needs were not being met, they had been bullied or they had not developed strong relationships with staff or peers. Conversely, YP were seen by parents to belong if they attended willingly and had good relationships with the teachers.

Parents thought their YP had survived the pandemic reasonably well, and they sometimes thought it had a more lasting impact on the parents or siblings than the YP with SEND. For those YP who had left education or who were about to, the issue of next steps to find employment or a purposeful role was challenging. Parents said that despite work experience or successful volunteering roles, and in some cases qualifications, paid work was still elusive:

So he had a really great time doing work experience at (the) Library. Loved it. Did the summer reading challenge and volunteered for them during the summer. But can I get him a bloody volunteering job or a job at library? No, I can't. (Parent J)

This impacted how the YP felt about their role in society, as parents mentioned that true acceptance by society would be if they were offered paid employment. Additionally, if a YP found paid work on a temporary basis, there could be difficulties as the LA then considered

them to be employed and ceased the EHCP which removes educational routes and support. This led to one parent deciding their YP should stop working in order to maintain the EHCP, and they found a Supported Internship programme instead, which is considered education even though it also includes work experience. Supported Internship work placements appeared to lead to increased life satisfaction and could lead to permanent work:

They say he's doing really well. He's got a very strong work ethic. He's on, so they've got a placement at (Local Hospital). So he's in the portering team. So he does a bit of portering, does a bit of security, does a bit of engineering, which means go around checking all the boilers and making sure everything's been serviced and yeah. So he put a parking ticket on someone's car yesterday, was very pleased about that!
(Parent F)

The uncertainties about what was available next for the YP meant that some parents reported them as surviving rather than thriving, but there were some who felt their YP was thriving. This was usually due to a successfully supported educational or social care placement or obtaining purposeful work, especially if it was a paid role. Thriving was also described as having a friend or social group to connect with, whether this was peers, colleagues or family. Regrettably, some parents felt the identification of their YP's needs and the implementation of support came too late for them to benefit, and they could see that their YP were struggling to find their place in the adult world:

I mean better late than never, but, but particularly for our eldest, way too late.
(Parent A)

5.4 DISCUSSION

5.4.1 Summary of findings

Parents' experiences in the pandemic were not uniform even for this small group of parents. However, it appeared that feelings of isolation were universal to varying extents but worse if their YP had more complex difficulties. This isolation led to greater vulnerability for families due to the lack of support and increased the risk for intra-familial conflict. Parents felt they could not adequately fulfil all the roles required of them during the pandemic and the

burden appeared to be disproportionately on women. Some YP were reported as being happier at home, however hard-won skills were lost and this study found that YP had not always regained these.

It was found that parents had to fight to get their child into school during the pandemic even if they had an EHCP. If YP subsequently attended school, parents were grateful for the provision, but it was not education as normal. Furthermore, the variation in provision for home-learning was huge and could lead to large learning gaps due to lack of differentiation and support. Descriptions of the YP's past educational experiences showed that difficulties with education were not new and there had often been a mismatch between the YP's needs and suitable provision. Parents reported that YP struggled with home-learning with some doing none and others becoming obsessional about it. It was also found in this study that Alternative Provision (education not in a school or college) was not always able to provide continuity of education in lockdown, although it appears that not much is known about these settings' response to the pandemic.

Post pandemic, this study found that changes had been made by some parents as they re-evaluated their lives. Parents also reported remaining anxious about their YP as they approached the end of formal education with unclear paths to adulthood and a meaningful life.

These findings will now be discussed further under the headings of Home and Work Life, Education, Wellbeing and Post-COVID-19.

5.4.2 Home and Work Life

Several parents mentioned that COVID-19 amplified all the challenges they usually faced and stated it was difficult enough usually, without the complications of the pandemic, a finding that was first reported by Creswell (2021) and Couper-Kenney & Riddell (2021). In this current study, parents elaborated on this and said that friends and neighbours did not understand the difficulty of raising a disabled child and so would not understand the greater stress caused by the pandemic, adding to the sense that they were not *"all in it together"*, a slogan often used worldwide by the media during the crisis (Imran & Ahmed, 2024). In usual times, parents would have some relief from caring duties during the school day and by involvement in the workplace, whereas during the pandemic this was not possible.

All families found the pandemic challenging, but the reasons for that challenge were not alike. It is known that parents of disabled children face additional parenting difficulties which can result in isolation in usual times (Contact a Family, 2011). However, those with YP with more complex needs experienced a greater degree of isolation in part due to the protocols that were necessary to take part in activities, such as strict booking time slots and wearing a mask. These were stressful if not impossible for them, corroborating the study by Caton et al. (2024) and extending those findings to include young people with disabilities.

Study 2 found that the number of roles parents were trying to fulfil made their lives more stressful, especially if they were working, confirming initial reports in the Scoping Review in Chapter 2, for example in Canning et al. (2021), Rogers et al. (2021), and Shaw & Shaw. (2021). In Study 2, parents felt employers had little understanding of the fact it was already challenging to organise work around a YP with SEND, as had been highlighted by Lewis et al. (2000) prior to the pandemic. They also felt no account was taken by the government of their position as a parent of a YP with SEND, particularly for parents who had emotionally demanding roles at work, when it became difficult to create boundaries around work and caring responsibilities.

Seven of the parents continued to work during the pandemic, one was furloughed and two did not have paid work but had additional family caring roles. The working parents in this study commented they worked harder than their colleagues to show they were effective despite their caring responsibilities. They did not want to be defined only as a parent of a YP with SEND but sometimes needed support to be able to continue working. This was also confirmed by accounts before COVID-19 (Medlock, 2018). These parents felt let down by their employers when they lacked understanding of their situation and this was instrumental in post COVID-19 employment changes for at least three of the participants.

Some parents mentioned that their YP experienced behavioural difficulties, and although parents could not be sure these difficulties were caused by the pandemic, the sudden onset of the changes led them to believe this was the case. Cavanagh et al. (2025) found the family carers of people with PLMD in their study expressed *“a sense of deepening exclusion and inequality”* (p. 4) during their interviews, with which this study concurs, due to their greater reliance on outside agencies which left them isolated when they withdrew. Extreme challenging behaviour put families under additional strain, which was also found by Flynn et

al. (2021), who voiced concerns about the behavioural signs of distress of people with PMLD during the pandemic. These families received no support and felt invisible to society in addition to being criticised by neighbours, increasing the trauma experienced.

Greenway & Eaton-Thomas (2020) reported that some YP had appreciated not attending school, but the current study found this was only correct if they had enough resources and no behavioural concerns. The fact that wider improvements in wellbeing resulted for some YP when not attending school, raises concerns about the appropriateness of some placements. Additionally, the YP's sense of wellbeing is a major factor in achieving regular attendance, which as highlighted earlier, is still of current concern (Connolly et al., 2023).

5.4.3 Education

Interestingly, five of the ten parents in this study worked in some capacity with CYP with SEND and may therefore have had greater knowledge to support their YP with home-learning. Anecdotally, it is not unusual to find parents of a child with a disability drawn towards a career with CYP with SEND, as they seek to use their lived experience to support others. Research does not frame this explicitly but implies it by documenting a pattern of parents developing substantial advocacy expertise and knowledge of SEND systems (Saxton et al., 2025) which some then go on to use professionally. However, even this group of parents struggled with the advent of home-learning and adapting to the use of technology.

Vulnerable CYP were officially allowed to attend school as part of the Government policy developed at this time (DfE, 2020e), which included those with an EHCP or who had a social worker. However, this was only offered initially to one of the parents in this study, despite eight having an EHCP and at least 3 having a social worker, due to staffing and health and safety concerns. The decision was made by a school on a case-by-case basis which should have taken the individual's needs and their family's circumstances into account, but it was children of critical workers (teachers, doctors and nurses) who parents in Study 2 said were given priority. The outcome was that only 6.7% of vulnerable CYP attended school during the lockdowns in England, 4.8% in Scotland, 4% in Wales and just 1.5% in Northern Ireland (Sibieta & Cottell, 2020). Parents who were struggling to support their YP in Study 2 had to negotiate (or "*fight*", in their words) to get their YP into school via school management or their social worker. Although grateful if their YP could attend, as it retained some routine

and gave respite from caring, parents commented that attendance was more about childcare than education, which they felt contributed to their YP's learning loss.

The loss of school placements exacerbated the normal challenges experienced by families with a YP with SEND and they felt it showed a lack of understanding of their reality.

Furthermore, a report by Tirraoro et al. (2020) found that the risk assessment schools were advised to use by the government to allow the safe return of pupils to school (DfE, 2020g), were often used as a barrier to prevent them returning, stating that the YP could not be safely accommodated. Parents were reported by Tirraoro et al. (2020) to have not always been aware of these risk assessments taking place and so it is possible they may have created a barrier for the YP in Study 2.

Study 2 found that there was inequality from the beginning in the offer made to YP, as some started online learning the day after the lockdown was announced, but for others there was no provision initially. Although the type of provision often changed during the lockdowns, all the mainstream settings offered something online from the start unless the YP was in year 11 or 13 when very little was offered, which concurs with the Eivers et al. (2020) study. The Ofqual paper (Newton, 2021) which analysed the learning which took place during COVID-19 considered this was due to exams being cancelled and therefore schools focussing on other years. However, this study found that many schools did not provide any activities for these year groups despite the students remaining on roll, leaving them with no oversight.

Additionally, the special school provision in this study was slower to start as their offer was more problematic, with academic online learning not always pertinent for their students. However, they were also slow to provide paper-based materials, resulting in some of the most disadvantaged students receiving the least educational input with parents stating their YP's skills and confidence deteriorated during this time.

The expectation for YP in mainstream education was to complete all the work set for the class, with no differentiation, as was exposed by several early studies explored in the Scoping Review in Chapter 2, for example Greenway & Eaton -Thomas (2020) and Ludgate et al. (2021). This was not expected when the YP attended in-person and the added complications of understanding the educational platforms made it inaccessible for many, even with parental support. If this group of parents found the platforms difficult to navigate, those with less IT knowledge would undoubtedly have struggled. Some YP ceased trying to engage

with the learning and parents found alternative ways of providing education at home, such as board games and creative activities. This again may not have been a route open to all if parents did not have the resources or knowledge, with higher income families reported to have access to more home-learning resources (Andrew et al., 2020).

One parent mentioned that their YP did more work at home under her supervision than they did when they attended school in-person. The parent was ensuring the YP was logging in each day, sending work in and looking at messages. Beaton et al. (2021) found that for some parents, home-learning increased their understanding of their YP's education, and this parent discovered their YP was not always working to his ability at school. She then challenged the school on his return about this as it appeared that the parent's experience of home-learning had made her more confident in what was expected at school.

Due to the lack of teacher support and differentiation, some parents reported YP spending an excessive amount of time trying to complete the home-learning, which was also observed in the Scoping Review studies (Canning & Robinson, 2021 and Greenway & Eaton-Thomas, 2020). This current study found that this new mode of learning could create a tendency towards perfectionism in some, resulting in mental health difficulties. The open-ended nature of the internet meant that there was not the same sense of completion that one would gain from a lesson completed or the end of a school day, which could then blend into nighttime gaming activity. Although the difficulty of being given too much work had been identified, the predisposition of some YP, particularly those with ASC, to want to continue until the work was perfect and complete had not been previously identified.

This research also found that alternative provision such as that provided by community football clubs, that offered educational programmes for young people interested in sports development, struggled to provide any education during the lockdowns. YP were not provided with online learning for several months, as the staff and premises were redeployed for food preparation or COVID-19 testing. The families affected by this felt let down, with little contact during this time, as the priority moved away from the educational offer. Non-traditional providers of education during the pandemic may not have had the same focus on maintaining education as a school or college, but little information about this is available.

The use of digital means to connect with YP was helpful for some students but was not appropriate for all. Some YP could not manage the videoconferencing format, and some felt excluded by its use. There are reports of connection via digital means widening to include more disabled people during the pandemic, which have had positive outcomes for many (Clayton et al., 2023). However, it is clear that this should not be seen as the sole communication channel as accessibility problems remain even for those without complex disabilities (Hersh et al., 2024). Some schools used the telephone to contact YP, but parents said this was not an effective method to communicate with them as YP were uncomfortable using the telephone and would not always speak, but they were not sure what method would have been effective and there appears to be no research about this. This study found however, that parents themselves valued telephone contact from schools as it lessened their feelings of isolation.

5.4.3.1 Past Educational journey

Past educational experiences were discussed to understand the context of the YP's current circumstances and to explore the parents' opinions of their YP's sense of autonomy, belonging and competence. Nine of the ten families described past difficult situations with educational settings, and words such as traumatic or struggle were used in this context. Consequently, the parents had to battle with professionals for a more appropriate placement or greater support, which was both time consuming and emotionally demanding. Some parents also requested special education after experiencing the failure of mainstream provision to meet their YP's needs, due to the realisation that inclusion in mainstream can be more of an illusion than reality, as Webster (2022) discovered.

It was clear from this study that YP felt they belonged to their school community when their needs were met, and that they had autonomy and experienced competence once the provision and support were appropriate. The relationships with their peers and teachers at the placement were also key to feeling part of the school community. The study found that those who struggled with school before the pandemic were relieved not to have to attend and found it more challenging to return than those who had a good experience of school.

5.4.4 Wellbeing

Many parents appeared at least as concerned about their elderly relatives as their YP in this study. This generation of parents are often known as the 'sandwich generation' as they look after young children, teens and aging parents (Cosco, 2024), which together with paid work creates a stressful environment in usual times. The addition of a child with SEND and a global pandemic increased that pressure enormously. Currently there appears to be no safety net for older adults as health and social care provision declines and informal care is increasingly required to fill this gap (Thorlby et al., 2018). In the Thorlby et al. report, 75% of informal carers said they had not received any respite during the last 12 months, a situation that will not have improved over the intervening years with cuts to public services.

Supporting a parent with dementia during the pandemic was extremely problematic. Social interaction is known to help both delay the onset of dementia and ameliorate its effects, so when this ceased, it is reported that symptoms increased (Alzheimer's Society, 2020). It was also found in Study 2 that the combined responsibility of caring for a relative with dementia and a YP with SEND greatly increased the pressure on parents, especially for women.

Adaptations to following the guidance were made as the pandemic progressed, with many reporting that their own mental health and that of their wider families necessitated finding ways to lessen the isolation. The isolation also enhanced any feelings of vulnerability families usually had, as they often considered their YP vulnerable due to social communication difficulties and cognitive ability. The lack of physical exercise and socialising meant all families were more at risk of both mental and physical health difficulties, as they are both protective factors for good health (Banyard et al., 2017). The guidance also left families vulnerable to intrafamilial abuse when schools closed and support ceased (van Gelder et al., 2020). As a result, a rise in demand occurred for domestic abuse services during the lockdowns and professionals also reported increases in violence to parents from CYP (Christie et al., 2022). This current study also indicated that families who showed no propensity to violence normally, when support was withdrawn could reach a breaking point caused by the circumstances of the pandemic.

Parents became used to medical and other appointments on the phone and thought they were usually an efficient way to conduct them. However, they did think that the vaccination programme was not adapted for YP with disabilities. Although adults with an ID were willing to be vaccinated (Hatton et al., 2021), some parents in this study needed more support with

this for their YP. One parent suggested a social story was needed to prepare her YP for the vaccination, but this was not offered. Beyond Words, a charity which produces picture-based, word-free resources (<https://www.booksbeyondwords.co.uk/resources-dl>), produced a book entitled 'Having a Vaccine' in 2021 and also produced a range of social story books about other aspects of COVID-19. However, although they were available free online, parents were not aware of them. Some pandemic information was published by Public Health England in an easy read version, but parents were not directed to these resources either (PHE, 2020a). Additionally, despite individual medical staff being helpful, parents said they were not trained sufficiently to work with disabled YP. YP with ID or ASC need more time for the vaccination process and this was not always available. Furthermore, it would have been beneficial to some for the vaccination to be offered at home, which was not offered to these parents.

Support from the wider family was vital for many families, with sibling, cousin or grandparent support being mentioned. Siblings or cousins could provide a ready-made peer group with whom the YP could socialise and experience mixing with peers without disabilities. Friendships were seen as important to the YP but parents recognised these were focussed on the companionship of peers and adults rather than reciprocal relationships (Friedman & Rizzolo, 2018). Those without family support relied more on services in usual times and felt more isolated from the community.

YP with SEND can be more vulnerable when making friends, as they are keen to respond to overtures of friendship which may not always be what they seem (Garolera et al., 2020). This was noted in Study 2 as a difficulty with both in-person and online communication, with the latter becoming more important during the pandemic and afterwards as the opportunity for online connection with others increased. The particular circumstances of YP having more time at home, with online socialising and the difficulty of parents overseeing what they were doing, could potentially have led them to become involved with people who were not looking out for their best interests. For example, they could have been exposed to conspiracy theories or gangs looking to groom them (Chadwick, 2019). Previous research has shown that for adults (Triantafyllopoulou et al., 2025) and older adults with ID, using technology during the pandemic was helpful despite the risks attached (Chadwick et al., 2023), but for many of the parents in this study, the experience was less positive. This study

found that YP were often unable to engage with the technology or they used it too much, which then could negatively impact their wellbeing. Additionally, closed doors were needed in small homes due to requiring privacy for work which meant it was difficult for parents to monitor their YP's online activity or to prevent lengthy time on devices into the night. A key protective factor for good mental health was therefore removed, as a regular sleep schedule is needed for health and resilience (Allan et al., 2023).

Conversely, some YP were happier during the lockdowns as was found in some of the Scoping Review studies in Chapter 2, such as Couper-Kenney et al. (2021) and Gillespie-Smith et al. (2021), as the need to attend school and socialise was removed. However, this masks the complexity that was found in Study 2, that although some were indeed happier to be at home, they also lost skills and did not continue to develop socially or academically. It would be of interest to investigate how attending school could be made a more positive experience for the YP as absence rates have increased post pandemic, but currently there is little data which could explain all the reasons. In 2022 -2023, 21.2% of pupils were persistently absent (at least 10% of the time) but up until 2019 it had been fairly flat at around 10.5% according to the FFT Education datalab (2023). Severe absence, defined as missing half of all lessons, affected 3.5% of secondary age pupils in the spring of 2023-2024 which was three times as many as in 2019 (ffteducationdatalab.org.uk, 2024).

5.4.5 Post COVID-19

COVID-19 and its impact caused many families to re-evaluate their lives, which appears to have happened in many countries, as people questioned societal elements that had previously been norms, such as school attendance and socialising (Beaumont et al., 2023). Changes of jobs or even country occurred after the acute phase of the pandemic ended for participants in Study 2 and they also mentioned that staff at their YP's settings had changed when the YP returned, with familiar staff having left and new or supply staff in their place. Some changes were potential future plans brought forward in the light of the unprecedented nature of the pandemic. An attitude of why wait, as no-one knows what could happen next, prevailed for some. Priorities became more about health, relationships and work-life balance rather than career and wealth accumulation (Beaumont et al., 2023). At the same time, there was a lack of trust in services and authorities that had previously served people (Bear & Simpson, 2022), furthering this re-appraisal.

There were difficulties for most families when normal life resumed, due to a loss of confidence in undertaking previous activities. Challenging behaviour remained for some YP but lessened once society opened up and routines were reinstated. However, this study found that YP's skills, originally achieved with much training and support from parents, had not all returned even four years after the first lockdown. It takes longer for YP with SEND to learn new things that are taken for granted by their peers without disabilities, (Mencap, 2024) therefore parents felt these losses acutely.

Anxieties about the future were expressed by most parents with the ultimate anxiety being what would happen when they were no longer able to support the YP, which is a well-documented concern for parents of YP with disabilities (Bowey & McGlaughlin, 2005). The difficulty of finding a place in the adult world was mentioned by many parents as the YP approached the end of formal education. This was not specific to the period after the pandemic but was compounded by the disruption and reduction in services for YP with SEND during and after the lockdowns (Mullen, et al., 2024). This compared unfavourably with YP without disabilities whose transition to employment was found to have progressed almost as usual in the immediate aftermath of the pandemic (Roberts, 2021). However, a few YP were considered as thriving post-COVID-19 and it was clear that parents had provided substantial support to facilitate this outcome, often at a cost to themselves and their family. Parents in this study considered their YP were thriving if after education, they had some paid work or meaningful activity with some social contacts, which concurs with the findings of Kraemer et al. (2003) who found that having paid work in the community and a larger social network correlated with the highest Quality of Life score for YP with ID.

Parents' own work lives had permanently changed during COVID-19 as almost all meetings were now online resulting in less travel and in-person interaction. This was not popular with all and was a factor in some parents' re-evaluation of their working life, especially if their work had involved in-person interaction with vulnerable YP prior to the pandemic. It was felt by some that it was impossible to deliver the same service online to YP.

5.5 LIMITATIONS

Most of the participants in this study had a steady income during the pandemic, which meant they had the ability to provide extra resources for their YP. They also had enough

devices for their family either through their schools or privately. Nine of the families had enough space for homeworking and had a garden, therefore this was not a cross section of the UK's population, many of whom would not have these resources.

Additionally, it was clear that those who worked with YP in some capacity were drawn to participate in this study. Therefore, there are other groups whose voice has not been heard in this research, such as single parents, those of lower socioeconomic status or who were unemployed. A reasonably diverse geographic area was covered for a small study, but there was less diverse ethnicity, despite advertising in areas of mixed ethnicity such as Bradford and London. Only 20% of the YP and 10% of the parents were not white British, therefore further research is needed to discover the experiences of a wider ethnic range of parents and YP. Diverse disabilities were included but the study was weighted towards ASC, with 75% having this as part of their diagnosis and 50% as their sole diagnosis.

Furthermore, only one father and no foster carers were involved so it would be beneficial to extend the sample to a wider range of carers of all genders. Finally, this research was completed two years after the acute phase of the pandemic so memories may be less clear. However, there is much research available which took place during the first few months of the pandemic, with less completed after the crisis had passed, when parents were more able to reflect.

5.6 CONCLUSION

5.6.1 Home and work life

Parents said they felt able to discuss the pandemic now some time had passed, and some aspects were reflected on for the first time during the interview, with parents expressing surprise at how recalling the events had affected them. A small number of participants became upset at times as they remembered and described what happened. Parents found the pandemic had greatly exacerbated their usual challenges with the addition of new challenges working from home and managing increased demands on their time. It appeared that women bore most of the emotional load for the family, encompassing caring, educating and dealing with any challenging behaviour of the YP, whilst also caring for their other children, and often working themselves.

5.6.2 Education

Only one of the YP was invited to attend school at the start of the pandemic, and home-learning was not appropriate for most of the YP in the study. Even those who were able to engage with it found it onerous and anxiety provoking, and it required considerable effort from parents to ensure their YP had any kind of education. There was a wide variety of provision reported with no differentiation and little support, setting many up to fail. Additionally, the work could become intense, leading to an unhealthy perfectionism in some.

5.6.3 Wellbeing

The negative impact of the removal of all support was highlighted in this study, as most felt isolated when they lost wider family and community connection. Parents were already struggling with many roles before COVID-19 and then more was demanded of them. They were coping with managing elderly relatives, their YP with SEND, siblings, home-learning and work. The parents of YP with the most complex needs appeared the most vulnerable, as staying at home increased risks within their family. A small number found there were advantages for their YP in the lockdowns, giving them time to relax, which allowed self-development and improved health, but this was sometimes reported as the positive effects amongst other negative impacts.

5.6.4 Post COVID-19

It appears that people's lives changed permanently after the pandemic, contributing to a review of priorities. Work had changed significantly with digital methods bringing both positives and negatives but was not universally liked. The families in this study reported fragile resilience in usual times, and experienced enhanced risks during Covid-19. Parents' concerns were greatest for the future of their YP, as they had lost skills and confidence which are key to independence. Additionally, trust in employers, colleagues, services and even the government had been lost during the pandemic, therefore it is essential to learn from families to create improved systems for the future. To create a more complete picture of what happened for the YP and their families, Chapter 6 (Study 3) will look at the professionals' view.

Chapter 6: The views of professionals working with YP with SEND during the pandemic.

6.1 INTRODUCTION

The purpose of this thesis was to understand the views of the YP with SEND, and in order to do this it is necessary to consider the views of those who support the YP during their development towards adulthood. The views of professionals are therefore an important part of gaining a broad perspective of the circumstances surrounding the YP. After their parent/carers, professionals are the people with whom YP with SEND spend the most time (Matheson et al., 2007). This is usually more contact than they have with their peers, and far more contact than their non-disabled peers would have with professionals (Goodley & Runswick-Cole, 2012). YP with SEND often engage with a wide range of professionals across assessment, diagnosis, treatment and education throughout their lives. These professionals are therefore well placed to reflect on how the pandemic affected services, YP with SEND and their own professional roles.

The final part of this thesis was therefore set out to consider the views of professionals who worked with the YP. There have been previous studies which gathered professionals' views, but these were mostly set in the early days of the pandemic and in the immediate aftermath, such as Spain et al. (2021) and Theis et al. (2021). Furthermore, most professionals in these and later studies reported on the impact the pandemic had on younger children but did not cover YP. This study aimed to enable professionals to reflect back on their experiences in relation to YP with SEND during the lockdowns with the benefit of hindsight and having adapted to post pandemic circumstances. However, during recruitment many professionals commented that they did not wish to be part of the study as they did not wish to re-visit this time as it had been too traumatic for them.

6.1.1 Research concerns

This chapter deals with three of the four research concerns from the professionals' stance but omits the third question regarding the YP's sense of belonging, autonomy and competence as the professionals would not have enough information about this aspect. The last question is to gain an insight into the professionals' views of how well they considered

they were able to support the YP during the pandemic and what support they had received to do this. The research questions are listed again below.

1. How did YP with SEND experience the pandemic?
2. Did the YP receive appropriate support and information?
3. In what ways did young people's pre-pandemic experiences of autonomy, competence, and belonging shape their lived experiences during the pandemic?
4. Were the families and organisations who delivered services and care to YP with SEND given the resources to enable them to cope with the pandemic?

6.2 METHOD

6.2.1 Participants

Professionals who worked with YP with SEND who attended an educational setting were invited to take part in this study. The participants could have been involved with the education of YP as a teacher, manager or Teaching Assistant (TA) in a school or college or have delivered therapy such as occupational therapy or psychological therapy to the YP. Professionals were recruited based on the following inclusion criteria:

- Professionals who worked with YP with SEND between the ages of 14 and 25 for at least some of the time during the pandemic (2020 -2022)
- The YP they work with were enrolled at an educational setting
- Professionals delivered their service in-person or online or provided a hybrid offer

Twelve professionals were recruited from various geographical areas of England who were working in a wide variety of roles, with half of them working in senior positions. Nine participants were involved in educational provision, two worked with YP in psychological services and one worked for a LA special needs team for those at risk of hospitalisation due to unmet needs. The participants who were involved in educational provision worked in a wide range of jobs which can be seen in Table 6.1.

Abbreviations used in Table 6.1 are as follows: ASC stands for autism; MLD and SLD are abbreviations for mild and severe learning disabilities which is the terminology used in education (but means the same as the internationally and academically used term of Intellectual Disability); ADHD for attention deficit hyperactivity disorder; Sensory refers to a

visual or hearing impairment; MDC for Medical or health condition; PD for physical disability; LD for Learning difficulty e.g dyslexia or dyspraxia; SLCD for speech, language and communication disorder; SEMH for social , emotion and mental health difficulties; DS for Down syndrome, PMLD for profound and multiple learning disabilities; WB White British ethnicity; OW Other white ethnicity and for ME Mixed ethnicities.

Table 17. Professionals' Demographic Information

Ref	Area of UK	Job role	Type of setting	Age of YP work with	Length of time worked with YP with SEND	Type of SEND work with	Other roles	Gender	Ethnicity	Interview duration mins
A	SE	Senior support worker, providing in-person education throughout COVID	Individual educational provision for a charity	23-25	7	ASC, MDC, SLD, SLCD	HE student	F	Mixed	45
B	SE	SENDCo at mainstream secondary school. Mix of home learning and in-person education	M/S school and 6 th form	16 and under	20 7 as SENDCo	ASC, ADHD, MLD, MDC sensory, SEMH, SLCD, LD	Family care	F	WB	88
C	SE	Head of specialist college: management/ SLT. Mix of home learning and in-person education	Specialist college	19-25	20	ASC, SLD, ADHD, MDC, SEMH.	Family care	F	WB	44
D	N	Management/ SLT of LA SEND music service. Mix of home learning and in-person teaching	Special school, and units in mainstream	16-18	34	ASC, ADHD, MLD, SLD, MDC, PD, sensory, DS, PLMD	Trustee and practitioner for a music disability charity	F	WB	67
E	SE	Teaching assistant-supporting in person education.	Special school	16 and under	30	ASC, ADHD, MLD, MDC, PD, SEMH.	Family care	F	WB	60

		Furloughed in lockdowns								
F	SE	Management/SLT	Private college	16-18	10	ASC, ADHD, LD, SEMH.	P/T psychot herapis t	F	WB	60
G	SE	Teacher in special school; home learning only during COVID	Special school	16 and under	20+	ASC, ADHD, MLD, SEMH	No	F	WB	35
H	N	SEND music teacher – mix of home learning and in-person	Special schools + mainstream units.	16 and under	15	ASC, ADHD, MLD, SLD, MDC PD, DS, PMLD	Family care.	F	OW	50
J *	SE	Systemic psychotherapist for CAMHS providing therapy and other services to YP	CAMHS	16 and under	20+	ASC, ADHD, MLD, MDC, PD, LD, SEMH	Family care	F	WB	66 (inclusive of questions as part of the parents' study)
K	SE	Clinical psychologist providing therapy to YP and advice to schools	Special school	16 and under	10	ASC, ADHD, MDC PMLD, SEMH, SLD	No	M	WB	51
L	E	Specialist study skills tutor online during lockdowns, later some in person	HE	18 -25	8	ASC, ADHD, sensory, LD	No	F	WB	50
M *	SE	LA SEND planning officer for complex YP at risk of being hospitalised	LA	Up to 25	Not known	Any	Family care	F	WB	79 (inclusive of questions as part of the parents' study)

There are more disabilities listed for the professionals to select as they had more precise knowledge of the types of disabilities of the YP they worked with.

*These professionals were also parents of YP with SEND and volunteered to be asked about both their parent and professional roles in interviews. Professional M is also parent J and Professional J is also parent F.

6.2.2 Measures

6.2.2.1 Interviews

Semi-structured online interviews were chosen as the most appropriate measure to use, being convenient for both the participants and the researcher. This allowed the study to be advertised via a wider geographical area than would have been possible if in-person interviews were conducted. Additionally, almost all professionals involved with education or health would have become familiar with digital methods of working with colleagues and families during the pandemic. This is especially important to encourage busy professionals to participate who may be working long hours. However, one interview was conducted face to face as Professional E requested an interview in-person.

6.2.3.4 Interview questions

The questions asked in the interviews were based on the knowledge gained from the scoping review, the YP study and the parents' study. They were designed to gather the professionals' perspective of the pandemic as it related to their work and lives and their views of the impact on the YP with SEND they worked with.

There were times that the exact wording of the questions was not appropriate for the role of the particular professional and had to be adapted. For example, if the professional was not involved in education, it was not appropriate to ask about how YP's school attendance was decided upon, but they could still be asked if they thought attendance had been affected. Therefore, the questions were similar for each participant and referred to the same issue but were adapted to each participant. See Appendix S for the list of questions together with prompts used if required.

Table 18. *Interview Questions for Professionals*

Interview questions for Professionals
1.What do you remember about the pandemic and its impact on you and the YP you work with?
2. How did you find out what was going on and what you needed to do as a professional?
3. How was it decided who attended the school/college?
4. What happened for those who attended school/college as usual?
5. What changes did you have to make in how you work?
6. How did home learning work out for the YP and you?
7. What was your own experience of work and home life?
8. What happened on return to school/college
9. How important do you think friendships were and are for the YP?
10.Do you think the YP got enough support through the pandemic?
11.How well do you think inclusion is working in education for the YP you work with?
12. Is there anything else you would like to tell me about your experiences during Covid?

6.2.3 Procedure

6.2.3.1 Ethics

Ethical approval was gained for this study from the Tizard Centre ethics committee at the University of Kent on 24.7.2024 (see Appendix M). Additionally, the ethics committee endorsed the materials used to advertise this study (Appendix T), give information to the participants (Appendix U), gain their consent (Appendix P) and request demographic information (Appendix V). A comments form was also given to the professionals who took part to return if they wished (Appendix D(i)) along with a thank you for taking part. The same ethical considerations were necessary for these interviews as for the parent interviews, with informed consent being central, as should be the case with all social research (Cohen et al., 2011). As part of informed consent, professionals were invited to ask any questions and to see the main topics to be discussed if they wished. Obtaining informed consent can come at a cost to the researcher as potential participants may not wish to enrol

in the study once they have explored it further. However, it *“is a cornerstone of ethical behaviour”* (Cohen et al., 2011 p.77) to respect individual’s rights to choose for themselves.

At the end of the interview the opportunity for a debrief about what had been discussed was offered. This was mostly an informal conversation when recording had finished, which happened naturally for those who wished to talk further at the end. They were also offered signposting to further support if that was needed (Appendix R).

It was explained that the interviews would be anonymised and the original data deleted and that any information connecting them to particular educational settings or workplaces would be removed. Professionals were asked not to name individuals but were assured if they did accidentally, that this would be anonymised in transcription. Additionally, the limits to confidentiality were also clarified, with the usual safeguarding parameters in place. This meant that if they mentioned that they or a YP was at risk of harm or of harming others, then these concerns would be referred on to the relevant authority, such as the YP’s safeguarding team at their setting or to the Local Safeguarding Board for the local authority area the adult worked within.

6.2.3.1 Recruitment

Recruitment was initially sought via the same sources as when recruiting for the YP but the professionals in the two main sources for that study were not able to participate in this study. Gatekeepers such as managers advertised the study for the researcher but responses were not forthcoming. One manager of a college said that although she had spoken about the study in their staff meeting and had put flyers up around the college, she thought they did not wish to revisit that time because they wanted to forget about it as it had been so traumatic.

Additionally, there were some who made initial contact who had heightened concern about anonymity and confidentiality. Their concerns were regarding anything they said going back to their employers, particularly those who worked in education. They were apprehensive that comments and opinions made about their setting’s actions during the pandemic would become known to their colleagues, as they appreciated that they were all doing their best and did not want to appear critical of their managers. Even though the anonymity and confidentiality were further explained, many of those expressing doubts did not follow

through with taking part. This was even the case for some who were no longer in the job they had been doing during Covid-19. However, one hesitant participant was reassured after she was sent the transcript to check before finally giving permission for the data to be used.

There was certainly more anxiety around taking part than was noticed when recruiting the YP or the parents. It therefore took considerable time to gain the participants for this study. Participants were recruited by professionals passing the information on to their contacts and suggesting individuals or groups rather than advertising generally. Two of the participants were also parents of YP with SEND and had replied as a parent initially but then subsequently agreed to discussing both of their roles.

6.2.3.2 Data collection

As reported in Chapter 5, the data collection for both the parents' and professionals' studies took place between September 2024 to July 2025. Once a potential participant had shown interest, an information sheet was sent to them. If they then agreed to take part, a demographic form and a consent form were sent to be returned before the interview. It was at this point that the concerns around anonymity arose. If the professionals then agreed to take part, an interview was arranged at a mutually convenient time, with the flexibility of an online format allowing the busy participant to choose a convenient time. One participant completed all necessary paperwork and arranged a date but then did not attend the interview, with no reason given and no response to any follow up emails. This stood out as it was the only time in any of the studies that this happened without an explanation.

The first interview undertaken acted as the pilot interview, as the participant was happy to give feedback about the questions and format. Only minor changes in wording were made as a result, but it was useful to be made aware of any potential differences in interpretations. Two professionals asked to see the questions before the interview to gain an understanding of what was going to be asked, and one of those had expressed concerns about anonymity but went on to agree to an interview.

6.2.4 Analysis

Braun and Clarke's (2019) six phase reflexive thematic analysis was again used for data analysis, as explained in more detail in Chapter 3. All data were transcribed, anonymised

and uploaded to NVIVO where line by line coding took place. Codes were then collated into potential themes, reviewed and named. The codes and themes chosen reflect the purpose of the study and provide continuity between the three studies in this thesis, whilst allowing new themes to be recognised.

6.2.5 Reflexivity

Again, as a professional working with YP with SEND at the time of the research and for many years beforehand, the researcher had inside knowledge of many of the education professionals' worlds. However, some participants were from the healthcare sector and although the researcher lacked direct experience in this sector, previous professional collaboration with these practitioners provided valuable insight into their working environment. The researcher's understanding and empathy effectively encouraged participants to share detailed accounts and a reflexive journal was again kept in order to check for any biases or preconceptions that would need challenging.

6.3 FINDINGS

Four main themes were created from the participants' data, and the themes and subthemes are shown in Figure 6. The diagram below shows how the themes are arranged.

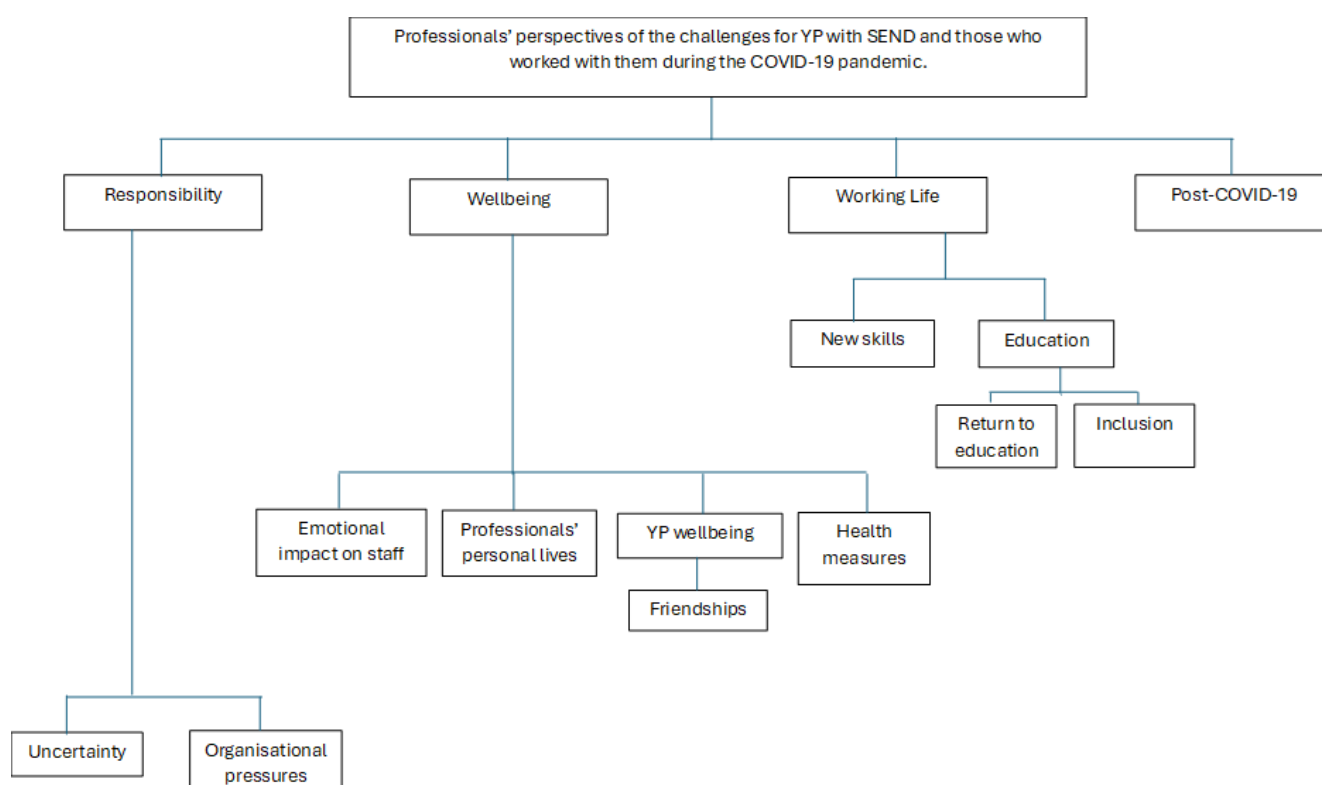


Figure 6. *Diagram of Themes and Sub-themes for Professionals Study*

6.3.1 Theme 1: Responsibility: *Almost every major announcement from the government took heat [intense pressure] and time. (Professional F)*

Professionals spoke of feeling responsible for people and getting things done in uncertain times and having to embrace new ways of working.

6.3.1.1 Uncertainty: *That's the kind of theme - chaos and anxiety. (Professional F)*

Professionals remembered the early days of the pandemic as being ones of confusion and uncertainty. Those in education commented that usually everything was planned within their setting but now it changed moment by moment. No-one knew what the correct thing was to do in an unprecedented situation, all they could do was follow any guidance given by the government or their managers:

There's a lot of things that we didn't know, but it was up to us to kind of present as quite steady and calm and you know, reassuring, even though underneath we're

going [mimes paddling fast]. (Professional F)

Professionals did not get any advance notification of what the government was going to say in their daily media bulletins which left them in a difficult position when it came to imparting the information to families, many of whom worked with YP for whom anxiety around uncertainty was an issue. Guidelines could change daily or even more frequently, resulting in many meetings of the Senior Leadership Team (SLT) with risk assessments then updated based on the guidance. This changeable situation was difficult for all parties:

It was difficult because we weren't able to give any sense of clarity to young people. You know, that's what we work on usually, that sense of being able to make things as predictable as possible, communicate that in a way which is as accessible as possible so people can anticipate what's going on around them. (Professional K)

Not all YP understood what was happening, which was especially difficult for YP who were non-verbal, but staff mentioned that many understood the basic premise of the changes being necessary to keep people safe. Professionals were also aware that most of the YP had had difficult experiences within education and may have had several placements, creating a greater apprehension towards change and uncertainty and felt responsible for managing that uncertainty as much as possible.

SLT members were checking the online government documents to ensure they were accessing current information, which was time consuming and often changed within the week. Parents also sometimes thought the guidance was coming from the school rather than from the government and would take issue with the staff about some of the protocols or contact them before they had discussed them with their teams:

I think we were all very aware that we were getting the same information live, so if a parent heard on TV, the very next morning you'd be getting a call at 7:30 in the morning going so what's happening with this then? And you think, we haven't had a chance yet to talk as a team! So that fielding all these questions was difficult. (Professional F)

Communication within the organisation was usually by email and online meetings, either daily or weekly. Some were expected to watch the daily government media briefings in the evening and then attend an online meeting the next day or one in-person if their school was open. The plan for any safety measures, attendance or online learning was then discussed in the light of these government directives. These were not always as illuminating as they

hoped for:

And initially, of course, there was mass panic. There were all sorts of misinformation, misinterpretation of information. Who did it apply to? Who didn't apply to? [...] The head was amazing all the way through, but he was obviously scared and he didn't really know, so he had to present this, OK, we've got this. This is what the medics are saying. This is what we've got funding for. This is what we've got to do. Go off, all of you. SENDCo, pastoral leaders go and tell your teams how to communicate that to the parents. (Professional B)

Much of the stress on staff was during the initial weeks, but once a new routine had been established, subsequent government guidance would mean changes, resulting in staff living from day to day:

We were just in crisis, and we lived it day after day, week after week, then it stopped. Then it started again. (Professional B)

One spoke of a protocol to follow up YP who had not attended online learning which she did every day by phoning the YP or the parent to see why they had not been online and see if there were any issues. Not all YP would speak to her but her class size in the special school was small with only 5 students, so it was not burdensome to do this. However, for the SENDCo at the mainstream secondary school, it was much more challenging to keep up with all the students who were known to her department and contact was often with parents via an email, text or phone call. Furthermore, short phone calls often needed to be extended:

[I would call to say] so child X needs to come in at 10:30 today and meet us at this point, and then they [the parent] would break down and you would end up going from what was supposed to be a 10 minute conversation to 45, knowing that you still had 30 phone calls to make. (Professional B)

It was more challenging to keep in contact with the parents who did not reply to emails or answer calls, and some teaching professionals stated they were spending more time contacting parents and YP than they were teaching. Professionals were aware that some parents had no access to technology and so phone calls were the main way to contact them, and they needed to ensure that the YP were safe if they had not heard from them. For educational settings, the first concern was how to get everyone engaged with online learning as they considered continued attendance in some form was important for YP to keep a routine and to keep up with their learning. This topic is explored in detail later under the theme of Education.

6.3.1.2 Organisational pressures: *It was just manically busy. (Professional N)*

It became apparent that the impact on many professionals was intense and multifaceted, as most professionals had to consider the impact on the YP, the parents of the YP and their own staff or teams as well as on themselves and their own families. In addition, they had to consider what their managers were recommending along with any LA, NHS or government directives. This put immense pressure on the professionals who then had to make operational and personal decisions adapted for their specific situation and inform staff, parents and YP. Even within staff teams there would be different responses:

For different reasons, some of them were fine. Let's get on with this. We're a team, we can do it. Others were, well, I'm not coming in. It's not safe to come in. And others were, well, I'm vulnerable, medically vulnerable, or someone in my family is, and therefore I can't come in. (Professional B)

Consequently, staff teams were reduced in size due to a combination of factors, putting strain on the remaining team members resulting in some students then not being able to attend for safety reasons. In addition to concerns about medical vulnerability for themselves or family members, other factors affecting staff absence included being unwell, being in quarantine due to being in contact with the virus or having a family member with COVID-19. Some staff worked from home either throughout, or in parts, but this was not offered to participants who worked in large schools or colleges, where they were expected to attend as usual. An exception was one participant who was furloughed due to being over 65 and therefore in an age range considered more at risk of serious illness. Staff had to assess each YP, together with undertaking risk assessments and providing adequate staffing which created considerable challenges:

So it was a logistical nightmare, to actually make sure that all the students were catered for, the families felt supported, but also that the staff were able to manage under the duress of walking around deserted streets and trying to get from A to B when nothing was working. You know, because some of them live quite a way away and at times there wasn't the ability to travel. (Professional C)

Managers needed to know which staff and which YP were attending each day and in addition, contact needed to be made to transport services to let them know which YP were requiring transport for those having taxis or minibuses to their setting, all of which added to the workload. In addition, some managers expressed doubts as to whether staff were always being truthful about their health status, which increased the difficulties around risk

assessments and staffing and required diplomacy to support a staff member whilst also challenging them.

6.3.2 Theme 2: Wellbeing: *It was beyond exhausting. (Professional B)*

For those living alone, or with disabilities themselves it was a challenging time, but one participant acknowledged that having the routine of work had been beneficial for her despite the difficulties. There was however the feeling, *“like what choice did we really have in that situation, like it was a desperate time?”* (Professional A).

6.3.2.1 Emotional impact on professionals: *I think people just want to obliterate it from their memory (Professional C)*

There were some professionals who suffered less of an impact from the pandemic than others. These were the participants whose work was not at the frontline of services in schools or mental health services and were considered more peripheral, such as special needs music teachers or HE learning support. These professionals reported a less stressful experience of the pandemic overall, with less pressure on them, although there were still challenges in their work. There was also a minority who enjoyed the pause in their social life and once the initial fear and confusion had passed, they leant towards the situation and made the best of it. However, the majority of the participants reported high degrees of stress and commented that they could only just talk about it now:

There was a time where I just couldn't look back. I think that's the thing. And now I can, which is why I can talk to you today. But I think a lot of the staff are actually still in a place where they can't, they can't look back because it was, it was awful.
(Professional C)

With hindsight, some staff expressed pride and amazement that they had actually survived such a demanding situation but recognised this often came at the expense of their mental health or family life. Additionally, some staff members were considered vulnerable by their managers at times, if they were younger people doing emotionally challenging work, sometimes from their bedrooms or colleagues who lived alone:

I think the sense of isolation for some people who are living alone as well and maybe from other countries, we have people from you know Spain, Italy, France, Mexico, we have, you know people that are away from their families. And you know, they felt

quite alone some of the time. So I was trying to bridge that gap as well to an extent. (Professional C)

Extra online check-ins were instigated in many organisations to give staff more connection as a result of these concerns. Those deemed most isolated were allowed back in the workplace as soon as possible, especially if they had emotionally demanding roles. Managers were sometimes aware that not all the guidelines were being followed precisely by staff, but they disregarded this at times as they considered their team's mental health was more important:

Some people lived on their own and that was, you know, younger people, living in kind of shared digs and stuff that was quite, you know, they were some of the young nurses, you know, I think they probably all snuck out and met each other anyway. There was you kind of, been dealing, working all day with suicidal teenagers, and then the idea you go home on your own to a, to a microwave meal just, you know, I think they didn't directly tell me, but I'd often hear like, there would be sneaking out to other people's apartments and drinking of wine and ordering the takeaways. But they were in a bubble at work. (Professional J)

Support was needed for professionals themselves as well as being provided from them to colleagues, YPs and parents. Professionals found that their teams, even if diminished in numbers, were generally supportive and extra support was made available for some:

There was an acknowledgement both in the school locally, nationally, that this was going to impact people's mental health as well as their, you know, their ability to learn and etcetera. And actually, within the local authority, that was basically the mental health advisory team, they were still there and they would either do zoom sessions or offer them or come in. (Professional B)

Professionals offered support where they could, either online, by phone or in person. In the smaller schools, staff were expected to be persistent in trying to contact YP and this was not too burdensome for a class of five. However, in the larger schools, it was challenging to meet the needs of all YP who needed support, and YP in certain categories had to be prioritised. These were YP who had an EHCP, were Children Looked After, or who were students eligible for pupil premium plus and in receipt of free school meals, which are all government measures of deprivation and increased support needs. However, a larger school often had more staff available for this support with a separate pastoral team:

And if there was a young person that they noticed that wasn't engaging, they would ring up and they would say, what can we do to help you? And that was happening a fair amount and then they would say, can these three students come in for a day next

week so they can have some help getting online [...] It wasn't as if anyone was more important than anyone else, but we were told who we had to prioritise and there's a finite number of minutes and hours in the day as to what you can realistically achieve. (Professional B)

6.3.2.2 Professionals' personal lives: I never want to do it again! (Professional C)

For those working from home, the space was often also used by partners and children. Staff had to manage their workload along with supporting home-learning unless their children had a place at school as the children of keyworkers. These professionals then experienced many of the difficulties reported in the parent study, especially the two professionals who were also parents of a YP with SEND. Balancing family members' needs at this time was difficult, especially if their work was sensitive or challenging. The demands on senior managers' time during the crisis meant that they felt they were not able to do everything required for both family and work:

I was just at work, if I wasn't actually at work, I was thinking about work. [...] You're constantly reacting. I like to be strategic and it was reactive all the way through. (Professional B)

For one professional, who had lost her brother during the pandemic, learning about the behaviour of government members and particularly that of Boris Johnson, the prime minister at the time, was particularly difficult:

I think the thing that really impacted was Boris having the party. He had that on the day my brother died and I couldn't go because of the restrictions. And there he was. That really impacted and it made me question all the regulations that we'd actually adhered to. (Professional C)

6.3.3: YP wellbeing: People's worlds contracted (Professional K)

Professionals were aware of some of the turmoil experienced by families and YP they worked with. They felt many YP had to grow up quickly due to bereavements, job losses and domestic issues for families previously considered stable:

We saw all sorts of things. I think one of one of the hardest things was the whole, you know, the furlough business and then people losing their jobs and people that had never, you know, been in trouble with the police before. Suddenly these domestic violence cases and social services suddenly being involved [...] And so that was horrible. That was quite ugly actually. [...] Children definitely were affected by that. They would come into school and tell us about that. And that's quite sad. (Professional B)

There were also concerns about paying the bills and housing:

Homelessness was a big thing after the return as well. People with eviction orders and, you know, children then still trying to go to school in the midst of all of that. (Professional B)

However, apparent calm did not necessarily mean all was well, as although some were experiencing a reduction in school-based stress, they were also facing a more impoverished environment. Professionals emphasised that staying at home did not equate to a good quality of life for the YP. Some professionals were working with vulnerable YP at risk of suicide or being hospitalised and challenging behaviour and mental health issues escalated for some of them during the lockdowns. The professional's aim was then to provide interventions which would enable them to safely stay at home.

Some YP did not attend school even if they were eligible for a place, if they were considered to be at a heightened risk due to existing medical needs or the medical needs of the parents. This appeared to be the parents' decision and professionals did not speak about preventing YP from attending. Although most YP happily returned to education, some found the uncertainty of when the pandemic was over difficult to gauge which affected their confidence to return.

Additionally, the pandemic occurred at a developmentally important time for YP:

COVID, you know, was quite a long time and for a child, developmentally, that's a big section of their childhoods. So developmentally and you know formatively, it feels that it's, you know, this is where young people are learning about the world and themselves and all those important things. (Professional K)

A spate of unexpected suicides in one county resulted in a hasty return to face to face working for one mental health professional. The suicides involved teenage boys who were not always known to services or who were considered low risk:

Anybody that was low risk, just wasn't initially having any contact. And then obviously after the suicides, we had to then go through all the caseloads, including all those who are waiting to be seen, who'd never been assessed. They all had to be screened, and all had to have what was started the process of risk calls to everybody, you know, anyone was on a waiting list which was very long for some things like ASC assessments - at that point was two years. (Professional J)

There were also areas that the professionals knew were not being supported, such as speech and language therapy, which one professional reported as having ceased during the lockdowns. Professionals were aware that many YP were not receiving what they needed for their wellbeing or for educational purposes:

All of the students here have a social worker of some description, and it was notable that they weren't available, but also the local authority also ended up working from home, so everything had to be online. There wasn't any physical presence of people coming in to support. Which I think was a bit challenging. (Professional C)

For the smaller specialist providers, there was the opportunity for YP to talk to tutors about any concerns they had about the pandemic, although many did not want to, as they “*were a bit too scared and worried about the whole situation*” (Professional G)

Decisions about vulnerable YP being given appointments or staff members attending work had to be made day by day depending on risk ratings. Staff would contact managers in the evenings after hearing a government briefing, saying they no longer felt it was safe to come in the next day, due to the vulnerability of their own families, which meant that team managers “*just had to keep replanning the plan*” (Professional B).

6.3.2.3.1 Friendships: *It's a real treasure for them. (Professional C)*

Friendships were considered important for all the YP and appeared to be a protective factor for some during the lockdowns if they were able to sustain some connection. However, even for those who were unable to do this, friendships and peer groups were considered valuable:

They are aware of other people around them that they're familiar and they do communicate with each other in different ways. And you know the peer group is really important for them because very often, in their families, there's high stress with other siblings who are struggling with having an autistic brother or sister. (Professional C)

Additionally, some YP in specialist provisions have been together since starting school, so parents have connected over the years which enabled the YP to find connection with each other too. It was thought that the impact of relationships ceasing abruptly was not always acknowledged for some YP, despite recognising the importance of relationships for the YP:

And I think more about those young people who might have more significant communication or learning needs who I support, sometimes we mightn't look at their

relational needs with quite the same frame. You know, young people who are no longer going to their respite or no longer having that familiar staff member interact with them. Really important relationships that might be key individuals in their life, who, for unfathomable reasons, are no longer part of their world, and they don't know why. All they know is that that person is not there. (Professional K)

Professionals knew of several YP who used social media in lockdown to create an online community, but this was usually when they already had an in-person friendship network and if they were more able. However, one professional reported a What's App group being set up by the students when the college-led offer of an online quiz proved unpopular. This then connected any student in the college who wished to be included, which was a new mode of social connection. The supported interns at the specialist college had also set up a Zoom group for exercise and had a What's App group to maintain contact during the pandemic. For the more vulnerable students still attending college, however, online groups were not encouraged due to safeguarding concerns.

For those still attending school, the groups were small and age groups and classes were blended. This meant YP had the opportunity to talk to students that in usual times, they would never have been in the same room with:

I suspect that the older ones, if their peers could have seen them talking to a year seven who's always got a teaching assistant with them, they wouldn't really have spoken to them, but it happened, [...] And then this kind of nurture was born out of that. (Professional B)

This unexpected interaction between older and younger students was considered by the professional to be as a result of “*replicating some kind of family*” (Professional B) and was something she had never witnessed in a school before. Sometimes it was the younger student advising the older one:

And the year 8 student said to the older one, who had said I never get this, and he was kind of talking him through how he approached things. And then he said, you know, you can come up here after school when you want to, because they have a homework club and they're really good because they help you. And he did. [...] And there's no way, because the year 11 was actually seen as quite cool - that wouldn't have happened in a normal situation. (Professional B)

Other informal connections were made in this more relaxed school setting, such as a student with a particular skill developing a club and encouraging and teaching other YP. This

benefitted all who were involved and required very little organisation from the staff. It also created fertile ground for forming friendships:

I think adults can really try hard to manufacture a relationship or a friendship amongst children and go to that club, it'll be fun and all, you know, do this. But actually, they work it out for themselves. They find that they've got some kind, something in common, either an interest or a vulnerability and they decide how they're going to move that forward. (Professional B)

However, there was also a negative side to this, where a student was not a positive role model for others, and this may not have occurred in usual times. It was then difficult to separate them as there were not enough staff available.

On return to school, many YP relished being back with their friends , however, some YP struggled to reintegrate:

We did end up with a quite a lot of young people who just became non-verbal. You know that just might have said the odd word to a few people and then suddenly couldn't make any sense of anything and didn't talk anymore [...] they were quite significant for the fact that they were almost in shock and didn't have any friends and didn't know who to talk to. (Professional B)

6.3.2.4 Health measures: *Work was stressful. Like when coming home and going to have a shower when you get in the door, changing your clothes. (Professional J)*

Professionals reported feeling concerned about infection risk at the start, especially those still in the workplace. However, their anxiety diminished due to the protocols they were following and because they reported being too busy to feel anxious about themselves. If they worked from home, then being isolated was reassuring. For some professionals, their premises covered more than one site, or used community facilities, which caused additional organisational challenges:

The trust is quite big [...] (and) has got two big schools and various units across the borough, and the college and obviously X Hospital, and we weren't allowed to travel between sites without leaving time between and things like that. We had to stay home for like a few days to make sure you're all right. And it was all very complicated. (Professional C)

Special schools' staff stated that the impact of the pandemic was felt before any government measures were announced, as concerned parents kept some YP at home, with class sizes

reducing as a result. Masks also appeared for some YP and staff at this early stage. The use of masks was variable, and staff modified their use depending on the level of risk and the needs of the YP as masks were not possible for all situations due to causing distress for some students:

Our students at this particular site, which is part of the college, are very complex, wearing the masks actually caused quite a lot of issues because they didn't like the staff wearing the mask, but also they weren't able to tolerate the mask. (Professional C)

It was also reported that some YP continued to wear a mask long after it was advised to do so due to fear of infection but also because they liked doing so, as the YP found that, being “used to wearing a mask, all of a sudden, taking it off, you feel quite naked” (Professional G).

Full PPE was used in some situations, such as in-person mental health support, together with sitting two metres apart. Despite these strange circumstances, the professional reported that this was accepted by the YP and they were grateful for the assistance. PPE was not successfully used however for one-to-one support with a student with complex needs as he did not like it and the staff decided to just try to keep the premises clean and not use PPE at all. Those who still visited vulnerable people in their homes, however, were exposed to a high level of risk:

There was a couple of people who were really, really risky and they (nursing colleagues) had to go out to them. They wouldn't come in. And then the following three days later, they're all out with COVID. (Professional J)

The lack of consistency of staff due to absences was problematic for some YP:

It was difficult to provide certainty for students who were in school about who would be supporting them. Only because even within bubbles, people were dropping like flies and having to isolate for a quite long periods of time when they tested positive. (Professional K)

Windows were kept open as advised by the NHS and professionals recall YP keeping their coats on throughout the day to keep warm in the cooler months. Measures to keep classes and groups separate were put into place with separate lunch and break times and care around classes mixing when using the toilets. Testing for infection “was a challenge in itself” (Professional G) when it was required for students to prove they had tested at home, or they had to be tested at school. Furthermore, most of the YP attending special schools

arrived by taxi or minibus funded by the LA, which proved difficult when the taxi was no longer allowed to be full and which bubble the YP were in at school had to be considered. Much staff time and energy were spent on monitoring the YP to make sure not too many were mixing and that all health protocols were being followed.

Additionally, there was hand sanitiser available in the classrooms and throughout the schools. The use of hand sanitiser was not always beneficial for all YP however, as those with health or contamination anxiety or OCD (Obsessive Compulsive Disorder) developed compulsions around using it, making their “hands raw” (Professional E) and others would not use it at all. The social distancing guidance of keeping two metres away was also enthusiastically adopted by the YP with OCD:

COVID was brilliant for them because everyone was abiding by a rule that they would have wanted to have in place. (Professional K)

Distancing guidelines were difficult for special schools or those working with more complex YP to follow, as their students needed more physical care or instruction. This guidance was therefore not possible to adhere to in those circumstances.

When vaccinations became available, some YP were offered them early and there were reports of health professionals visiting YP at home if they were not able to attend a centre. Staff in schools and health services were prioritised for the vaccination, but not everyone wanted to take it up, but those who did hoped it would enable some normality to return. Other measures were put in place for some schools when all YP returned, which included using one-way systems, marking out the floor in two metre portions or the use of Perspex screens around desks. Often a professional had a conversation around masks and other measures to see how the student felt about its use and they would be guided by them. Friction arose, however, when a student wanted certain measures, but the staff were unwilling to accommodate them:

And actually, we did have to move some students to different tutors because the SEN students wanted safety - physical, you know, kind of like the health side of it. And if a tutor wasn't willing to do that... well, we couldn't have them taught by them, because ultimately, they're here to get this very bespoke package. (Professional F)

Other challenges appeared for managers at this later stage of the pandemic, as staff did not always want to say if they had been vaccinated, so managers could not reassure nervous YP

or parents that their teacher had been vaccinated, which affected the trust between families and the setting. Furthermore, once the vaccinations became available, testing and other measures in schools decreased, despite the infection still remaining in the community:

Students, also families, being irresponsible with not testing because we insisted that if they were snotty or unwell, they had to test before they came in. We weren't doing everyday testing, but some students still came in and they weren't well. We tested, it was COVID, so we sent them home. But by that time it's kind of too late, isn't it? (Professional C)

Additionally, other health issues obviously continued throughout the pandemic but with reduced support available and with the added stress of the unique situation:

In the middle of it all, in June 2020, I lost my brother as well, so he developed cancer a little bit before that and in the March he had the operation [...] But just after that they announced the lockdown and they also announced that the (hospital) weren't taking on any new patients for radiotherapy or chemotherapy. And my brother wasn't able to get that support, but also they stopped visiting him at home, so he was very isolated and he died in the June because he didn't get any treatment. Which was super tough, but also I couldn't get there because the restrictions meant that I wasn't allowed to drive out of the city or travel out of the city. So, you know, it was, that was very challenging dealing with that on top of dealing with what was going on here. (Professional C)

6.3.3.1 Theme 3: Working Life: *A real shift away from any form of familiarity, wasn't it to entirely novel ways of working. (Professional K)*

Working life changed significantly for most participants. Work for most became very busy, going online and becoming more intense:

So the groups stopped. Lots more psychotherapeutic work stopped. It was lots of risk, lots of duty appointments. We call them risk appointments, risk assessments and kind of just managing people who are acutely unwell. Young people who are acutely unwell, young people with parents who are acutely unwell. (Professional J)

For many professionals there was both an increase in what they were expected to do and a change in the types of work they undertook, such as checking YP had enough medication or purchasing equipment or activity packs for those with complex needs to use at home. Many reported working longer hours and took on greater pastoral roles. For some this change left them initially “somewhat rudderless” (Professional K), but also unexpectedly gave time to pause, reflect and work on ideas or developments for which there was not usually time. Most reported having more meetings than usual in response to the pandemic and because it

was possible to do more online meetings than in-person. The meetings themselves created structure for some professionals:

So these were management meetings, but actually I think that's what kept me going in lockdown because they were Monday, Wednesday, Friday and phone calls in between. So I had sort of a social life! (Professional D)

Some found they were doing more administrative tasks than teaching, trying to connect with YP and families and check on their welfare or ensure they had some structure to each day. For some in senior roles, the changes made a pre-COVID-19 occupation, which had already pushed them to the limits, extremely challenging, particularly for those in education:

The impact for me was that just before lockdown, I was already having conversations with my head teacher about the number of hours that I was doing, and we'd already tracked that to be between 50 and 70 a week before lockdown. When the pandemic hit, my hours just went completely through the roof [...] all (the team) working effectively around the clock really. (Professional B)

Increased pressure on staff meant work encroached into early mornings, evenings and weekends and most professionals were exceptionally busy. However, some professionals, had a very different experience:

So the first lockdown, hardly anybody that I knew in the music service was working. The second lockdown I could use a computer and use Google Classroom and Google Meet to teach remotely, which was interesting and sometimes successful and sometimes not. (Professional H)

Professionals who provided therapeutic input were initially concerned about moving their service online as they had not been trained to provide therapy in that mode. They would normally be expected to be certified by the UK Council for Psychotherapy or by the British Association for Counselling and Psychotherapy to provide online therapy, but there was no time to undertake this training.

Some staff remained working in their setting throughout or partially, and they were grateful for the social contact, even if this was socially distanced. They felt it was important to be able to ask for others' opinions and have time to discuss difficult cases during casual conversations between colleagues as a way of sharing the burden. They felt it provided support and a chance to share difficulties and as Professional J commented, *"I think not being with people in the office was a big stress, making clinical decisions on your own"*.

6.3.3.1 New skills: *At that time, nobody had any clue what they were doing.*

(Professional J)

Overnight digital and technological skills became paramount. This immediately disadvantaged some professionals who usually taught or supported in person and also disadvantaged some services and curriculum areas which were challenging to provide online. The special needs music service was one provider that struggled to offer an online service. Schools could not let the professionals attend in person and all events and groups were cancelled. The service managed to be creative about this by videoing themselves singing or playing and sending the recordings to schools to use in classes or to send to children at home. However, it was unclear how successful these were or how much they were used, as little feedback was given. The professionals who were videoing themselves had a steep learning curve with not only the technology but also initially in presenting themselves professionally:

Like for example this woman, lovely woman, but she was in her shorts and a summer top and I just went, and that's a lovely song, thank you, but can you change your clothes and do it again?! (Professional D)

The music service was a peripatetic service that would not have used online technology previously and it took some time for the managers to find an appropriate software solution:

When we finally got permission to set up Google classrooms, we had to pay a consultant £25,000 or something like that to set up Google classrooms for all the children. You're talking a lot of children here, 200 staff, you know, huge number of children and all the staff using Google classrooms had to have a laptop. So the Council had to dig out all the old laptops. (Professional D)

Even when software was eventually agreed upon, difficulties remained with the technology due to time lapses and poor sound when presenting a live class remotely, which made some contributions ineffective and class teachers gave up engaging with the service due to this. A small private college allowed tutors to use whatever software they were used to using in order to set up remote learning speedily, which meant students had to adapt to multiple formats when they engaged with their tutors online. There were technological difficulties for all professionals at times as not everyone had sufficient internet connection at home, which could be unreliable, resulting in aborted sessions and frustration for all concerned. Professionals did not have the knowledge at the start of the pandemic of the platforms used

by their settings and had to learn quickly. None had done substantial work online before, so almost all mentioned feeling out of their depth to start with and staff also had to train the students. Some felt that older members of staff did not always have enough knowledge about digital systems and needed more time and support to feel confident using them, but even younger professionals struggled with this.

Additionally, some reported that not all students had a device to work on at home and so laptops were delivered to them. One professional mentioned requesting laptops from the government when this was offered, but none materialised. However:

*We worked out in the end, even if we did get the laptops, the ability for parents and students to actually utilise those without any form of training is impossible.
(Professional C)*

This lack of cohesion was underlined by professionals who said they had received laptops from the government and delivered them to families, but the families did not have the broadband to connect them to the internet. Additionally, YP eligible for laptops were prioritised according to a government list of who met the threshold for additional support, but this did not consider the number of devices needed by families with multiple children:

And in theory they were truanting if they weren't attending their lessons. Well, quite a few of these young people were desperately trying to attend their online lesson and just couldn't get past the password bit at the beginning. Or their Internet failed them or their older brother's taken it because he needs it for his GCSE and you're only year eight, so you don't need it. [...] And there was no global, certainly in our school, reaction to that in terms of, OK, well, maybe someone else needs an extra laptop. Maybe it isn't just these people on this list. (Professional B)

Initially schools' systems remained inflexible, sending out truancy warnings to parents if their child had not attended an online lesson, however, this was corrected when the situation was understood as more complex than just non-attendance. Even on school premises there were difficulties with getting a reliable signal across the site, especially if technology had not been at the forefront of their approach pre-COVID-19:

*I used to have great difficulties because we'd be advising before COVID that young people would use their phones for voice recognition technology. That kind of thing. But they weren't actually allowed to in class because our school had a no phone policy. So it was actually really very, very challenging to make that switch.
(Professional B)*

Some settings provided work online which took a long time to produce, but then found there was no active use of this by YP with more complex needs, as the technology was not available at home. Professionals were also aware that many students were not able to generalise learning from home as this was an unfamiliar practice, and professionals therefore felt it was an ineffective educational tool. More able students were able to access online learning if they were given training before being asked to use it, with some accessing it on smartphones if they had no other device.

Services also offered online activities as something for YP to do and as a way of monitoring how they were:

We couldn't do home visits to our young people. So we were doing online cooking sessions, via teams with our young people, so we were kind of doing a lot of this stuff online. We were doing music quizzes. We were doing all sorts just to keep that interaction going with the children we were working with. (Professional N)

The engagement of YP with the remote format was variable. Some YP were unable to engage with it at all, some were able to manage it, and some did better with this mode. However, it was difficult to monitor online sessions, as YP would not talk during lessons or in a group therapeutic intervention, which made it challenging to assess how it had been received, if it had been received at all or how effective it had been. Some professionals found it difficult to make the online sessions enjoyable, whereas in person:

You can play a game of football with them whilst talking and, you know, get the art stuff out and scribble on things and life's the poorer for not being able to do those things with kids. (Professional K)

A professional working one-to-one with HE students found their work adapted well to remote sessions and in some ways it was easier. The ability to share screens and for the YP to use the software they needed without it impacting the tutor, such as screen magnifiers or readers, meant the experience for some students and tutors was considered comparable to in-person:

If you've got more than one person, there are downsides to meeting online. And you must miss out on certain non-verbal communication when you're online. But I sort of feel that for the purposes definitely of study skills and when it's just two people, I think it works almost as good as in person. With all the added benefits of no travel. [...] I personally think it's 100% OK. (Professional L)

Other new skills professionals mentioned they developed at this time, were those of videoing and editing themselves in order to present pre-recorded lessons to YP at home and using technology to present live lessons. The recorded lessons allowed the YP to still connect with the teacher and the subject, but the professionals found it difficult not having immediate feedback to see how it was received.

6.3.3.2 Education: *We didn't actually stop functioning as a college, so we sort of scraped through. (Professional C)*

For those participants involved in education (ten of the twelve), providing appropriate education was a challenge. Continuation of education was considered important for YP to have a routine and to continue familiar relationships when everything else was changing around them. Routines were not incorporated for all however, as some YP were reported to be missing lessons due to sleeping longer as they no longer had their customary morning taxi waiting to take them to school.

How settings reacted at the start varied, as some shut completely, only developing their educational programme once they could see the situation was not going to change quickly. For some this took at least a month, whereas others started online immediately lockdown began. The delivery from some providers was not always academic, with an emphasis on offering games and ideas for activities to fill the time for some. However, some settings did continue as usual and their YP responded well to the new routines:

I think probably some of them quite like having lessons or liked having supervision because that was their known and their safety. So maybe that's why it didn't really drop, people kind of needed that structure (Professional F)

For those who moved to online delivery of education, the response of YP was mixed with some attending and some not:

And then there are other students who absolutely wouldn't come on video, wouldn't do it, access it that way and you could chat to them over the phone and try and talk them through it. And then there'd be some students that just wouldn't access it at all, wouldn't come on at all. (Professional G)

Some professionals commented that they quickly got to know the individual learning needs of students and how best to enable them to access their learning. However, some of the YP in specialist provisions were not able to engage with online learning and physical packages

were sent home to give YP something to keep them occupied. However, professionals did not always know if these had been used as *“I never saw any of that work come back”* (Professional E).

Many settings reduced their range of subjects, which particularly affected the special schools and colleges as they were more likely to be offering curricula based on social skills or practical subjects. Any work or activities in the community stopped which was distressing to YP who did not understand the reasons for this. Core subjects were just English and maths and sometimes personal, social, health and economic education (PSHE). Additional subjects were offered but these were limited if the YP did not have access to outdoor space for example for horticulture or have the ingredients for cooking. Some YP attended the things they liked and then went offline, and as one professional put it, some YP knew there was nothing much the teachers could do if they did not attend and that *“They're teenagers, aren't they? So they're going to push!”* (Professional G).

If parents were supportive and available to help, the attendance of the YP was positively affected, and these parents reported the YP were glad of some structure in their lives. Those YP whose parents were out at work or who were not able to assist were reported to have had worse attendance. Conversely, there were some YP who had better attendance online than they had in-person:

And I think it's because they have more attention because it was more 1:1 because not everybody would turn up, so they felt they had more attention. Although maybe they just missed the face, I think, you know someone to talk to. (Professional G)

Some providers continued with a full school day with their in-person education, but their online provision was over fewer hours in a block if it was live and timetabled to ensure YP did not disappear between classes. Others continued with the same timetable online that would have been offered in-person. Each provider was a different size and type of setting which had distinct student profiles, so each had to work out what was possible to do for their particular YP, staff and setting.

HE students accepted their study skills sessions online, but most did not like remote lectures, despite the convenience of them, such as being able to pause recordings and listen when convenient. This was understood to be because the students could not ask questions or ask for clarification. Because classes were not live and there was little personal contact,

there was the danger that some students went unnoticed if they were struggling, resulting in some students failing their courses or not understanding what was required of them, especially if the lockdowns coincided with their first year at university.

Despite schools being given leeway by emergency amendments to the law as to how an EHCP was implemented, the SENDCo in this study reported that a minority of parents insisted on the full provision being offered when the YP attended in-person. For example, demanding one-to-one teaching if that was stated in the EHCP, even though staff shortages meant this was challenging to provide. Other parents were more flexible and asked for tuition for their YP on the new platforms and also asked for activities which would help their YP socially and emotionally, such as playing board games. Some settings offered a place to all YP with an EHCP and some were unable to do this due to staffing and selected those they considered most at risk at home.

Due to the smaller number attending schools, cross-age teaching was developed, and some TAs began online teaching if they had subject specific expertise. More creative approaches to learning were also tried:

Once we've got our head around the fact that, they weren't gonna really make academic progress, the majority of the children, we were quite free to say should we go down and walk around the forest at break time and then five of them would go and we wouldn't get back to the next lesson on time and we'd just explain where we were and we might have an extra half an hour wandering around just looking at the birds or something. Well, you wouldn't normally get away with that in a secondary school! (Professional B)

Teachers could respond to needs of the YP as they arose and provide more personalised care and education:

And one of his (a YP) big frustrations with lessons was that he would be in art and he'd be drawing something. And then the bell would go and then he'd have to stop, and then he'd have a meltdown. We had all these meetings, but we knew what he needed. He needed to finish his cartoon. We could say, shall we spend 2 lessons doing this then? OK. Well, as long as in the speech bubbles you cover verbs and adverbs that's English and art sorted! (Professional B)

In a large school, this flexibility also allowed professionals to respond to who was in greatest need of attending if contacted by a social worker or parent, rather than just those on the official vulnerable list. Teachers were also able to be more responsive in the moment:

Like you would in a special school, really. But being able to make those adaptations yourself just like that because you know that you need to, without filling in a form, sending 25 emails, having three meetings. Obviously, I'm being a bit facetious there! (Professional B)

The closing of community provision for YP meant that some settings also had to be creative in providing alternative opportunities. These included a classroom café instead of going out in the community or providing sports facilities within their grounds rather than attending a leisure centre. It was acknowledged that this was not the same experience for the YP but was felt to be better than nothing. Professionals felt the lack of work experience, which was hard to replicate, greatly disadvantaged the YP during the pandemic.

One special needs college mentioned they had applied for and been granted funding for their students to do up to three extra terms on their course as they had been badly affected by the interruption to their education. This was because their programme was a supported internship which has considerable work experience as part of the qualification, which for several weeks they were unable to complete.

Annual reviews, a statutory meeting to update the EHCP to ensure they remained relevant (DfE & DoH, 2015), still took place for YP but they were held online or by phone if the parents did not have the required technology. Attempts were also made by one school to hold them socially distanced in-person, but these were not successful. When they were held the usual criteria appeared somewhat irrelevant in the pandemic circumstances:

When you're going into that annual review meeting, you are thinking about what's gone well and what do we do need to do now, particularly when there's an upcoming transition, you know, who do we need to speak to, which professionals do we need to involve. Who needs visits where, most of that stuff just couldn't happen because we couldn't engage with the professionals that were needed to support that work. So it was just a paper exercise. (Professional B)

Applications for new EHCPs were also put on hold, certainly for some LAs, with applications being accepted into an email address, but no decision being made about them until the LA was able to resume processing them several months later. This was then too late for some YP as they had already moved to a new placement, and the new setting did not have sufficient evidence to apply for one. This resulted in some YP never receiving an assessment

for an EHCP nor the support they needed, which risked them becoming NEET (Not in Education, Employment or Training).

Professionals were also aware of some advantages of the quieter pace for YP during lockdowns. They reported that some who enjoyed books *“discovered the world of reading and escaped into it” (Professional B)*. Mental health professionals recognised that some YP were also relieved not to be in school as it was not meeting their needs, with one professional asserting that *“80% of my caseload [...] are young people who are in the wrong school” (Professional J)*.

Regarding the teacher assessments which replaced exams, some professionals felt these were not seen by the YP as holding the same value as when they were assessed by external examiners. However, they saw that some YP did better than expected. Queries were also expressed about the reliability of a system where the teacher will obviously want to

Make sure that students succeed and you want to succeed as a teacher, resulting in them not being quite as strict with the marking schemes as maybe you should be.
(Professional G)

6.3.3.2.1 Return to education: *You would expect engagement for about 25 minutes and then say, right, we're going to go and do a movement break.*
(Professional G)

When YP returned to school, some appeared to be more withdrawn and others were excited to be back. Most professionals reported that although it took some time to settle back into the routine, most YP were relieved to be back to their familiar surroundings. Some settings went back to routine immediately, whereas the specialist providers were more likely to bring them back on a phased return building up to a whole lesson over time. This phased return also helped those with anxiety, which had increased for some during the pandemic. Additionally, those with additional health problems took longer to return due to the concerns of the families about infection risk, but they did return when they felt it was safe to do so. Professionals reported that most of the YP quickly acclimatised to being back to the familiar routine as the YP felt secure. There also had to be a gradual re-introduction to community activities, such as using public transport, going to work experience or to cafés. Differences were observed with the YP on return to education, with YP showing greater

anxiety and some finding it difficult to tolerate each other in a group. Furthermore, some YP had forgotten how to behave in a group setting with some appearing to have regressed:

I worked in a mainstream school. I did nurture music groups. And so there were quite a lot of people who had chewy toys and fidget toys that they would bring with them as well. And those started sort of just after COVID. I think they were started up in response to COVID, to be honest. (Professional H)

The catch-up tutoring funding, which was announced by the government in June 2020 was not felt to have been well considered. Most of the professionals believed there were other more important aspects that needed attention, rather than focusing only on the academic and there were also problems with the delivery of the tutoring:

It was kind of like one of those policies that was presumably made by some really well-meaning people that had never worked in education. Let's run a four-week summer school. Yeah, great. All these children could come in for four weeks and by the end of four weeks, they'll all be back on target. How are you going to fund that? How are you going to staff that? OK, you've given us the money, but who's actually going to lead it? Sounds quite sad saying it out loud actually. (Professional B)

6.3.3.2 Professionals' views of Inclusion: *So, the question is why do so many young people struggle? Not how can we make them fit better with what we have. (Professional K)*

Professionals were asked to reflect on how the policy of inclusion was operating in practice, in order to illuminate the educational context that young people were likely experiencing as they entered the pandemic. For some YP these experiences could explain why they were relieved not to attend school/college in the lockdowns:

So, I do think it does depend maybe on the culture of the school and what its priorities are, and whether you measure those predominantly by academic success or whether there are other things. And there are other things aren't there that you could be measured by. (Professional B)

Professionals in special schools were particularly aware that many had come from difficult experiences within mainstream schools first:

I think a lot of the conversations I have are thinking about challenging perceptions of how we organise education. There's so many people for whom education in this current form is an ill-fit. (Professional K)

Those in mainstream settings could see that teachers had not had adequate training for the wide range of SEND that YP may present. They mentioned that YP did not want to stand out in the teenage years, so inclusive practice had to be usual class practice not an additional extra for a few YP. This was especially important as YP moved into secondary education and beyond due to peer pressure. They also felt the emphasis on academic achievement missed opportunities for inclusive practice and meant YP often felt they were failing if they were not able to achieve in this way:

And I think that that (the impact of academic failure) lasted and probably has continued to last for some of those people as they've become adults because you know it's like, if you're doing those standardised tests that are for age-related expectations and you're always falling short of them, that has to have an impact on your self-esteem overall, doesn't it? (Professional B)

The professional who worked in a small private college thought that the large, busy environment in mainstream schools did not suit many of the students with SEND who transferred to their college. The intensity and competitiveness were also mentioned as something with which special school students had struggled in previous settings. Additionally, the impact of the wrong provision on CYP was described by a CAMHS professional:

I've had young kids who were cutting up their arms, banging their head against the wall. Parents are dragging them out every morning to school and then they move them. They move them somewhere and it just (clicks fingers). And we don't see them again; they get discharged within months and we don't see them ever again because it's not a mental health problem. It's a wrong school, wrong child problem. (Professional J)

6.3.4 Theme 4: Post Covid-19: The impact on everybody was immense, wasn't it? (Professional C)

Professionals working with YP within mental health services could see the lasting impact of COVID-19 on some YP in schools:

So we have a grammar school that insists it doesn't have any mental health problems in its school, and you walk out to the waiting room and all the girls are sitting there wearing the grammar school uniform. It's massive mental health crisis in schools and secondary schools. (Professional J)

Prior to the pandemic, mental health professionals were used to dealing with YP who had been traumatised by their school experiences who were then either school avoiders or attended a specialist provision. For some of these YP the pandemic had been a welcome relief:

They went home and they realised how much better they felt. They're not gonna get them back in there - would you? (Professional J)

Professionals found that services did not all return to normal after the general restoration of education, with an “impoverishing of services since then. So some of those relationships and experiences that were lost have never been reclaimed”. (Professional K). Furthermore, some outside spaces, such as cafés, community halls or leisure facilities had closed, either due to funding constraints or staff having taken up new jobs during the pandemic. This then restricted settings’ social skills provision and wider curriculum offer at a time it was especially needed to allow YP to become used to living in a more social world again. One professional in a specialist post-16 college noted that the achievement figures for some of their students had not yet returned to their pre-COVID-19 levels, with many unusually not reaching a pass in their courses. The reason for this was explained by certain social elements of the criteria of the curriculum:

Yeah, it's the behavioural things of like autism that's dragging it down. So I think there's still adjustments being made to what's happened because our young people here on this site aren't able to verbalise what they might be feeling in terms of what happened or other understanding of what happened. So I think it continues a little bit longer with them. (Professional C)

Music teachers also noticed that behaviour had changed after the pandemic due to YP only being in informal situations for two years and missing key events:

They didn't really know that they were expected to be quiet and not talk for a certain portion of it until they did their performance and they didn't really know how to show things had concluded, so they needed a bit of performance skills, but they also needed a bit of audience skill building as well. And about maybe things like we don't get up and move about normally during a concert in the middle of somebody else's song, or even in the middle of our songs! (Professional H)

Similar difficulties arose during post pandemic residential trips, where YP did not know how to behave:

I've done those for 10 years, except in lockdown, and I thought this is a bit more difficult than ever. You know, they've never, they've never been out of their houses, they've missed a residential opportunity, so they didn't understand anything about not being at home. (Professional D)

It was felt that for some YP “there's a developmental stage missing” (Professional D) post pandemic, as they behaved as though they were much younger than they were, even allowing for any SEND. A specialist provider commented that new students had arrived from mainstream provision after the pandemic as they were unable to return to their previous settings. These YP appeared not to have engaged in any learning during the previous two years and were significantly behind in their level of achievement and arrived with high anxiety levels.

Post pandemic, more inexperienced staff who did not know the classes were employed, which meant previous relationships between peripatetic professionals and schools changed:

There have been huge shortages of staff, it was different staff, supply staff every week, very discontent feeling everywhere because it wasn't secure. After, staffing problems were the biggest problem. Massive. (Professional D)

Additionally, post pandemic it became difficult to attract schools and YP to some of the big concerts and events that had previously been so well attended, as people's social behaviours had changed. Staff had become used to accessing events online and did not want to complete risk assessments and drive a minibus with the YP to an external event. This was acknowledged initially as linked to the fear of infection and the absence of permanent staff but was also seen as arising from the school's expectation that things would now be delivered to them online. Changes in practice and expectation were mentioned by several professionals, in terms of remote or hybrid working:

I think there's more of an expectation now that if we can't physically be somewhere, that we send something that they can access in our absence. (Professional H)

Professionals noted that many meetings were now online and that social workers and LA representatives appeared to still be based at home rather than in offices and often preferred online meetings. Additionally, some mental health work with YP had only just begun to

return in-person in 2025, with the majority still being offered online. This was despite the mental health professionals saying that work in-person with YP was essential and preferred by the YP. All said their use of technology was a larger part of their working life now and that they had far greater knowledge of its effective use. There had also been some beneficial innovative modifications during lockdowns made in response to the pandemic. Some professionals were hopeful that these changes would continue and be built on after the pandemic:

We retain a very Victorian model of education in our minds where we think kids have to be sat at a desk. That's where learning happens and that's the bar we measure success in relation to, and all that went out the window and people were thinking about something which is more useful, I think something more fundamental about individual need. So I'd like to think that the experience challenged our collective perceptions on what children need in education. Hopefully introduced some flexibility in practise and thinking. [...] But I hope if there's a legacy, it might be some of that thinking and some of that practise. (Professional K)

There was an example of this creativity with the mainstream secondary school who, post pandemic, trained staff and sixth formers as mental health first-aiders. This came as a result of acknowledging the need for mental health support after the lockdowns and also of seeing that the mixing of ages within the school during the lockdowns was often beneficial for the YP. Additionally, they continued to build on the mixed aged clubs that had started in the pandemic and found funding for innovative projects such as a therapy dog and Forest School in order to encourage some reluctant YP back into education.

Conversely, in this same mainstream school, the professional found the expectations post-COVID-19 upsetting, as they had hoped that greater change would be possible afterwards. However, only a few months of leniency regarding attendance was allowed, and then it became more punitive. This was because the school was a high-achieving school and experienced pressure from parents who gave donations to the school and wanted high standards to be set and followed. The school was also following the government guidance regarding YP returning to education, of prioritising attendance:

And those punitive measures meant that many more children were being excluded. [...] The overwhelming wish from other teachers and other leaders was, if we're not

hardline and strict with these children, then we're never gonna get them to do what we want them to do again. (Professional B)

Personal changes were also prompted by the pandemic, such as new career paths or a re-evaluation of their work or lives:

It became much more about getting people through the door, assess them, put the six-week plan in place and then out. [...] It's delivered, you see, you can tick the box and say it's been delivered. I'm being a bit sarcastic here, but I think that was my view. That's what shifted. (Professional J)

I was already beginning to think this is not humanly possible to do this job properly and it was what really kind of tipped the decision for me. (Professional B)

6.4 DISCUSSION

This was the final study completed with the aim of gaining an understanding of the impact of the pandemic for YP with SEND and those who care for them. Several of the professionals said they could now look back without the trauma that many had experienced, enabling them to discuss their experience during the pandemic. Some commented that they had never been asked to think about what had happened before and found it helpful to reflect back, enabling them to process what had occurred. As a result, they said they had themselves discovered new things whilst discussing the questions about how they had managed or what it had been like for the YP.

6.4.1 Summary of findings

Professionals had diverse experiences of the pandemic, but for the majority of the participants in this study it resulted in longer hours and more stress. Initially, the uncertainty was difficult to navigate, especially as they did not have prior warning of changes made by the government. This difficulty was combined with the need to respond to those who were vulnerable whilst maintaining safety protocols in their settings. Additionally, measures directed by the government were not always appropriate for the YP the professionals worked with, and they had to create original ways to adapt them to their settings.

Furthermore, professionals' working lives were completely changed by distance learning and service provision. However, some professionals continued to work in-person which also

brought challenges as to how education or therapy was delivered. Professionals' wellbeing therefore decreased for most participants due to increased stress, especially for those in senior positions. They also considered the YP's lives were made more challenging, and their wellbeing impacted by the loss of routine and less of all that makes life interesting. This included a less varied curriculum which took time to return to normal after the pandemic, as did some of the YP's achievement levels and behaviour.

These findings will now be considered under the headings of Increased challenges for professionals, Challenges for the YP and Post pandemic impacts.

6.4.2 Increased challenges for Professionals

Responsibilities increased for professionals in leadership positions during the pandemic, and a SLT role is one that already pre-pandemic involved dealing with a multitude of external and internal pressures coming from *“national government, local government, education agencies, children's services and allied health professions, news media, professional associations and parent and community groups”* (Hulme et al., 2021, p.165). Mahmud and Castro- Kemp (2022), reported that SEND professionals' experiences were leading many in 2022 to consider leaving the sector. Study 3 found that the additional pressure of the pandemic on those who were already struggling with their workload meant this consideration did translate into action to leave after the pandemic, with several making career changes.

Although participants in the current study understood that in this unprecedented situation guidance would change, professionals felt they were hearing the government media bulletins each day at the same time the general public was informed. This gave no time to be able to discuss the ramifications and alternatives before parents and staff began contacting them and asking for information after seeing the bulletins themselves. This was also reported in the study by Hulme et al. (2021) which was undertaken in the first part of the pandemic in 2020, but the current study found that this continued for as long as the media bulletins were issued with no improvement. Professionals were also overwhelmed with policy and guidance documents each day. Settings received fifty guidance documents from 18 March to 18 June 2020 from the DfE and for the first ninety days from the announcement of the first lockdown, two hundred and one policy updates were issued by the DfE to schools

(Fotheringham et al., 2021), which significantly added to managers' workloads. It was a finding of Study 3 that it was difficult for managers to plan ahead if they continued to work in-person as they did not know which staff would be coming in due to illness or staff feeling it was unsafe. Managers also did not know which YP would be coming in, as this was influenced by how many staff they had that day, along with the health status in the YP's family and that of any taxi drivers or travelling companions if the YP had transport to school. Many issues for YP with SEND had not been considered, such as the inability to social distance in a special school or the problem of YP mixing with others on school transport (Crane et al., 2021).

The change to online working was a major shift in working practice. As Floyd et al. (2023) also found, few of the professionals had used the technology they were required to use before the pandemic. Study 3 found that it took some settings several weeks to develop an online educational plan, train staff and deliver that to YP, which created a gap in education continuity. Some professionals stated that provision was delayed by managers who had safety fears regarding Zoom (Paul, 2020) and the fact that Skype, which was also familiar to some, used too much broadband for everyday use (Yatsenko, 2025). Finally settling on an appropriate platform meant education resumed, but it still took time for professionals to learn how to use the systems effectively. There was no standard approach to education, and each setting adapted learning to their own staff and YP, resulting in much variation in quality and mode of delivery (Howard et al., 2021). This varied from packages of physical activities sent home or static worksheets put online to a live online or in-person lesson. The production of packages of work was time consuming and costly to deliver and for the majority, it was not known whether these were used or not. Additionally, music teachers produced videos of songs and activities for classes which involved the class teacher being more involved than usual in the delivery and so was dependent on their interest in doing this. The music professionals also did not know how much this resource was used, and sometimes they tried to engage online with a class but could not be seen or could not hear due to the poor quality of the technology being used in the school or lack of knowledge of the teacher on site. In a DfE 2020/2021 survey 54% of secondary leaders reported they had a digital strategy, which had increased to 68% by 2023, but still did not include all providers (DfE, 2023).

YP's educational experience during the pandemic was therefore diverse and may have been almost as good as usual for some but nothing at all for those who could not engage at home (Pensiero et al., 2022). Education and other services were not set up for distance delivery pre pandemic and online delivery was hampered by some people not having a device, having poor internet connection or a lack of knowledge (Coleman, 2021). Even if there were sufficient devices, YP with SEND were found in this study to need specific training to use them, and this did not always happen.

The increase in responsibilities and pressure at work, together with any family commitments such as having their own children learning at home, created a stressful environment which the majority in this study stated they would never wish to experience again. It was found that the usual social network for staff and the ability to ask others for their opinion or ideas disappeared for those working from home, resulting in increased responsibility with greater risks but less support. Working from home also meant there was a blurring of work and home life boundaries, with confidential spaces having to be found and multi-tasking across the day between work and home demands (Kim & Asbury, 2020). However, despite work being stressful for most professionals, this study found that for some, work had been helpful for keeping a routine, which lessened their own anxiety about the unfolding situation.

6.4.3 Challenges impacting the YP

Concurring with Crane et al. (2021), professionals in this study wanted specialist settings and YP with SEND to be considered as a priority in the crisis as they are some of the YP with the greatest needs in society. However, they felt they were an afterthought in pandemic policies, if they were considered at all. This was confirmed by the 2025 Covid-19 inquiry where it was revealed that the government had no specific plan for schools even up to the announcement of the lockdown, and no specific guidance for YP with SEND (Hayes, 2025). This resulted in schools having to be creative in their interpretation of the guidance. However, prioritising the YP's needs was a difficult task as the government priority list (DfE & Cabinet Office, 2020) did not include all those who emerged during the pandemic needing support, leaving some families without the safety net of school or professional contact. The Covid inquiry also revealed that there was no prior agreement of which children would be considered vulnerable before the pandemic (Hayes, 2025). It has been reported that on average, special schools, where every child would be considered a priority, only took 30% of their intake

during the first lockdown (Skipp et al., 2021b). In Study 3 of this thesis, the large mainstream school was able to accommodate all YP with an EHCP as they had more space and more staff available, but smaller settings were not able to do this. Some YP who had not been on the school's SEN support list before the pandemic, emerged as YP who would also have benefitted from being allowed to attend school or having a school laptop. For example, families with multiple children or the siblings of YP with SEND. Additionally, those with parents who were unable to support them at home also needed to be prioritised.

Many families who were on the margins of vulnerability before the pandemic were made newly vulnerable by the crisis as reported by Driscoll et al. (2020), which was also found in this current study. Some of these were unknown to professionals, as they were on a waiting list for an assessment, but some of these YP reached crisis point during the early part of the pandemic and in some instances professionals were not able to act before YP took their own lives. This then resulted in stringent risk assessments for all YP on a waiting list (National Child Death Mortality Database, 2020). Being on a waiting list was a vulnerable situation for YP as their needs were not known or being met, and no professionals were supporting them. YP who lived in a chaotic home also suffered, as the unique situation pushed families beyond their ability to cope (The Children's Society, 2021). Additionally, professionals were aware of an increase in domestic violence which was confirmed after the pandemic (Piquero, 2021), resulting in some taking the initiative to visit homes to offer support which was beyond their usual remit. The study by Perryman et al. (2022) found that 29% of teachers had made home visits, 77% had made pastoral phone calls, 45.8% had helped arrange broadband and 45.8% had delivered food packages, all tasks not usually undertaken.

Section 42 of the Children and Families Act 2014 states that the LA have an absolute duty to ensure the provision stated in the CYP's EHCP is delivered. However, for practical reasons during the pandemic this was relaxed by the Secretary of State through the Coronavirus Act, 2020. This meant that LAs and providers only had to do what was 'reasonably practicable' (Coronavirus Act, 2020, SI 2020/471) to keep to the legal timeframes for assessment for an EHCP or to fulfil the stated provision. There was no definition of what was reasonably practical, and this resulted in the provision being diluted for most YP causing less differentiation and support (Canning et al., 2021). Study 3 found that Annual Reviews of the EHCP were also affected as many became paper based online meetings which professionals

felt was not an appropriate way to discuss the YP's future transition out of education or to another placement. The preparation that would normally have occurred for transition was absent which this study found resulted in unsuccessful moves to new placements for some YP.

There were advantages for some YP of the changes to learning. There was a small number of YP that did better learning from home than they did at school and were more engaged. It had been found through earlier studies with parents that some YP preferred home-learning (Greenway & Eaton-Thomas, 2020) and this current study found that some YP attended more of their online lessons than they attended in-person and produced more work than usual. Teachers in this study felt this may have been as a consequence of more individual attention and the reduced environmental stress for those YP. One teacher also commented that she understood her class's individual needs more than she had in normal times after having to adapt work for them online. Those who attended in-person also benefitted from the quieter, more relaxed setting, which concurs with the findings of Canning et al. (2021). Staff in this study also reported that they were able to give more individualised teaching with a more flexible curriculum to the smaller numbers who attended.

However, Study 3 found that there was a narrower range of subjects delivered online for many, with a focus on the core subjects of English and maths. Conversely, the small private provider was able to continue with a full timetable of lessons online. For most, this study found that the curriculum offer was less rich, especially for those for whom community activities were an important part of their experience. Professionals responded creatively to this challenge, setting up experiences at the setting but acknowledged it did not replace the reality of visiting a community café or leisure centre. Activities were suggested for remote learning of more practical subjects, but these were challenging to provide if the families did not have the resources to put them into practice, thereby widening the range of YP's educational experience. The support of parents was key to the success of online learning as parents would ensure the YP attended a lesson, understood what they had to do, complete the work and submit it. Without this support, most YP struggled to engage with learning online with some not engaging at all (Floyd et al, 2023). However, a teacher participant in Study 3 commented that the YP knew there was little a teacher could do if a YP would not engage and they could not be forced to complete any work.

Professionals felt that the funding which was to be spent on supporting YP to catch up with missed learning during the pandemic, should not have been just for academic subjects but should have been more holistic and include the developmental and social skills that the YP with SEND had missed out on. This is also what Kevan Collins the education recovery commissioner proposed, but the funding was not agreed by the treasury, resulting in his resignation (Centre for Studies on Inclusive Education, 2021). In Study 3, the professionals agreed with him that this funding was not considered thoroughly and that there would be future repercussions and costs of this decision for YP. One of the psychotherapists felt that generally, the education system tried to fit the child into the system with a narrow focus on the academic, when many YP cannot achieve the baseline set by the government but still have much to offer (Williams-Brown & Hodkinson, 2020). Academic subjects alone were not thought to be the most important aspect of whether a YP would become a fulfilled adult who was able to take part in their community.

Professionals appreciated the importance of community, socialising and friendships for the YP, at whatever level was appropriate for them, but most left the YP and their parents to develop this. Although the availability of clubs was mentioned in some settings, which can facilitate social interaction, it was acknowledged that friendships could not be manufactured, and they needed to develop naturally (Matheson et al., 2007). However, it was observed in this study that the smaller groups who attended schools during lockdowns gave rise to greater opportunities for developing friendships. Some YP felt safer and more accepted in the school community in these smaller groups and received more attention and a more flexible approach to their education.

6.4.4 Post pandemic impacts

Professionals could see that even for YP who preferred learning at home, due to the stresses of socialising and school being removed, this did not necessarily have a holistically positive impact on them, as it resulted in diminished skills when they returned to education and socialising. Restoration of some of these skills was observed over time, but professionals commented that many YP showed a noticeable reduction in grades at the time of the interviews despite having been back in education for at least two years. Statistics for YP with SEND show that this recovery is ongoing and that they have been more affected than YP without SEND (DfE, 2025b). YP with SEND already started from a position of disadvantage as

their academic achievement is significantly below those YP without SEND and only 4.8% of adults with a learning disability who receive support from social services are in paid work (DfE, 2024d). This study also found there were repercussions of not being exposed to the usual experiences of childhood and adolescence on the YP's behaviour and maturity, such as not going on a residential trip or taking part in concerts. It was not known how long these impacts would last, but YP were reported to still be showing signs of greater anxiety and poorer social skills which led to school attendance difficulties. Attendance was already an issue pre-pandemic, but this has worsened and is still increasing according to the Education Policy Institute (2024) statistics. This was found in this study to have resulted in some YP moving from mainstream to specialist provision after the pandemic as they could no longer cope with the mainstream environment.

Professionals found that post pandemic many of the community resources they used pre-pandemic were no longer available, as they had to close down due to funding or staffing issues. Almost all had to close at the start of the pandemic (Whitehead, 2020) but it appears many did not resume their activities afterwards. It was found in this study that changes in how working life and education could be achieved meant staff had different expectations post pandemic of what could be done remotely with a permanent shift towards online meetings. This was useful in being able to attend more meetings with less travel but there were still times when an in-person meeting was more appropriate, for example if a therapeutic intervention was offered to a YP. However, offering a choice of mode was considered important for YP as some did prefer to meet online as was found by Kwok et al., (2022). Additionally, the creativity and flexibility that occurred in some settings was seen as a positive of the pandemic time, but professionals were saddened that this did not last once normal education resumed.

6.5 LIMITATIONS

This study began two years after the main impacts were felt from Covid-19 on society. Therefore, memories may have faded or been altered in the intervening time. However, although the finer detail of the memories, such as dates, may have been lost, these had already been recorded and are available online (Institute for Government, 2021). The main events and impacts, because they were novel and exceptional, appeared to be clearly

recalled and if some events were not, professionals were comfortable in saying they could not remember.

Eight of the professionals were no longer in their pandemic occupations, which may have meant they felt freer to express their views in interviews. It may be that professionals still in their original employment would express differing views if more of those had been able to participate. However, the participants remaining in their original roles did not appear to be limiting their answers. Additionally, potential response biases to participating in this study mean the findings may not reflect the experiences and views of all professionals. There was also only one male participant, which may reflect the fact that many more women than men work with YP with SEND in education, of whom 76% were female in 2024/25 and only 24% of those who worked in special schools or alternative provision were male (DfE, 2025c). It would therefore be of interest to see if male views differed in any way to the mostly female views in this study.

Lastly, the geographic area covered was diverse considering the small sample, but only one participant was not of white ethnicity and one other who was not British. Therefore, further research would be beneficial to discover the experiences of a wider ethnic range of professionals.

6.6 CONCLUSION

The world contracted for everyone during the pandemic which the professionals felt highlighted the importance of community and human contact. They acknowledged they were trying to make life as safe and varied as possible for the YP, but nothing could take the place of personal contact and having pleasurable activities in their lives. Professionals conveyed a sense of being abandoned by policymakers when much of the advice given to them was unclear or irrelevant. Additionally, it appeared from this study that greater responsibility was placed on education staff to ensure that families were coping, as other professionals were redeployed or unavailable, resulting in huge workloads which they did not feel were considered by policy makers. Professionals felt they had to present an authoritative front at times of great uncertainty and high stress, whilst experiencing multiple pressures from many directions and with hindsight they expressed amazement at what they had survived. Additionally, some mentioned the value of being part of this research project,

as they were still seeing the impacts of the pandemic on the YP and wanted to add to the available knowledge.

Chapter 7: DISCUSSION AND CONCLUSION

7.1 INTRODUCTION AND ORIGINAL CONTRIBUTION

This research was developed to gather the views of YP with SEND, who are often overlooked in research (Castro-Kemp, 2022). The purpose of this thesis was to discover the experience of YP with SEND during the COVID-19 pandemic in order to learn from this. It also aimed to fill a gap in the literature, as participants were YP aged 14 – 25 at the time of the pandemic which is an age group not well represented in the literature, as highlighted in the Scoping Review in Chapter 2. Furthermore, this research was based on hearing from the YP directly, which had not been done before and by triangulating this information with data gained from parents and professionals. This is, to the researcher's knowledge, the first study to focus on this specific age group with SEND, who were still in education at the time of the pandemic and had therefore experienced severe disruption to their studies as they approached adulthood. As a result, several new findings were documented, the details of which are in the relevant chapters. It therefore gave the YP a voice which had not been heard before and has documented how this unprecedented time had impacted them.

The research questions sought an over-view of YP with SEND experiences during the pandemic and also asked about the support and information they had received. Additionally, the thesis sought to understand the intersection between young people's sense of belonging in their setting and their lived experiences of the pandemic. YP, parents and professionals were also asked if they had received the resources necessary to cope in the crisis.

7.2 SUMMARY OF THE THESIS

Chapter 1 gave the background to this thesis and laid out a summary of how COVID-19 had progressed in the UK, together with an outline of the framework of SEND in UK schools and the present situation. The rationale for this research was also outlined, with the researcher aiming to hear directly from YP in order to learn from their experiences and to better prepare for the future, whether in periods of stability or crisis.

Chapter 2 documented the scoping review which was completed to identify what academic knowledge existed at the start of the research project. The search terms were designed to select articles about CYP in the UK with SEND between the ages of 5 and 25 who were in

education for at least some of the pandemic. Twenty-one studies of relevance were found, which showed that only eight YP with SEND had been spoken to directly, and they were up to the age of 16 (Beaton et al. 2021 and McCorkell, & Lobo, 2021). Only two papers included data from parents of YP up to the age of 18 (Rogers et al., 2021 and Shaw & Shaw, 2021), with no studies at this time including YP above that age, despite many YP with SEND remaining in education up to age 25. The scoping review that informed this thesis has since been published (Paterson et al., 2023). Chapter 3 described the qualitative methodology employed for the thesis and the research questions developed for the three studies that followed.

7.2.1 Summary of the Study Chapters

7.2.1.1 Study 1: The YP study

Chapter 4 recorded the first empirical study which included 46 YP with SEND and aimed to find out what their experience had been during the pandemic via focus groups or interviews. Open questions were used to elicit responses that would shed light on the lives of YP with SEND at home and in education during this unprecedented time. Questions were also asked about the support and information the YP received. Further queries explored the YP's perceptions of belonging, competence, and autonomy to understand how these experiences related to their navigation of the pandemic and their return to post-pandemic education.

The themes resulting from the data for Study 1 reflect the rapid changes that occurred during the pandemic period. The first theme "New Ways for New Times", covered YP's initial responses to the news of the pandemic and lockdowns, the information they received and the changes in society that impacted them. Overnight there was a new way of living which for the majority of people was not a welcome change, as many YP with SEND struggle with uncertainty and need to be prepared to allow for a successful transition, which was impossible in this situation. However, some YP viewed these changes and pandemic restrictions in a more positive light as they were no longer required to attend their educational placement. The pandemic can be described as a time of loss for many of the YP as there was a sense of loss of the usual markers of adolescence, the loss of socialising, loss of their education and for some, the loss of family members.

The second theme "New Ways to Learn" recorded the YP's experiences, both positive and negative of a new way of receiving their education which was delivered online for most. This

was reported to not be successful for most of the YP in this study although there were a small number who preferred online learning, but only if they had adequate home support. YP complained about the lack of academic support, opaque digital platforms and technical difficulties. The practical nature of the courses and the complexity of the digital systems meant that continued education of any quality was inaccessible for most of the YP, exacerbating the existing learning gaps between those with and without SEND. Furthermore, some YP withdrew from home-learning, and therefore education, completely when they found it too challenging.

“Human Connection” was the third theme that emerged from the interviews and focus groups and for many of the YP this was the most important aspect of their lives. The ability to socialise with their families and to meet with peers and friends was vital to most YP. Having friends or social contacts was essential for most YP to feel they belonged at their education setting, with difficulties making friends, strongly negatively impacting their educational experience during usual times. Being alongside their peers, as opposed to making friends, was enough for some YP, but that too was of value. Additionally, the support of their family was paramount for the YP at all times and especially during the pandemic. Those without that support clearly struggled, especially as all other support services were reduced, ceased or moved online.

“Wellbeing” was the fourth theme and encompassed both physical and mental health. There were some YP who did better during the pandemic academically, which enhanced their well-being, but most struggled with finding a new routine to cope with the physical and mental health challenges. The change to support being offered online or by phone was a negative experience for most of the YP due to their struggles with communication and social interaction. Interestingly, YP appeared more concerned about their families’ physical health than their own and most did not see themselves as especially vulnerable to the virus. YP did not necessarily agree with all the rules, but most followed the guidance most of the time and wore masks and had the vaccinations. They had internalised the information that older people or those with underlying conditions were the vulnerable ones and so worried about their parents and grandparents, with only one YP mentioning the heightened risk she was at due to having Down Syndrome.

YP were honest about their struggles with the restrictions, expressing they had felt frustrated or angry at times. They admitted they had sometimes been hard to live with or that members of their family had been difficult during the lockdowns. There had been arguments in some families and poor mental health reported which was ongoing for some of the YP. It appeared that no one had asked about their experiences on return to in-person education, meaning that the discussions with the researcher were the first time they had talked about it.

“Surviving or Thriving” developed as a theme from the ways YP described their experiences of coping and adapting during and after the pandemic. YP spoke about times when they felt capable, hopeful, or in control of their lives, alongside times when they felt unsupported and did not feel listened to. Even with a strong sense of belonging to their settings, this did not appear to protect the YP from difficulties during lockdowns, especially if they were very social individuals, but it did appear to enable a smoother transition back into in-person education afterwards. Many YP felt competent at what they were doing and that they generally had autonomy in their lives and expressed optimism about their futures, even when they recognised that life was often harder for them than for others. Experiences of limited autonomy were most apparent within educational settings or services when they did not feel listened to or when provisions felt inappropriate, when parent/carers were then mentioned as their mediators.

As well as giving an overview of the YP’s experiences, this study revealed that YP generally felt they did receive enough information about the pandemic but that they would have liked more guidance about which sources were reliable. They did not however, feel they had enough appropriate support for their education or the changes in their social and home lives.

7.2.1.2 Study 2: the Parents study

Chapter 5 examined the impact of the pandemic from the perspective of parents of YP with SEND. This was to triangulate the information gained from the YP and to broaden what was known with a more comprehensive and nuanced understanding of the lives of the families with a YP with SEND during this time. Ten parents participated in online interviews and spoke about twelve YP, considering the impact of the pandemic on both them and their YP.

Some parents recounted how aspects of the restrictions during the pandemic had helped their YP to take a pause which had been beneficial to them, but for most parents it was a time of immense stress. The first theme of “Personal and Home Life”, documented how the parents’ lives had been profoundly disrupted, which exacerbated their already difficult life. The addition of the expectation for parents to continue to work from home whilst maintaining their YP’s education and attending to vulnerable relatives coupled with the removal of all outside support, seriously compounded the existing challenges and sense of isolation.

Most parents had difficulties with the expectation of home-learning which is reported in the second theme of “Education”. None of the YP were initially attending their educational setting during lockdown, despite most being eligible to, although some parents fought successfully for this provision later. There was considerable variation in the educational provision for the YP from their settings ranging from an unchanged timetable provided online the day lockdown began, to no provision at all. Parents found the digital platforms and expectations of academic work and online attendance difficult to manage for their YP, resulting in some YP not participating in any home-learning provided by their educational setting. Navigating this new demand for home-learning was often impossible for parents to support who now also often had home-based demanding work roles, and it was reported that it was impossible for the YP to access home-learning independently. The support for home-learning reported by the parents was variable, from regular contact by the school with a known contact to no contact at all, however all participating parents did not feel they received the support they needed.

The third theme in this study was that of “Wellbeing”, encompassing physical and mental health. The concern of most parents was directed more towards their older family members than their YP, especially those with health conditions or dementia. They considered older people were more vulnerable to the virus, as they had been informed via the government guidance (DHSC, 2020a), and the older generation were often living more isolated lives. The importance of connection with others was acknowledged for all the family, therefore as time went on, some guidance was adapted to support the whole family’s welfare. Parents found creative ways to ensure all family members had some sort of contact with each other, either socially distanced in-person or digitally. Those whose support systems collapsed at the start

of the pandemic when services ceased and people isolated, had an especially difficult time managing challenging YP. This caused lasting consequences of trauma and poor mental health for family members. Many parents expressed hurt and sadness at the lack of support from workplaces, family, neighbours or services.

“Post-COVID-19” was the fourth theme of Study 2 which reflected the huge impact the pandemic had had on the parents as they re-evaluated their lives and priorities, making changes to their employment or living arrangements. Parents expressed a lack of trust in the authorities that previously parents had relied on. They were also concerned about the impact on the YP of the loss of opportunities such as work experience and loss of learning during the pandemic. Additionally, they were worried about the fact that their YP had often lost skills, such as that of being able to independently travel or attend a club. These lost skills had not been regained by the time of the interviews and parents were unsure if the YP would ever regain them. Concerns about the YP’s future were also expressed, as it was more difficult to find appropriate work, either voluntary or paid, with gaps in their work experience and qualifications.

7.2.1.3 Study 3: The Professionals’ study

Study 3 is recorded in Chapter 6 and reports on the professionals’ study. This included twelve professionals who took part in interviews to explore their experiences working with YP with SEND during the pandemic. These participants consisted of a mixture of professionals who had worked with YP with SEND between the ages of 14 and 25 and who were in education during the pandemic. The purpose of this study was to add to the data obtained from the YP and the parents and see the pandemic from a different but related perspective to triangulate the information already gained.

“Responsibility” was the first theme documented from this study as the professionals reported a huge burden of additional accountability that was placed on them during the pandemic. The number of directives received from the authorities, which constantly changed, made the situation very challenging. They had to exhibit professional composure in the face of great daily uncertainty as to which staff would be at work, which YP would be attending and what they needed to do to keep everyone safe. The increased risks for YP if they were at home were also acknowledged and some felt the weight of the responsibility

for some of these vulnerable YP. Additionally, they also had to organise education for those at home or support for those at risk. Professionals working from home had the stress of facilitating their own CYP with home-learning, which was especially problematic if their CYP also had support needs.

The second theme of “Wellbeing” addressed the professionals’ own sense of wellbeing as well as their views on the YP’s wellbeing. Some professionals had concerns about how their staff were managing, especially those who were more isolated, such as those living alone or who were new to the UK. There was a minority whose roles meant they experienced less pressure and had appreciated the lockdowns, but for the majority, they had increased pressure and amplified stress. Many were working long hours before the pandemic and the additional duties resulted in even longer hours. Professionals also had concerns about their own family whose needs were important and took time to deal with. Additionally, most missed the interaction and support which would normally come from colleagues in the workplace as they were either home-based or not able to mix informally in staff rooms. They also found the health measures directed by the government onerous and difficult to implement as many YP were unable to adhere to them, for example being unable to wear masks or keep to the social distancing rule.

Professionals saw that the YP’s wellbeing was affected by their restricted lives and acknowledged that being with peers was important to all the YP which most had missed and lost social skills as a result. They felt the YP’s lives contracted as they lost most of the experiences that enhance life, such as celebrations and milestones such as exams and proms. YP also received a narrower curriculum in many cases, as the life skills and work skills activities ceased. Furthermore, they were aware that some families were experiencing pressures and anxieties about finance, housing, employment or familial abuse, which then impacted the YP. Professionals were also concerned that many of the support services or therapies had ceased for YP, such as Occupational or Speech and Language therapy which would impact the YP’s future health and development.

The third theme was that of “Working Life” which explored the complete change in working practices for most of the professionals, moving to online delivery of meetings, services and education. Even for those continuing with in-person work it was not the standard procedure, due to the health and safety considerations and additional responsibilities. All

staff learnt new skills and most had to provide a digital version of their service. Sometimes there were delays in being able to do this, as secure, appropriate systems needed to be found, distributed, training provided and then utilised. Difficulties arose due to technical problems and systems not being compatible for all users or unsuitable for the potential recipients. School staff struggled with unreliable technology and YP using inadequate devices. They also found it difficult to motivate some YP to engage with any online provision. Teachers found that parental support was vital for engagement with online learning and if parents were unable to do this, then the YP's attendance and work suffered.

It took time for YP to settle back into education once they were permitted to do so and the professionals had doubts about the focus on the academic catch up programme. They stated they felt there were other aspects, such as rebuilding the YP's confidence and routine of attendance, that were just as important. Professionals also recognised that some YP had had traumatic experiences at earlier placements, when their needs had not been met and that this experience had created fragile trust in education settings even in usual times.

"Post-COVID-19" was the fourth and final theme in this study which reported on the impacts professionals saw after the YP's return to education. One mental health professional who dealt with school avoiders, surmised there may be a link between those who had struggled at school prior to the pandemic and school avoidance post-pandemic. Professionals also recognised that some services and community provisions had not resumed, continuing the narrower offer for some post-16 students. They also noted that results for some students had not returned to pre-pandemic levels and that some YP had lost skills such as how to share and behave in a group.

7.3 WERE THE RESEARCH CONCERNS ADDRESSED?

This thesis supported much of the early survey research reported in the Scoping review in Chapter 2 but expanded on it and captured the longer lasting impacts of the pandemic for YP with SEND, their parents/carers and their educators. Before considering the findings of the three studies as a whole, it must be asked if the studies addressed the initial research queries.

The initial research concerns were as below:

1. How did YP with SEND experience the pandemic?
2. Did the YP receive appropriate support and information?
3. In what ways did young people's pre-pandemic experiences of autonomy, competence, and belonging shape their lived experiences during the pandemic?
4. Were the families and organisations who delivered services and care to YP with SEND given the resources to enable them to cope with the pandemic?

This thesis has given a clearer picture of the experiences of this age group of YP with SEND during the pandemic. It has highlighted many disadvantages and some advantages for the YP, and the parents and professionals involved with their care. The YP did not receive appropriate support from settings or services in many cases, although this is understood within the context that all professionals were also dealing with multiple exceptional conditions and were doing their best in fraught circumstances. Additionally, the information that the YP were given about the pandemic was considered adequate by the YP but could be improved upon should a similar situation occur.

It was found that a strong sense of belonging, autonomy and competence supported the YP to foster a more positive outlook towards their educational placements and that the foundations of this were good relationships with peers and teachers, with the opportunity to develop friendships. Although a strong sense of belonging supported YP in their return to education, it did not necessarily help them during the lockdowns as there were many other contributing factors, such as the personality or disability of the YP.

Families and organisations did not usually receive the resources they required, although many were able to be creative in response to this. However, this still came at a cost to their wellbeing for many. For those unable to access resources, the cost is likely to be even higher, though unproven within this research due to the lack of more disadvantaged participants.

However, there are opportunities to learn from what has been discovered and suggestions are made later in this chapter. Chapter 7 will now collectively consider the findings of the three studies and their implications.

7.4 LACK OF PREPARATION AND INITIAL RESPONSE

It was clear from the studies in this thesis that COVID acted to amplify existing flaws in society, which impacted those YP with vulnerabilities to a greater extent than YP without SEND. This finding was confirmed by the Centre for Young Lives report, published after the organisation attended the Children and Young People Module of the UK COVID Inquiry as a designated Core Participant (Centre for Young Lives, 2025). However, there was no universal experience for CYP with SEND, their families or professionals. Additionally, this crisis did not occur in a vacuum but came after a decade of austerity policies in the UK, resulting in community, health and social care services being underfunded and increased mortality rates, as reported by Watkins et al. in 2017. Therefore, when the hurricane of the pandemic struck, the foundations required to withstand such a force were wobbly at best and sometimes non-existent. The Executive Summary of Module 1 of the UK Covid-19 Inquiry (2024) concluded that emergency planning “*generally failed to account sufficiently for the pre-existing health and societal inequalities and deprivation in society...*” (UK Covid-19 Inquiry, Module 1, 2024, Executive Summary). Additionally, it stated that the disproportionate impact on ethnic minority communities and those with vulnerabilities was not recognised. A crisis cannot always be avoided, but preparation when possible, and a willingness to make society more resilient can moderate the impact (Buckingham & Ahmed, 2023). To do this, additional resources are needed for equity and to remove barriers, but this did not happen; in fact, resources were removed. Even in ordinary times, if institutions and relationships do not confer resilience for people, then a responsive state is needed (Broach et al, 2016). However, many YP did not feel supported in this crisis by either the state or their educational settings. This was despite professionals reporting that they did their best to support remotely and parents at times considered the school/college had been pro-active in contacting and supporting them. It appeared that despite attempting to involve the YP, some support had gone to the parents and the YP may have been unaware of this. Additionally, the YP often did not want to engage with the support even when offered, as most of the YP looked to their parents to support them rather than teachers or friends. This therefore would have left some YP without appropriate support if they did not have a network around them that was able to meet their needs and it heightens the argument for community and health services to be accessible and responsive to these YP as The Children’s Society (2020) had argued in their 2020 briefing report.

For the majority of YP the pandemic was a challenging time both socially and educationally, and those with strong support networks fared better in both domains. YP, parents and professionals all agreed that YP with SEND were not specifically considered during the pandemic, and it was the professionals and parents who brought difficulties to the attention of the authorities or were left to adapt ever-changing guidance to fit their circumstances. That these YP would be more greatly affected by the pandemic was also not considered, despite the DfE informing the Cabinet Office of the likely effects, as evidenced in the UK COVID-19 inquiry (UK Covid-19 Inquiry, Module 8, 2025). There was a lack of seeking the views and listening to the people who were at risk from greater negative impacts which this thesis has attempted to rectify.

The impact of the government's response resulted in the loss of skills such as independent travel and socialising with peers, that had been hard won for YP with SEND and there was no consideration of the potential impact this would have on their adult lives. Additionally, methods that appeared suitable in theory, such as telephone contact from professionals and the use of digital learning, proved not to be appropriate for many YP with SEND. That remote learning may not be suitable for all was again flagged up by the COVID Inquiry as something that the Cabinet Office had been made aware of by the DfE prior to lockdowns (UK COVID-19 Inquiry, Module 8, 2025). Furthermore, early in the pandemic, in May 2020, the Coronavirus Act 2020 (2020) downgraded the rights of CYP with EHCPs by permitting the absolute duty of the LA to provide the educational provision in the EHCP to be relaxed and become simply a reasonable endeavour to do so. Therefore, at a time of increased vulnerability, the protection and support for CYP with SEND decreased, with most services such as physical therapy, speech and language therapy and 1:1 support being discontinued, all of which are critical for YP to progress or even just maintain skills (Driver et al., 2024). This decision was made to absolve the LAs from their responsibilities to provide support during a time of crisis and challenge with staffing, but the impact on families, especially those with YP with more complex needs, was substantial and not considered (Driver et al., 2024). This together with government guidance that did not prioritise or even consider the needs of the most vulnerable, meant families with a YP with SEND and those providing services to them felt, at times, abandoned, as early studies indicated (Rogers et al., 2021 and Greenway and Eaton-Thomas, 2020). This want of care showed a lack of awareness amongst

government and LA leaders of the lived experience of those with disabilities and those who support them. In turn, this appears to have led to a loss of trust in the institutions and organisations which normally provide services and structure in society, such as the government, along with health, social care and education departments (ARI Working Group 3, 2020). Such institutions normally attempt via laws and policies to promote an inclusive society in the UK, one which values diversity, ensures equal opportunities and supports the marginalised as decreed by the Equality Act of 2010. The reality for many families was that this did not happen in this crisis, causing them to reconsider their own priorities and lives, as was apparent in Studies 2 and 3 of this thesis.

The concept of social justice which institutions normally try to uphold to some degree in the UK, depending on their political beliefs, has been defined by Bhugra (2016) as a concept that is

aimed at promoting a society which is just and equitable, valuing diversity, providing equal opportunities to all its members, irrespective of their disability, ethnicity, gender, age, sexual orientation or religion, and ensuring fair allocation of resources and support for their human rights. (Bhugra, 2016, p336)

Human rights were curtailed for most during the pandemic (Hodal, 2020), as part of the attempt to protect citizens from the virus. However, warnings from the UN Secretary-General António Guterres were already being issued in April 2020 that the pandemic was not only a health crisis but was becoming a human rights crisis with disproportionate and discriminatory measures being taken by some governments (Guterres, 2020). It is difficult currently to judge to what extent this curtailment was a necessity, but what has emerged from the UK COVID-19 Inquiry, is that an assessment of the impact of lockdown on society was not completed before it was ordered, nor was there a plan for coming out of lockdown (Reed, 2023). There are some that say the infringement of CYP's rights was excessive and could have caused greater harm than the pandemic itself, as reported in the early study by Couper-Kenney and Riddell, and that the closure of schools was unnecessary due to the low level of risk for most (Couper-Kenney & Riddell, 2021). Thus, it is possible that for very little public health gain, the education and support of all CYP was curtailed. The COVID-19 Inquiry concluded that at the time of the lockdowns, this was a necessary action to prevent further deaths. However, it also concluded that the government's "*failure to act promptly and effectively had put them in this position*" (UK Covid-19 Inquiry, 2024, Module 1, Executive

Summary). This response may have created social, educational, employment and mental health difficulties for CYP into the future and this could be especially true for any CYP already disadvantaged in society such as those with SEND or who live in poverty (Ofsted, 2021a).

Poverty was behind many of the disadvantages for people in lockdowns, with some groups being more likely to live in poverty (Social Metrics Commission, 2019). These groups include those with mental health conditions, ethnic minorities, refugees, single parent families, children with SEN and the disabled, amongst others. According to the Social Metrics Commission report in July 2019, nearly half (40%) of all those living in poverty live in a household where someone is disabled. 47% of families caring for a disabled child had a household income in the bottom third pre-pandemic (Contact, 2017), giving them no safety net for difficult times. Additionally, the extra costs of bringing up a disabled child further push families into poverty (Dobson et al., 2001).

For a society to be prepared to meet challenges, preparation is needed rather than just a reactive response during the crisis. At the start of the COVID-19 pandemic people were told that the government and health services had only been prepared for an influenza virus, which they claimed accounted for the lack of clarity at the start. However, it has since emerged that there was a report summarising a one-day exercise on preparing for the spread of the MERS coronavirus in 2016 (McKee, 2021), a coronavirus which spread throughout the Arabian Peninsula from 2012. This report was not acknowledged by the government at the time and the report's recommendations did not appear to have been used to assist the government during the COVID-19 pandemic (Iacobucci, 2021).

It was assumed that CYP would be superspreaders of the coronavirus as they are for the influenza virus, but in time it was discovered that CYP were not the spreaders of COVID-19 that was feared and CYP were also found to be less likely to become seriously ill (Munro & Faust, 2020). This information was identified quite early in the pandemic, as by May 2020 the World Health Organisation's chief scientist, Soumya Swaminathan said that children appeared to be less capable of spreading coronavirus than adults (BBC News, 2020) but still schools were closed for periods throughout the pandemic (Department for Education, 2020a). However, Swaminathan also warned that a rare syndrome called Paediatric Multisystem Inflammatory Syndrome (PIMS-TS) temporally associated with COVID-19 had

emerged in April 2020 that was linked to a child being infected even mildly with COVID-19 which caused serious inflammation (Shingleton et al., 2022). However, due to its rarity, it was not considered to be a reason for school closures. During the COVID-19 enquiry, it came to light that many more children may have been affected by long-covid and other post-viral syndromes than had been realised, with affected families saying the lack of information regarding this risk had affected the decisions they had made during the pandemic. Additionally, teachers may have been more likely to catch COVID-19 than other professions, especially those working in special schools, where children were unable to socially distance and needed more personal care (Whittaker, 2021b), but they did not appear to be at any increased risk of serious illness (Fenton et al., 2021). The risks for more vulnerable teachers being infected were alleviated by schools allowing staff at greater risk to remain at home in line with government guidance advising clinically vulnerable and extremely clinically vulnerable staff not to attend the workplace (DfE, 2020f).

7.5 INDIVIDUAL RESILIENCE

As well as a resilient society, individual resilience also needs to be encouraged to create individuals who can live healthy lives and contribute to their communities in usual times. This individual resilience can be developed through families, educational institutions and health and social care systems (Masten et al., 2018). The educational policy of inclusion can directly strengthen resilience when it works well, by creating supportive, safe environments where individuals feel valued, competent and that they belong (Li & Li, 2024). It can also create social networks which in turn support the YP and encourage that sense of belonging. Deci and Ryan highlight three fundamental psychological needs, that of autonomy, competence, and relatedness, which are essential for people to thrive (Deci & Ryan, 1985). Meeting these needs facilitates self-determination, which promotes personal growth, learning and wellbeing. Furthermore, feeling part of a community is a recognised protective factor that fosters resilience (Werner & Smith, 2001).

CYP have been shown to need a sense of belonging to their school/college to feel they are included and it is relevant to them (Osterman, 2000). They need to trust the staff and other students and know that they will be safe, and their needs met (Furman, 1998). Montero-Marín and his team concluded from their study into the mental health challenges experienced by YP in the pandemic that:

...to promote mental health and adjustment, policy interventions should foster home connectedness, peer friendship, and school climate; avoid full school closures; and consider individual differences. (Montero-Marin et al., 2023)

When school does not meet the CYP's needs, an Alternative Provision (AP) placement is sometimes arranged, and these education providers focus on cultivating a sense of acceptance and belonging in order to give the CYP another chance at their education (Halse, 2018). Belonging has a rather vague definition however, with CYP possibly interpreting it differently to adults around them (Allen & Kern, 2017). However, it always involves a relationship to others and a connection to them through a shared culture, language, activity or place (Halse, 2018). It could be argued that the success of many supported internship programmes centres on the fact that they support YP to forge relationships between themselves and their employer and also because they allow YP to connect with their peers and work colleagues (Evans & Padden, 2024).

One slight difference between the parents, professionals and the YP during this research was the emphasis on the importance of friendships and relationships by the YP, who focussed on this aspect as the most important factor in determining whether they felt they belonged in their educational setting. Parents and professionals acknowledged this was an important factor but did not appear to rate it as highly as the YP themselves. Good relationships are considered central to the development of resilience in YP, and many YP with SEND find social encounters complex to navigate (Brown & Murphy, 2025), therefore this aspect requires further action. Additionally, those with a strong sense of belonging to their setting and good family support appeared to recover better from the pandemic experience, even if they had struggled during the restrictions. Even with a strong sense of belonging, some YP found the pandemic very challenging, but it was noticeable that they seemed to have greater resilience in their ability to recuperate afterwards.

Friends were sometimes described in terms of classmates, and others described teachers or family as friends, contrary to how their non-disabled peers would describe a friendship (Matheson et al., 2007). Therefore, the loss of these relationships and possibly also social skills during the pandemic, which came at a formative time for adolescents, could be problematic for forging adult friendships in the future. When YP with SEND leave education, they are less likely to be in work (Department for Work and Pensions, 2023) and therefore have less chance of making the proximate relationships they had while in school/college

even in usual times. Disruptions to creating relationships and regression in social skills could have further implications if CYP with SEND missed out on these experiences and also missed appropriate relationship education. Brown and Murphy (2025) emphasise the importance of learning how to relate to others and make friends as the foundation for successful adult relationships, especially for neurodiverse CYP (Brown & Murphy, 2025). Without exposure to the ups and downs of social life, together with help in dealing with these via specific teaching of relationships by professionals, important learning may have been forgotten or not developed. This potentially could increase future risks for the YP experiencing harm either online or in person or the risk of inadvertently causing harm themselves by not understanding how relationships work (Brown & Murphy, 2025).

7.6 EDUCATION

Teasing out which YP with SEND benefitted or were disadvantaged by online learning during the pandemic is difficult as so many different modes of home-learning were employed with no standardised delivery across the country. Home-learning was only made mandatory in October 2020 with the Coronavirus Act (2020), with merely guidance for settings to provide it until then. However, the government created The Oak National Academy in April 2020 in response to the lockdowns to support remote learning by providing free lessons, virtual school assemblies and a virtual library as well as other educational resources for teachers to use from reception to year 11 (Johal & Davies, 2022). Since 2022 it has been converted into an executive non-departmental public body, sponsored by the DfE to provide online educational resources to support teachers with lessons (Oak National Academy, n.d.). However, in April 2025 it was found that only 13% of teachers were using it for their resources (DfE, 2024c) whereas during the pandemic, over 130 million lessons were downloaded between April 2020 and September 2021, and 59% of teachers in state schools used the resources (Johal & Davies, 2022). Time will tell if this remains a valued resource or was seen as something connected to the pandemic alone and no longer relevant.

However, what can be learnt from the YP in this research was that if education became more about reading and writing then they were more likely to disengage, but if it became more interactive and allowed them to have more control over their learning, they were more likely to participate. Additionally, it was found that support from parents was also vital. It would be a simplification to say that a certain disability would need a certain method of delivery for

example, but it did appear that some of those with autism were relieved not to have to attend school/college and they appeared the most likely to find the social challenges of attendance overwhelming. However as reported in some of the early studies (e.g. Canning et al., 2020), this thesis indicated that some YP did better during the lockdowns in terms of their education or their health. These responses imply there is cause for concern regarding the normal school/college environment or learning offer for some, as is upheld by the statistics showing poor attendance for YP with SEND before and after the pandemic (House of Commons Education Committee, 2023).

Furthermore, it appears that all YP with SEND would benefit from schools using a wider range of methods to deliver lessons, whether that is in a pandemic or in usual times, and to be given greater choice in how they complete work, for example by following the principles of universal design for learning (UDL). UDL is based on the work of Meyer et al, which emerged from their cognitive research (Meyer et al., 2014) and has three core principles which are:

1. to use multiple means of representation
2. to support multiple means of action and expression
3. to encourage multiple means of engagement.

These principles enable teachers to reach a diverse body of learners, such as those from different ethnicities or those who speak different languages, not only those with SEND (Levey, 2021). In the UK it is more commonly practiced at the higher education level but has been adopted by some schools as the focus on inclusion has intensified, for example by the Woodland Academy Trust in Bexley (www.woodlandacademytrust.co.uk/learning-and-innovation/universal-design-for-learning). This approach allows all students to flourish and moves the focus from what a CYP cannot do to what they can do (Catama, 2025). This also has the potential consequence of the needs being met of more YP with SEND within a mainstream environment. Many of the parents in Study 3 supported the view that inclusion is more of an illusion than a reality, as a result of unmet needs, meaning that mainstream education is not a real choice for all parents currently (Mann, et al., 2018). That parents are requesting alternative placements and are dissatisfied with the current SEND system is reflected in the increasing numbers of SEND tribunal cases which have increased sixfold (for

all appeal types) over the last ten years, whereas the increase of YP with EHCPs has only doubled over the same time period (GOV.UK. 2024a). Government statistics also show that 2023-2024 appeals increased by 54.53% from the previous year and recorded the highest number since the legislation created the appeals system in 2014 (GOV.UK. 2024), indicating dissatisfaction with the system. Furthermore, it was notable that the parents who were able to access special education in this study were all working professional people who were able to comprehend the complex system and acquire both a diagnosis for their YP and the appropriate placement. There is evidence that most YP with SEND are from socially disadvantaged families, however most YP with a SEND label are not socially disadvantaged (Holt et al, 2019), indicating that those more able to navigate the complexity of the SEND system may be obtaining more specialist provision.

7.6.1 Inclusion

It is social justice and human rights which are the bedrock of inclusion and equity in education and should provide security for CYP with SEND in times of crisis (Knight et al., 2025). Professionals depicted the culture of inclusion in their settings as coming from their managers, therefore, if the SLT prioritised SEND then that would cascade downwards to the classrooms and the ethos of the school (Warnes et al., 2021). However, during the crisis, although teachers did their best to meet the needs of those with SEND, they were under immense pressure themselves and from multiple sources and did not feel they were always able to deliver what the YP needed or that they received appropriate support from the government to do so (UK Covid-19 Inquiry, Module 1, 2024). The COVID-19 Inquiry reiterated the difficulties that were found in the professionals' study in this thesis, of constantly changing guidance, having the responsibility of health issues without training and insufficient support for their own wellbeing, resulting in burn-out and then subsequently leaving the profession (UK Covid-19 Inquiry, Module 1, 2024). The numbers leaving may now be stabilising, but they remain high according to the 2025 DfE report (DfE, 2025c). Both the pressure on teachers during the pandemic and the subsequent result of losing so many experienced staff will have had an impact on a CYP's experience in their setting. Furthermore, the pandemic exacerbated existing challenges in teacher recruitment and retention according to the Education Policy Institute (Education Policy Institute, 2022a).

Even in usual times, parents felt there was a lack of knowledge of SEND in mainstream education leading to unnecessarily difficult experiences for the YP. Research by Roberts shows that teachers agree with this and felt they did not have sufficient initial teacher training or Continuous Professional Development to deal with the wide range of CYP who are now in mainstream classrooms (Roberts, 2024). The government would like more CYP with SEND to attend mainstream provision, as this is viewed as socially and economically desirable, but the lack of expertise of the teaching and support staff endangers this goal. The advice for classroom teachers also needs to be feasible for a teacher with a large class and dwindling support, and this has appeared a major challenge due to school funding restrictions as highlighted by Warnes et al. (2021).

SEND cannot be explored without mentioning funding which has been a key issue in the news (Sibieta & Snape, 2024) as LAs have overspent their budget in order to provide the support documented in the YP's EHCPs. The number of EHCPs the LAs now fund has risen by 71% between 2018 and 2024, creating a financially unsustainable situation (Sibieta & Snape, 2024). Many special schools were closed during the 1980s and 1990s due to the impact of the 1981 Education Act which emphasised the importance of educating all CYP in a mainstream setting if possible. At the same time, the number of CYP being identified as having SEND was increasing, creating a scarcity of special education placements (House of Commons Education and Skills Committee, 2006). As a consequence of this, private providers have arisen to fill the gap, at great cost to the LAs who are legally responsible for the costs of support in an EHCP (Borrett, 2024). LAs in 2024 had accumulated deficits of at least £3.3 billion in their high-needs budgets, but a government accounting term known as the 'statutory override' means the deficits are not declared on balance sheets currently, or else the LA would become bankrupt. This solution is now due to end in March 2028 (moved from March 2026) when it has been confirmed by the Department for Education that future costs will be managed within the overall Government budget rather than the LA having to cover SEND costs from their budget (DfE, 2025a). Parents in the current study reported their frustration highlighting that high needs funds to mainstream schools did not seem to be delivering value for money for their YP in usual times or post -COVID-19, despite the LA allocating this for specific support. Additionally, this study highlighted the fragility of some

specialist SEND provision, when parents reported that courses could lose funding and close at short notice, leaving students with limited time to find alternatives.

Parents spoke of provisions not always meeting needs in usual times, even within a specialist setting. They wanted their children to be happy but also to progress as much as possible academically. Moreover, YP with SEND are at a higher risk of not being in education at all while a placement is sought and then sometimes being required to travel or board away from home due to a lack of suitable local options, thereby dislocating them from their local community (Downes, 2022). Going to a special school was seen as a benefit for most families whose YP attended them but was not without its disadvantages, as YP were then segregated from their non-disabled peers with limited chance to make non-disabled connections. Some YP had experienced mainstream education unsuccessfully before a move to specialist provision and parents spoke about the difficulty for a YP with a cognitive profile of noticeable strengths and weaknesses, common in a neurodivergent person, to have their social and communication needs met in mainstream, or their academic needs met in a specialist setting. Additionally, YP with SEND are more likely to experience changes of school due to exclusions or the placement proving unsuccessful (DfE, 2024a). Most of the professionals saw the hugely negative impact on YP of attending a school that was wrong for them, with the impact lasting well into life if their needs were not met, resulting in the YP considering themselves failures as they entered adult life.

7.7 RECOVERY

7.7.1 Trauma-informed practice

All three studies showed that participants agreed that the focus on educational catch-up only, on the return to education, was the wrong emphasis. Education will only take place if a YP feels safe, included and if they feel they are competent at what they are doing (Emerson, 2022), but the government, and therefore schools, quickly became intolerant of the behavioural challenges of the YP on their return and the increase in absences, despite the unprecedented nature of what the YP had gone through. The impacts of possible trauma existing for some YP and the adults who cared for them, especially involving YP with more complex difficulties, was not acknowledged by government policies, nor was trauma informed practice encouraged on the return to in-person education (Wilson et al., 2024).

Trauma-informed practice sees behaviour as communication and a chance for CYP to develop greater self-regulation if staff understand the reasons a YP is 'misbehaving' and handle it appropriately (Emerson, 2022). However, it is likely that the effects of trauma as a result of the pandemic will impact physical as well as mental health into the future for many people, as there is increasing evidence that ill-health of all kinds has a foundation in trauma (Bristol Biomedical Research Centre, 2023). There were definitely signs of trauma for parents and professionals in this research, sometimes as a result of the child to adult violence also mentioned in Rogers et al. (2021) and some were made newly vulnerable due to intra-familial conflict. Many of those living at the margins of vulnerability in usual times were thrust headlong into crisis by the response to the pandemic (Napier, 2020). Not addressing this trauma will potentially cost more in future health and social care costs than the cost of prevention or remedy at the time (Bellis et al., 2019) and has already been seen to have a likely impact on people's post-COVID-19 decisions, such as teachers leaving the education profession (Gillani et al., 2022).

7.7.2 Wellbeing

As Wilson et al. describe in their 2024 paper about the return to secondary school after the lockdowns, the promise of a new normal did not materialise, despite the willingness of many to embrace this (Wilson et al., 2024). Many teachers were aware that doing well academically only occurs if both the YP and the teacher are feeling well in a holistic sense and commented on the pressure they experienced due to the expectation of focussing on their academic subject rather than the YPs', or their own, wellbeing. Wilson and colleagues (Wilson et al., 2024) also recognised that the teachers they interviewed had not recognised the importance of a trauma informed approach and directives from politicians and managers had concentrated on the teaching role rather than a caring role. This approach has always disadvantaged YP with SEND as they have more difficulties with attention, self-regulation, executive function and memory for example (Emerson, 2022), which are all required to enable a YP to abide by rules in a school environment. Historically this has resulted in more YP with SEND being excluded from school and also accounts for some YP's school avoidance and absence (Emerson, 2022), but the opportunity to re-set this focus after the pandemic has now passed.

The recovery of health takes time and resources but waiting lists for services have increased since the pandemic for both adults and children. However, in January 2026, it was reported that 26% of children on community waiting lists were waiting more than a year for NHS community services such as speech and language therapy, an autism or ADHD assessment, mental health or disability support (Triggle & Bailey, 2026). This compares to 1% of adults waiting more than a year for community support. These delays can have a profound effect on a CYP's health and development at that young age, and the waits have increased six-fold since the start of 2023. NHS leaders say that this is due to underinvestment in CYP's health and services, which again predate the pandemic, but have now escalated (Triggle & Bailey, 2026).

There were some families in this research who thought it was the parents and siblings of those with SEND who suffered more from the impacts of the pandemic, once the acute stage of the crisis had passed, than the YP with SEND themselves. With hindsight some parents felt the siblings of the YP with SEND had also been vulnerable to mental health issues throughout their lives, due to the difficulties of family life and the amount of attention that needed to be given to the YP with disabilities. The difficulties of siblings of a child with a disability have been documented by Naylor and Prescott (Naylor & Prescott, 2004). However, there is seldom much awareness or support for siblings who are often expected to take on responsibilities early in their lives to help their parents and disabled sibling (Morris, 2004). The siblings' needs often had to take second place which resulted in having little one-to-one time with their parents, particularly the mother, resulting in the mother feeling guilty even in normal times, but this was amplified in the pandemic as was reported by Rogers et al. (Rogers et al., 2021) and resulted in sibling conflict, as discovered by Toseeb (Toseeb, 2021).

7.7.3 Post COVID-19 Education recovery

The National Tutoring Programme funded by the UK government was the main part of the education recovery programme (Department for Education & Williamson, 2021). This ran from the 2020/21 academic year until the end of the 2023/24 academic year and was focussed on school tutoring, a curriculum for core subjects for those aged 16-19 and language support in the early years (Education Development Trust, 2024). There is now a new National Curriculum being developed to ensure it is relevant and inclusive, to be published in 2027 and to be taught from 2028. This aims to integrate the use of educational

technology for all CYP and to encourage the use of the Oak National Academy to support students both in-class and for home-learning (Education Policy Institute, 2025a). It will include a focus on digital literacy, as the importance of this was highlighted during the pandemic, with a greater emphasis on ensuring all CYP have access to an internet-connected device (Education Policy Institute, 2025a).

Academic Tests in schools since the pandemic have shown a recovery from learning loss in writing but not so much recovery in reading and maths. Additionally, it is not equal across the country (Elliot Major, et al., 2021). The attainment gap has been found to be no longer closing, as it was pre-pandemic between lower socioeconomic status CYP and those with a higher household income, and it appeared that the ten-year improvement in closing this gap had been wiped out (Education Policy Institute, 2022b). After return to school the difficulties with attendance increased as was discussed in Chapters 4 and 5. However, as of 2025, absences were showing a decline apart from severe absences (missing at least half of all sessions), but the rate of increase for these was also slowing, possibly indicating they were stabilising (The Education Policy Institute, 2024). However, The Education Policy Institute also highlights that for CYP on SEN support (those with identified SEN needs but no EHCP), the absence decreased less than for those with no SEN, causing a wider gap between those with or without SEND. Furthermore, for those CYP with an EHCP their absence rates continued to rise creating an even larger gap (The Education Policy Institute, 2024). No detailed explanation was forthcoming for these figures, but it was hoped that as part of the SEND reforms, prioritising child development training and training in different types of SEND as a mandatory part of initial teacher training and early career development would help CYP with SEND to increase their attendance (The Education Policy Institute, 2024). According to the findings in this thesis, this is a much-needed improvement to allow CYP to feel they belong and therefore want to attend their educational settings.

Elective home education increased post-pandemic as some parents felt it was not safe to return to school, or they felt they could continue to home educate having had a positive experience during the pandemic (Paulauskaite et al., 2022). However, others felt they had no choice but to home-educate as their child's school avoidance and continued absence meant they would be fined or taken to court, resulting in the parent removing the YP from the school roll (Purcell et al., 2023). It has emerged in the COVID Inquiry evidence that those

CYP suffering from post-viral illnesses were also affected by this punitive stance and some CYP were encouraged by their schools to go off roll to avoid being recorded as an unauthorised absence (UK Covid-19 Inquiry, Module 8, 2025). The absence was considered unauthorised due to their illnesses not being recognised by the medical establishment, especially initially, despite the Office for National Statistics stating that an estimated 66,000 CYP had suffered from long covid symptoms for more than 12 weeks in 2022 (Office for National Statistics, 2022c).

There are many specific changes being prepared post pandemic for SEND education in the UK. The much-delayed Schools White Paper is expected early in 2026, which aims to reform the SEND system. The details of this are as yet unknown, but the aim is to involve schools more directly in the assessment and delivery of support for CYP to reduce waiting times for families who currently have to go through their LA. However, this assumes schools will have the expertise and capacity to perform this role and presents a potential conflict of interest in that the school will be both deciding on the support as well as providing it, with a limited budget (Education Policy Institute, 2025). The Government has also stated that the reforms will provide more local placements so that children do not have to travel so far for their needs to be met and that there will be greater collaboration between education, health and social care services. Collaboration was the intention with the introduction of EHCPs in 2014, but currently this process is very much education-led with health and social care not always involved to the extent they could or should be, resulting in a poorer EHC plan and unmet needs for the CYP (Department for Education, 2022). The Government also wishes to provide more suitable mainstream provision for CYP with SEND and more training for teachers to enhance their confidence and knowledge of SEND (Education Policy Institute, 2025). To combat staff shortages, the Government is also investing over £31 million to train new educational psychologists and has launched degree apprenticeships for speech and language therapists to attempt to fill these key roles (DfE & DHSC, 2023).

7.7.4 The importance of Work

Work changed for most people during the pandemic, which has repercussions for working life post-pandemic. Work is a fundamental part of adult life for most people; however, it remains a challenge for YP with SEND to find paid work. This will not have been helped by

the more practical courses, which many YP with SEND attend, being discontinued or curtailed during the pandemic. This may have resulted in some YP not being equipped with the necessary skills and experience to find work, nor the ability to continue in their education if their EHCP had come to an end. Supported internships can provide valuable skills and support to YP and data confirms that the education, training and support provided through these schemes can be effective and often lead to paid roles (DFN Charitable foundation, 2019) and if well run, are well considered by families and YP (Evans & Padden, 2024). However, they are not available without an EHCP, making it probable there is a generation of YP whose final years with an EHCP was of a reduced quality due to the impact of the restrictions during the pandemic. There were clear indications of the lack of planning for the YP affected in this thesis, and future plans were curtailed or changed due to the change in financial circumstances of institutions and services after the pandemic. However, this is an area that necessitates further research, as a thorough exploration was beyond the remit of this current thesis.

In Study 2, parents described situations where their YP had not been offered a job interview despite good references, having successfully completed work experience or possessing good qualifications. Since the pandemic, the move to using online methods or the use of AI to screen job applicants has accelerated (Department for Science, Innovation & Technology, 2024) and it was found in this study that YP had great difficulty with these application processes. As Trewin and colleagues report, even non-AI recruitment processes are often discriminatory, so if AI is trained on these processes, then this will accentuate the flaws (Trewin et al., 2019). Work therefore needs to be done to find ways not to perpetuate the discrimination experienced by people with disabilities as the use of AI grows.

Parents knew that some of their YP may not be able to work full time or may not be able to work at all. While it is right to be aspirational for YP with SEND to enable them to prosper, it is also important to find a way to create a purposeful life for those not able to work, but the focus within the EHCP process is on gaining employment (DfE, 2015). Services do not seem to collaborate to assist with the transition to adult life in the way it was envisioned with the Families and Children Act, 2014 and continue to present a disjointed picture (DFN Charitable foundation, 2019). Furthermore, the investment in the YP throughout their education is wasted if they are then not able to access work or find a good quality of life in alternative

ways. Parents are right to be concerned about the transition to adulthood for their YP, as government figures show that in 2021 only 5.1% of adults with an ID were in paid employment (Burnett, 2021) and in 2023 only 30.6% of people with autism were employed either full or part time (Abreu et al, 2024).

Working as a parent of a YP with SEND can give a sense of purpose to that parent and the ability to be someone other than a carer and to mix with colleagues outside the SEND world, in addition to it being a financial necessity (Topolewski et al, 2024). A report from the Working Families charity by Adamson et al. found that it was not enough to allow people to work from home during the pandemic, but that employers needed to be mindful that their employees were experiencing diverse circumstances due to variable health, disability and caregiving roles (Adamson et al., 2023). The report suggested that workload support and the monitoring of wellbeing were required for the best outcomes. However, this was the first time many employers had overseen their workforce remotely and were learning along with their staff, resulting in many parents not being well supported in their work.

Parents' general view of the time at home during the pandemic was that it was difficult, if not impossible, to navigate all the challenges of family life whilst also managing work and their own wellbeing. The development of flexible working theoretically should allow men to take on more unpaid caring roles and allow women to more easily fulfil caring duties and remain in work. However, it could also lead to a perpetuation of existing gender inequalities, as found by Wang and Cheng using the Understanding Society, UK household longitudinal study data (UKHLS) (University of Essex, Institute for Social and Economic Research, 2024). This study found that women completed more household tasks even when their partners also worked flexibly and that men prioritise work over other duties and so working flexibly meant doing more work or other activities rather than sharing household duties or caring roles. Therefore, a way forward in which employers ask employees what would work best for them is important if parent/carers generally and women in particular are not to be disadvantaged by the move to more flexible work settings.

7.7.5 Gendered Inequalities in Caring Responsibilities During the Pandemic

Of note is the fact that nine of the ten participants were women in the parent's study, and eleven of the twelve in the professionals study, despite being open to all, an imbalance

which was notable for other research about CYP with SEND during the pandemic (Ashworth et al., 2025). It was not possible to tell if women were always the main caregivers, as no specific questions were asked about this, and some did talk about sharing aspects of the care of their YP with partners. However, it appeared from how the women spoke of the tasks that needed doing, that they were often carrying the main emotional and practical load of caring within the family for the home, the CYP and additionally often grandparents. This has been highlighted by others as an additional way inequalities for women during normal times were exacerbated during COVID-19 (Power, 2020), even for those without the additional duties required of caring for a YP with SEND. Women's position in the paid economy is often reliant on other organisations to take care of some of these caring responsibilities for some of the time (Power, 2020), such as daycare or schools, and these were removed during the crisis leaving women more exposed to the stresses of unpaid care if it was not shared.

This thesis found that the intersection of acute needs from many directions created unique challenges for parents. Some were caught between the needs of their immediate family and elderly relatives, who had also lost all support services, and it was a situation made more critical due to the needs of their YP with SEND. This study found that it was especially difficult if they were trying to care for relatives with dementia. The Alzheimer's Society survey found that 44% of carers of those with dementia reported struggles with their own mental health and 42% stated they experienced additional difficulties in their relationship with the person they cared for during the pandemic (Alzheimer's Society, 2020). However, one parent in this study realised with hindsight that although it was stressful to try to impart the importance of the guidance to her elderly mother, the relative had been safer obviously riding the bus around her town than she would have been in a nursing home. Government statistics for deaths in nursing homes subsequently concurred with her view (GOV.UK, 2023).

7.8 THE UK COVID-19 INQUIRY

The inquiry was announced by Boris Johnson, the prime minister, in May 2021, to start in spring 2022 with hearings beginning in June 2023 (Prime Minister's Office, 2021). It is of note that initially the terms of reference did not include any focus on children and young people at all, and the module regarding CYP was added after the chair to the inquiry, Baroness Heather Hallett, requested that this be included separately in response to the consultation prior to the inquiry (UK Covid-19 Inquiry, 2022). It was therefore added as

module 8 of 10 and the evidence was heard between 29.09.2025 and 23.10.2025 (UK Covid-19 Inquiry, Module 8, 2025), which was after the research in this thesis had been completed and the writing up was nearing conclusion. It is surely uncommon to have a national inquiry occur at this stage of a PhD let alone one that was presented as one of the largest listening exercises to be completed by a UK public inquiry (UK Covid-19 Inquiry, n.d.) and potentially one of the most expensive in UK history (Verbruggen, 2023). The evidence heard in the inquiry (UK Covid-19 Inquiry, n.d.) appeared to align closely with the findings of this thesis, both of which have highlighted the disproportionate impact of school closures on SEND learners, the widening of educational inequalities, and the systemic failures in educational decision-making which are all issues identified earlier in this thesis. Additionally, the research contained in this thesis adds a specific focus on older YP aged between 14 and 25 with SEND who were in education during the pandemic. This remains an aspect that has not been the sole focus of other research.

The report and recommendations from Module 8 of the Covid Inquiry have yet to be published at the time of writing, but the evidence presented so far is consistent with this much smaller study and confirm the validity and reliability of this work. This thesis also adds greater depth and nuance through the education lens and SEND-specific insights across many domains. Therefore, the Inquiry's findings situate my research within the wider recognition of the disproportionate impact of the pandemic on young people with SEND.

7.9 LIMITATIONS

This study has been primarily concerned with the voice of older YP with SEND during the COVID-19 pandemic and the research was conducted as close in time to the pandemic as was possible. However, it must be considered that people's accounts of their experiences may have altered over time and been influenced by information that emerged post-pandemic. Many of the participants expressed their appreciation of being involved in the study and stated that they had not had an opportunity to process what had happened until the interviews/focus groups. Participants appeared to recall the events and emotions of that time, and it must be understood that it was not possible to do in-person research with YP any sooner. However, it seemed challenging to recruit participants to the parents' and

professionals' studies due to the event being in the past and some people not wishing to revisit this time.

Despite attempts to increase the reach of the research to diverse participants, it was difficult to recruit participants from a wide range of ethnicities. This makes it impossible to know if the results are applicable across ethnicities or may have been different if this had been accomplished. Likewise, there were no single parents or foster carers involved in this research and only two men took part – one professional and one parent. However, there was a good mix of genders represented in the YP sample.

The study with the YP was a mix of focus groups and interviews as a result of time constraints for both the institutions who supported this research and for the researcher, but this could potentially have affected the results, which may have been different if the data collection used one method. However, consideration also needed to be made of the YP's own preferences in how they wished to be involved and to be flexible when capturing the voice of YP who may find the experience challenging. The YP also came mostly from two settings who generously allowed their YP to take part on their premises, but a wider range of settings would have been beneficial to the research if that had been possible. The YP included in this research were all able to consent to their involvement but there is a wider group of YP with SEND who may have been able to take part but would have required more significant support to achieve this, such as those who used augmentative and assistive communication. It was not possible to reach this group of YP in this study, but they would be a valuable addition to future research about COVID-19.

Socioeconomic data and a record of the types of schools/colleges attended during the pandemic were not collected from the participants of this research in order to make the YP's contributions simpler and achievable for the YP themselves to complete. This information would have been a useful contribution to consider more precisely who was affected and how, but it was a necessary decision made in order not to present the YP with too much information that they would not know how to answer. Furthermore, the intention of the research was not to be a comparative study of YP without SEND or with other age groups as there is already research reporting on how CYP without SEND fared (for example Viner et al., 2020) and about younger age groups (for example Children's Commissioner for England,

2020). There was a gap in the research of hearing the direct voice of YP between 14 and 25 with SEND who remained in education, and this research helps to fill this gap.

Further research could be undertaken with a more diverse group, however any future research about the pandemic will not benefit from being as close to the actual event, but finding a more diverse participant group could be a priority for research if another pandemic occurs. Further data is also needed regarding the after-effects of the pandemic, which may appear in the coming years. The Education Policy Unit and the Children's Commissioner for England, both declared that the data during and immediately after the pandemic was patchy and did not reflect the varied experiences of YP across the UK (Education Policy Institute, 2021 and Children's Commissioner for England, 2020). There are, for example, suggestions that those who found it better to be at home during the lockdowns are now driving the figures for the high absence rates, but this connection is by no means certain as there is no firm data to prove or disprove this currently. Other lapses also occur in the data so far, for example there is no data on the hours spent on learning in universities during the lockdowns (Office for Students, 2022). Additionally, learning loss at the university level is difficult to gauge as students were allowed to take exams multiple times in 2020 and 2021 (Office for Students, 2022) under the 'no detriment' policy, and were still impacted in 2022 (Higher Education Statistics Agency, 2023). Therefore, exam results from these dates affected by this policy cannot be compared with pre-pandemic exam results to see what impact this had on achievement.

7.10 RECOMMENDATIONS FOR FUTURE CRISES

Even if similar safeguards were needed for a future emergency, a stronger foundation of societal and individual resilience in normal times could provide better protection for vulnerable families. Therefore, there are recommendations at the society level as well as at the education level to better weather a storm of this nature. Impact assessments were not completed by decision-makers in the COVID-19 pandemic (UK Covid-19 Inquiry, 2024) but should in future be undertaken as soon as possible in an emergency situation to see what impacts various decisions would have on vulnerable groups. Disadvantaged groups need to have a voice in this assessment as soon as is practicable and key roles should be identified prior to an emergency as to who is responsible for gathering this information and to whom this information should then be relayed. Additionally, parents/carers can be the greatest

support for a family, but they were greatly stressed by the pandemic, as were the siblings of the YP with SEND. Family carers and siblings need to have sufficient support and resources in normal times as strengthening families strengthens the resilience of society (Children's Commissioner for England, 2020). This support should then be prioritised during a crisis rather than being suddenly withdrawn if they are to withstand the increased trauma.

What is considered normal in society also requires challenging, as the idea of normality results in ableist attitudes in society. This challenge is a fundamental necessity so that the differences of peoples' lives are better understood and catered for rather than being judged or penalised. To avoid harm to CYP with SEND, or indeed to any CYP, it is important to listen to a wide section of society to prepare for future emergencies, taking their distinctive circumstances into account, as it was found that the voices of those with SEND and those who support them were not heard during this crisis (UK COVID Inquiry, 2024). CYP's rights must be protected by fully incorporating the UN Convention on the Rights of the Child (ratified by the UK in 1991) into domestic British law (Green, 2025). While Scotland achieved full incorporation within its devolved competence via the UNCRC (Incorporation) (Scotland) Act 2024, the rest of Britain has yet to follow suit.

There also needs to be comprehensive planning within education to prepare for the closure of schools. This would prevent some of the last-minute changes which occurred and the disrupted education during COVID-19, although clearly not remove them entirely in any novel situation. Settings are developing plans of action for lockdowns in British schools in case of shootings or violent incidents (National Education Union, 2022) which seemed unthinkable just a few years ago, and the reality of another pandemic should mean the DfE and educational settings develop a plan of action and know how to prepare for this too, learning from lessons of this pandemic. YP themselves expressed the need for an emphasis on relationships which were severely fractured during the isolation of the lockdowns but were also often fragile before the crisis (Children's Commissioner for England, 2020). This aspect was not considered during or after the crisis which could compound any trauma experienced and impair learning (Wilson et al., 2023).

Following a prolonged immersion in the field through the researcher's employment and subsequent research, together with a systematic analysis of existing literature, this thesis culminates in the following evidence-based recommendations shown in Table 19. The

recommendations are particularly focused on the information given by the YP who participated in this study, who were the core of the work, but that information was triangulated by the information given by those who support them and together this could promote greater resilience for a future crisis.

Table 19. *Recommendations for supporting YP with SEND in a future crisis*

Recommendation	Source of recommendation in the data
Focus on maintaining and developing relationships both in-person in normal times but also how to do so safely online if that became the only route.	YP particularly described relationships as vital to belonging and engagement with education, the development of resilience and life satisfaction, which was also reinforced by parents and professionals.
To have a plan as to how to communicate with the students if schools/colleges are closed: who is responsible and the modes that could be employed, such as What's App, text, email, the learning platform, via parents, or the phone, acknowledging the phone may not be the best option.	YP wanted more support, but the use of the telephone was not appropriate for most. However, parents appreciated telephone support which did indirectly support the YP.
Deliver appropriate information about the crisis from the setting for CYP with SEND to access and for parents to use with their CYP.	YP wanted a reliable source of information and parents needed support in explaining the crisis to their YP.
Focus on the holistic rebuilding of relationships once returned to education through activities, such as mixed-age grouping or extra-curricular activities as well as academic subjects. Gradually build up to a normal school day if necessary.	YP, parents and professionals all considered a holistic focus was needed on return to education with more understanding of the impact of the disruption and potential trauma some had experienced. Social and life skills had been lost and needed to be retaught.
Allow extra time for students to complete courses on return to education for those with EHCPs or those doing practical courses and ensure parent/carers and settings are aware of this.	Young people appreciated an extra post-16 year for work experience after college reopenings, but access was inconsistent even for practical courses.
Listen to the families of those YP who have more health, learning and behaviour challenges as to what they need and incorporate their views into emergency planning.	Parents with more challenging CYP felt completely abandoned with severe and ongoing impacts to their family's wellbeing.
Ensure all CYP have access to internet linked devices.	This was a problem found in initial surveys such as that of Beaton et al., (2021) and Canning & Robinson, (2021) and throughout this research.

To have a comprehensive IT policy in all settings but to also have a back-up plan for when IT is not available, for example in the event of an internet or electrical blackout or if devices are not available.	Inadequate pre-lockdown IT integration for education and other health and social care services resulted in them being unable to respond effectively to providing remote provision. However, planning for the possibility of no internet availability also needs to be considered due to the volatility of the world (International Telecommunication Union, 2026).
To have full training for staff and students in the use of software that would be used in a lockdown and integrate it into the normal school day.	Professionals and YP were not familiar with the IT systems used which added to the stress of home-learning for both groups. YP wanted professionals to use it consistently amongst themselves and to know how to use it effectively.
To provide opportunities for parent/carers to learn about how IT is used within education such as an internet skills café for parents at the beginning of each school year to show how the systems are used by the school and the YP.	Parents similarly were unfamiliar with online systems and therefore found it challenging to support the YP effectively.
Develop a policy of using hybrid methods of teaching and learning (partly online, partly in-person) for students who cannot attend full time in normal times or for use in a period of absence or a lockdown.	Some YP benefitted from home-learning and did better academically and saw their mental health improve. Some YP with ASC or a mental health or medical condition would benefit from more flexible learning patterns, with some saying this had helped them if continued at their setting after the pandemic.
Settings to foster the use of relevant educational websites which include fun and engaging activities used in normal times as well as if a setting is closed/YP is absent.	YP commented that some websites made learning more fun than when they were learning in a setting in-person. The Universal Design for Learning framework, which could be utilised, optimises learning by addressing the diverse needs of all learners through flexible instructional methods, materials, and assessments (Meyer et al., 2014).
A plan as to how to continue or catch up with practical learning if settings are closed so YP do not miss out on aspects of the curriculum.	Young people felt unprepared due to pandemic-shortened curricula and missed practical training, while parents worried about their lack of essential life and work skills as they approached adulthood.
Develop a plan for CYP regarding who to prioritise for attendance using different potential scenarios, depending on the nature of the crisis and infection risk. Rotas of YP and/or staff could be considered from the outset if YP were not considered to be high risk.	Despite guidelines permitting attendance for YP with EHCPs, most stayed at home due to staff shortages and misinterpreted guidance, causing disruption to their education and social development and their families' wellbeing.

Alternative provision settings should have guidance to follow regarding their continued operation in a crisis and what is the safety net for the YP concerned if those settings are redeployed in an emergency.	The complete closure of the non-traditional alternative provision reported by parents meant that no education was provided for many weeks.
Provide advice and guidance for parents to use if YP are unable to access home-learning, such as activities to create a routine and continue informal learning.	Home-learning was not appropriate for all YP. Both YP and parents would have benefitted from alternative ideas and suggestions from their settings if online learning was not possible.
Guidance for parents of YP with SEND as to how much academic work the YP are expected to do with a smaller essential part and then additional optional parts.	Not all YP in mainstream settings took part in all lessons or were expected to complete all work set when attending in-person, leaving parents uncertain as to how much work their YP should complete when home-learning.
Work should be differentiated at source for the YP in accordance with their learning plans or EHPCs.	Work was found to be undifferentiated in early surveys (Ludgate et al, 2021; McCorkell & Lobo, 2021) and also in this thesis, leading to overwhelm and a deterioration in mental health resulting in some YP disengaging completely from online learning.
Enable YP in residential settings to return home or have in-person access to their families if at all possible if there is a lockdown.	The YP left at a residential college over Christmas due to travel restrictions in the lockdown was clearly distressed by the experience and this should be avoided if at all possible.
Opportunities for YP, professionals and parent/carers to debrief if desired either informally or via formal therapeutic channels once in-person education resumes. Although YP may not want a formal approach, an informal tutor led individual or group opportunity would be of value.	None of the participants had spoken of their experiences until this research and many expressed appreciation of the opportunity to do so.

7.11 CONCLUSION

Despite the immense difficulties of the pandemic, the lack of preparedness of both government and institutions for something that had been predicted for some time (Iacobucci, 2021), undoubtedly created more trauma to more people than there need have been. Due to the precarious state of the disadvantaged in society which existed pre-pandemic, the impact on them was also amplified. If there had been a foundation of a more resilient society and a greater focus on the most vulnerable in society once the pandemic

was better understood, then this deleterious effect may have been somewhat mitigated, but lessons were not learnt during the pandemic. The consequences of this now for some families are a lack of trust in institutions and authority generally.

Without fundamental changes in health, social care and education, any changes in the preparedness of the UK for future crises are in danger of becoming more like sticking plasters over a gaping wound. Even when considering the well-intentioned UK COVID-19 Inquiry, CYP were not originally included at all and were then listed as module 8 of 10, indicating that CYP were still not a high priority. Furthermore, in the Module 1 report of the covid inquiry executive summary, it discusses the *"massive financial, economic and human cost of the covid-19 pandemic"* (UK Covid-19 Inquiry, 2024) listing the human cost last. Ultimately, whatever recommendations are given, if the importance of the connectedness and the relationships within society are not at the centre of them, they will only ever result in slight modifications that fall short of addressing systemic inequities. Paying attention to and rectifying existing inequalities when life is calm, such as those relating to housing, food, health, education and local communities, would potentially help with both societal and personal resilience.

This research gave YP with SEND a voice which they had not had before and highlighted the impact of the pandemic on them. It exposed the failures in decision-making which resulted in widening educational inequalities and attainment gaps and showed that the disruption had a disproportionate impact on these YP, together with unknown future consequences. Future research will be needed to investigate these consequences for some years to come but it is important to appreciate, as Nelson Mandela said in his 1995 address at the launch of the Nelson Mandela Children's Fund in Pretoria, that *"There can be no keener revelation of a society's soul than the way in which it treats its children"* (Mandela, 1995).

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APPENDICES

Appendix A: Children of critical workers and vulnerable children who can access schools or educational settings

Early years and childcare settings, schools and colleges continue to be open for all children and young people in England and attendance of school age children remains compulsory.

These settings may however need to change how they are delivering education and childcare for a short period of time in line with the Contingency Framework. In all circumstances, and in all settings, priority should continue to be given to vulnerable children and young people and children of critical workers (as defined below) to attend full time.

Vulnerable children and young people

Vulnerable children and young people include those who:

- are assessed as being in need under section 17 of the Children Act 1989, including children and young people who have a child in need plan, a child protection plan or who are a looked-after child
- have an education, health and care (EHC) plan
- have been identified as otherwise vulnerable by educational providers or local authorities (including children's social care services), and who could therefore benefit from continued full-time attendance. This might include:
 - children and young people on the edge of receiving support from children's social care services or in the process of being referred to children's services or who have previously received support from children's social care services (as identified by local authorities)
 - adopted children or children on a special guardianship order
 - those at risk of becoming NEET ('not in employment, education or training')
 - those living in temporary accommodation
 - those who are young carers
 - those who may have difficulty engaging with remote education at home (for example due to a lack of devices or quiet space to study)
 - care leavers
 - children and young people in a family circumstance presenting challenges for them, such as drug and alcohol misuse, parental offending, adult mental health issues and domestic abuse
 - others at the provider and local authority's discretion including pupils and students who need to attend to receive support or manage risks to their mental health

Critical workers

Parents whose work is critical to the coronavirus (COVID-19) response include those who work in health and social care and in other key sectors outlined in the following sections. Children with at least one parent or carer who is a critical worker can go to school or college if required, but parents and carers should keep their children at home if they can.

Health and social care

This includes, but is not limited to, doctors, nurses, midwives, paramedics, social workers, care workers, and other frontline health and social care staff including volunteers; the support and specialist staff required to maintain the UK's health and social care sector; those working as part of the health and social care supply chain, including producers and distributors of medicines and medical and personal protective equipment.

Education and childcare

This includes:

- childcare
- support and teaching staff
- social workers
- specialist education professionals who must remain active during the COVID-19 response to deliver this approach

Key public services

This includes:

- those essential to the running of the justice system
- religious staff
- charities and workers delivering key frontline services
- those responsible for the management of the deceased
- journalists and broadcasters who are providing public service broadcasting

Local and national government

This only includes those administrative occupations essential to the effective delivery of:

- the COVID-19 response
- essential public services, such as the payment of benefits including in government agencies and arm's length bodies

Food and other necessary goods

This includes those involved in food:

- production
- processing
- distribution

- sale and delivery
- as well as those essential to the provision of other key goods (for example hygienic and veterinary medicines)

Public safety and national security

This includes:

- police and support staff
- Ministry of Defence civilians
- contractor and armed forces personnel (those critical to the delivery of key defence and national security outputs and essential to the response to the COVID-19 pandemic)
- fire and rescue service employees (including support staff)
- National Crime Agency staff
- those maintaining border security, prison and probation staff and other national security roles, including those overseas

Transport

This includes those who will keep the air, water, road and rail passenger and freight transport modes operating during the COVID-19 response, including those working on transport systems through which supply chains pass.

Utilities, communication and financial services

This includes:

- staff needed for essential financial services provision (including but not limited to workers in banks, building societies and financial market infrastructure)
- the oil, gas, electricity and water sectors (including sewerage)
- information technology and data infrastructure sector and primary industry supplies to continue during the COVID-19 response
- key staff working in the civil nuclear, chemicals, telecommunications (including but not limited to network operations, field engineering, call centre staff, IT and data infrastructure, 999 and 111 critical services)
- postal services and delivery
- payments providers
- waste disposal sectors

Department for Education, & Cabinet Office. (2020, March 19). *Coronavirus (COVID-19): Maintaining educational provision – Critical workers and vulnerable children*. GOV.UK. <https://www.gov.uk/government/publications/coronavirus-covid-19-maintaining-educational-provision>

Appendix B: Interview and focus group questions for YP.

1. Tell me about your experience of lockdown: Was there anything good about it?
Was there anything bad about it?
Did you get enough support and help?
Prompts to include queries around: home learning and homelife, mental health, physical health and activity, social life and school/college.
2. How did you find out about what was going on during COVID and what you should do? (e.g. parents, news, school, friends, social media etc)
 - a. Was this a good way to find out?
 - b. How would you have liked to find out?
 - c. Was this the right amount of information?
3. Do you like going to school/college?
Why is this?
4. Do you usually feel included in your school/college community?
Why do you feel that?
What would make this even better/ better?
5. Did you still feel part of your school/college during lockdown?
Why was this?
Was there contact from school?
6. Did you change school or college during COVID?
What was that like?
7. How are things now you are back at school/college – how is it going?
Are things different/ better/worse/just the same?
8. Do you like what you are doing at school/ college?
9. Do you think you are doing ok at school/college?
10. Do you feel that the adults around you at school/college and home listen to your views and what you need?
11. Is there anything else you would like to tell me about your life during the pandemic?

Appendix C: Ethical Approval notification



13/11/2022

Application 699

Dear Jacqueline Patterson,

Favourable Ethical Opinion for *“The Impact of COVID-19 restrictions on Children and Young People with Special Educational Needs and/or Disabilities.”*

Your research project has now been granted a favourable ethical opinion from the Tizard Centre Ethics committee.

Please notify the committee about any ethical problems or questions that arise during the project using the email lssjethics@kent.ac.uk

Yours sincerely

P. Triantafyllopoulou

Dr Paraskevi Triantafyllopoulou

Chair of Research Ethics Committee

Tizard Centre

University of Kent

Appendix D(i): Feedback/comment form

Thank you for agreeing to talk to Jacqueline Paterson to help with her research about the impact of the COVID-19 restrictions on Children and Young People with Special Educational Needs and Disabilities.

We hope that everything was alright when you talked to Jacqueline. We would be interested in any comments you would like to make, positive or negative.

When things go well, we like to encourage researchers by giving them good feedback.

But if things don't go well, it will help us to know this.

Please send any comments you have to:

Jacqueline Paterson: jmp54@kent.ac.uk or phone 07734 002717

Or her supervisor Michelle McCarthy: m.mccarthy@kent.ac.uk or phone 01227 827997

Or send it to the ethics committee at the Division for Law, Society and Social Justice at the University of Kent: lssjethics@kent.ac.uk

Thank you once again for helping the Tizard Centre with our research.

Tizard Centre Research Ethics Committee



Thank you for taking part in this research and helping us to find out more about what young people think.

Appendix D(ii): Easy Read Feedback / Comments Form

This is Jacqueline Paterson



Thank you for agreeing to talk to Jacqueline to help with her research. The research is about the views of young people with special educational needs and disabilities and what happened during the COVID-19 pandemic.



We hope that everything was ok when you talked to Jacqueline.

We would like to hear about anything that went well.

Was she polite?

Did she let you know what was happening?

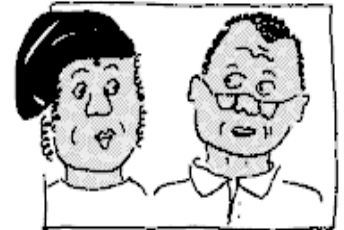


We would also like to know if anything did not go well. You can tell us if you did not like something that Jacqueline did and we will try to do something about it.

You won't get into trouble for doing this.



You could ask someone else to tell us for you if you want to.



- You can tell Jacqueline by emailing her at jmp54@kent.ac.uk
- Or you can tell her boss Michelle McCarthy. Michelle's number is 01227 827997 and her email is m.mccarthy@kent.ac.uk .
- Or you can tell the ethics committee at the University of Kent at lssjethics@kent.ac.uk

We will let you know what has happened after a short time.

Thank you for taking part in this research and helping us to find out more about what young people think.



Appendix E(i): YP Consent form for Study 1

Researcher: Jacqueline Paterson

Email: jmp@54.kent.ac.uk

Supervisor: Michelle McCarthy

E-mail and telephone contact: m.mccarthy@kent.ac.uk 01227 (82)7997

	Please tick if you agree
I have been given information about this study and I understand what it is about.	☐
I understand that I can choose to take part or I can choose not to.	☐
I can stop taking part at any time without giving a reason.	☐
I can ask questions any time if I want to.	☐
I give my permission for things I say in the conversations to be used in writing about the research but without using my real name.	☐
I understand that conversations will be recorded but only the researcher is allowed to do this.	☐
I understand that if I tell the researcher I am at risk of harm, then the researcher will have to report that to keep me safe.	☐
I have read and understood the consent form and agree to participate in this study.	☐

Name of Participant: _____

Signature: _____

Name of parent/carers if participant is under 16 years _____

Signature of parent/carers if participant is under 16 years _____

Date: _____

Appendix E(ii): YP Consent form for Study 1 easy read version

Researcher: Jacqueline Paterson

Email: jmp@54.kent.ac.uk

Supervisor: Michelle McCarthy

E-mail and telephone contact: m.mccarthy@kent.ac.uk 01227 (82)7997

**Please tick if
you agree**

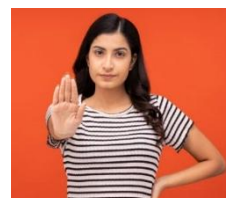
- I understand what this study it is about.

☐

- I understand I can choose to take part or not.

☐

- I can stop taking part at any time without giving a reason.

☐

- I can ask questions any time if I want to.

☐

- I agree it is ok for things I say to be used in writing for the research but without using my real name.

☐

-
- I understand that conversations will be recorded but only the researcher is allowed to do this.

☐

-
- I understand if I tell the researcher I am at risk of harm, then the researcher will have to report that to keep me safe.

☐

-
- I have read and understood the consent form. I want to be part of this study.

☐

-
- Name of Participant: _____
 - Signature: _____
 - Name of parent/carer if participant is under 16 years

 - Signature of parent/carer if participant is under 16 years

 - Date: _____

Appendix F(i) Information sheet for young people for Study 1

The Impact of COVID-19 on Young People with Special Educational Needs or Disabilities



Information Sheet

Jacqueline Paterson

Email: jmp54@kent.ac.uk or phone 07734 002717

Supervisors: Michelle McCarthy m.mccarthy@kent.ac.uk and
Paraskevi Triantafyllopoulou p.triantafyllopoulou@kent.ac.uk

Hello! I am Jacqueline Paterson, and I am studying for a research degree at Kent University.

I used to be a teacher but now I offer support to young people with special needs and their families.



Purpose of the study: I really want to hear about your experiences of COVID-19.

- What happened to you?
- How did you feel?
- What was good or bad about it?

It is your chance to say what you think about what happened. Were there some things that you liked or hated? Can you tell me about them?

Young people with special needs or disabilities don't often get the chance to talk to someone doing research, so here is your chance!

What you will be asked to do:

- To have a conversation with me about how living through COVID was for you. This will last about 30 -45 minutes but could be less if that is too much for you or more if you have lots to say!
- It can be in a small group with 3 other young people.
- Or it could be on your own with a friend or family member to support you.
- It can be in-person if you live in the south-east of England or online if you prefer or live further away.
- We will talk about what life was like for you during the COVID restrictions and what it is like now. I can give you the topics we will talk about before the session so you can think about them first.
- You could help by answering some questions on the phone or by email if you prefer.
- I can meet you before we talk about COVID so you can meet me, ask questions and decide if you would like to be part of this study.

More information:

- You can choose to take part, or you can choose not to. It's up to you.
- You can change your mind about being part of the study at any time up to when I look at all the information young people have given me after we have met. You don't have to give any reason for withdrawing and it won't affect anything else you want to do at school or college.
- If you would like to help with this study, you will be given a form to sign to say that you are happy to be part of it if you are 16 or over.
- If you are under 16 then you can choose to take part and your parent will be asked to sign a form saying it is ok for you to take part.

What will happen to your information:

- The conversations we have will not be able to be linked to you – they will be made anonymous by using a fake name.
- The information will be stored safely and kept confidential.
- The only reason for not keeping information confidential would be if you said you were in danger or it seemed you may be a danger to someone else. Then I would have to pass this on to someone who could help you at your school or college.

What happens if you wish to make a make a complaint?

- You will be given a form at the end of our conversation so you can say what went well or if anything did not go well.
- You can contact my supervisor at any time if you are not happy.
She is Michelle McCarthy and you can email her on m.mccarthy@kent.ac.uk

Thank you very much for showing interest in this study. I look forward to hearing back from you if you would like to take part.

Many thanks

Jacqueline Paterson

Accessible privacy notice

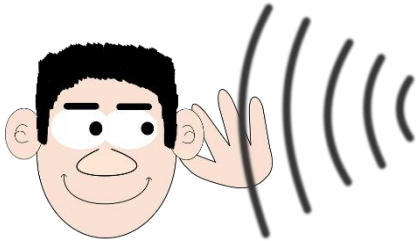
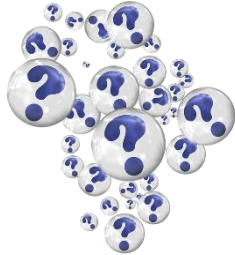
Researchers must follow the law when they collect information for research. We have to follow the law to keep the information you have given us safe and private. The law is called General Data Protection Regulations and is known as GDPR. Researchers should remove all information which can identify people at an early stage – this means names, addresses, contact details and any other information that could identify you. If you have any questions about what will happen to your information, please ask the researcher working with you.

The law says we have to give you a link to the University's Privacy notice
<https://research.kent.ac.uk/researchservices/wp-content/uploads/sites/51/2018/05/GDPR-Privacy-Notice-Research.pdf> That document is difficult to understand and you may want to ask someone to help you go through it.

Appendix F(ii) Information sheet for YP for Study 1 Easy read version

Jacqueline Paterson Email jmp54@kent.ac.uk or phone 07734 002717

Supervisors: Michelle McCarthy m.mccarthy@kent.ac.uk and Paraskevi Triantafyllopoulou p.triantafyllopoulou@kent.ac.uk

Hello! I am Jacqueline Paterson	
I am studying for a research degree at Kent University. I was a teacher but now I support young people with special needs and their families.	
Purpose of the study: I really want to hear about your experiences of COVID-19. • What happened to you? • How did you feel? • What was good or bad about it?	
It is your chance to talk to someone doing research who wants to know what you think. If you would like someone you know to be with you when we talk, then that is fine.	
I will ask you some questions about what the lockdowns were like for you and what happened afterwards. I will give you the questions before we meet so you can think about them.	

You can be in a group with 3 other young people. Or you can be on your own or with a friend, teacher or parent to support you. It could be online on the computer or face to face.	
We can meet before I ask you the questions so that you can ask anything and get to know me.	
You can change your mind about being part of the study at any time without having to say why. You can change your mind right up to when I look at all the answers people have given me.	
You will be asked to sign a form to say you agree to take part.	
Your real name won't be used in the research.	
The information will be stored safely.	

What you tell me will be confidential. But if you tell me you are in danger I will have to pass this on to someone who could help you at school or college.	
You will get a chance to say what went well or what did not go well for you	
You can contact my supervisor at any time if you are not happy.	
I look forward to hearing from you if you would like to take part. Ask your teacher, group leader or parent if you would like to be part of the study.	

Many thanks

Jacqueline Paterson



Accessible privacy notice

Researchers must follow the law when they collect information for research. We have to follow the law to keep the information you have given us safe and private. The law is called General Data Protection Regulations and is known as GDPR.

Researchers should remove all information which can identify people at an early stage – this means names, addresses, contact details and any other information that could identify you.

If you have any questions about what will happen to your information, please ask the researcher working with you.

The law says we have to give you a link to the University's Privacy notice

<https://research.kent.ac.uk/researchservices/wp-content/uploads/sites/51/2018/05/GDPR-Privacy-Notice-Research.pdf>

That document is difficult to understand and you may want to ask someone to help you go through it.

Appendix F(iii): Information Sheet for parents and carers

Jacqueline Paterson PhD candidate.



Email: jmp54@kent.ac.uk or Phone: 07734 002717

Supervisors: Michelle McCarthy m.mccarthy@kent.ac.uk and Paraskevi Triantafyllopoulou
p.triantafyllopoulou@kent.ac.uk

Tizard Centre, University of Kent, Canterbury, Kent, CT2 7LR

Hello! I am Jacqueline Paterson, a PhD candidate at the Tizard Centre at the University of Kent. I used to be a teacher but now I work for a SEND information, advice and support service, supporting young people with special needs and disabilities and their families. I am also doing research at the University of Kent.

Purpose of the study: I am interested in finding out about the impact of COVID-19 from the point of view of young people who have special educational needs and/or a disability. So far, research has focussed mostly on the adults' views, but the purpose of this study is to find out what the children and young people think about what happened, to give them a voice. Young people with disabilities don't often get a chance to feed back their experiences directly to a researcher and so this is an opportunity to make sure their opinions are heard.

To take part in this research, I would like to hear from you or your child if they have special educational needs or a disability and are between 14 and 25 years old. If they would like to take part but need some support, that is ok – you or someone else of their choice can be with them to support them – a teacher or a friend for example. If they use augmented communication aids, I would still like to talk to them. To take part they need to have been in an educational programme for at least part of the pandemic (2020,2021,2022).

What your young person will be asked to do: your young person can choose to take part in any of the following ways:

- In-person in a small group of up to 4 young people or by meeting with me individually. They can have a supporter with them if they wish. There will be topics about the pandemic to discuss which will be given to each participant before the session so they can think about them.
- Online - using Teams or similar software – again either in a small group or individually with support if wished and with the topics given before so they can think about them.
- A young person could help by answering some questions on the phone or by email if they prefer this method.
- There will also be an opportunity for you as parent/carers to contribute to the research if you would like to in a separate interview.

I can set up a meeting before the actual research session, so you and your young person can meet me, ask questions and decide if this is what they would like to do. Participation is completely voluntary and if they would like to be involved, they are free to withdraw at any time up to when the data is analysed, without giving a reason.

Attached is an easy read version of this information sheet so you can share it with your young person. If they are 16 or over then they can sign the consent form themselves. If you would like to take part then you will sign a consent form for yourself.

What will happen to your information: All information from the conversations will be anonymised – a fake name will be used for each participant. The information will be stored securely and kept confidential, with recordings of the sessions being destroyed once the information has been studied. The only reason for not keeping information confidential would be if the participant declared during a session that they were either at risk themselves or a risk to others, when that piece of information would then be shared with a safeguarding professional.

What happens if you wish to make a complaint?

You will be given a form at the end of your involvement, so that you can give feedback about what went well or make a complaint. In addition, at any time, you can contact my supervisor, Michelle McCarthy by email m.mccarthy@kent.ac.uk

Thank you very much for your time and I hope to hear back from you if you would like to take part in this study.

Many thanks

Jacqueline Paterson

Link to University of Kent privacy notice: <https://cdn-researchkent.pressidium.com/ris-operations/wp-content/uploads/sites/2308/2020/06/GDPR-Privacy-Notice-Research.pdf>

Appendix: F(iv): Information Sheet for colleges and teachers

Jacqueline Paterson PhD candidate. Email: jmp54@kent.ac.uk Phone: 07734 002717



Supervisors Michelle McCarthy m.mccarthy@kent.ac.uk and Paraskevi Triantafyllopoulou p.triantafyllopoulou@kent.ac.uk

Tizard Centre, University of Kent, Canterbury, Kent, CT2 7LR

Hello! I am Jacqueline Paterson, a PhD candidate at the Tizard Centre at the University of Kent. I used to be a teacher but now I work for a SEND information, advice and support service, providing support for young people with special needs and their families.

Purpose of the study: I am interested in finding out about the impact of COVID-19 from the point of view of young people who have special educational needs and/or a disability. So far, research has focussed mostly on the adults' views, but the purpose of this study is to find out what the young people think about what happened. Young people with disabilities don't often get a chance to feed back their experiences directly to a researcher and so this is an opportunity to make sure their opinions are heard.

I would like to talk to some of your students who are now up to 26 years old, who have SEND and were in education during the main pandemic years (2020, 2021, 2022). If they would like to take part but need some support, that is ok – a learning support assistant, teacher or friend can be with them to support them. To be eligible they will need to have been in education for at least part of the pandemic, have SEND and fit the age groups above.

What the students will be asked to do:

- Meet with me as a small group or individually (with or without a supporter) to discuss their thoughts and feelings about their experiences, views and feelings during the COVID restrictions and afterwards.
- There will be topics discussed which can be given to the group before the session so they can think about them if that is useful. It may be helpful to have a learning support assistant or teacher present during the session who knows them.

I can set up a meeting before the actual research session, if the young people would like to meet me first, ask questions and decide if they want to take part in the study.

Attached is an easy read version of this information sheet so you can share it with your students. Participation is completely voluntary. If your students decide to volunteer their time, then they will be given a consent form to sign if they are 16 years or over. The session will be recorded but anonymised so that their own names do not appear in any reports or writing. They are free to withdraw from the study at any time up to when the data is analysed, without giving a reason, and there will not be any adverse consequences for them.

What will happen to the information: All information from the conversations will be anonymised. The information will be stored securely and kept confidential, with recordings of the sessions being destroyed once the information has been transcribed. The only reason for not keeping information confidential would be if the participant declared during a session that

they were either at risk themselves or to others, when that particular piece of information would then need to be shared with the college teacher or safeguarding lead.

What happens if they or you wish to make a make a complaint?

The students will be given a form at the end of their involvement, so that they can give feedback or make a complaint. In addition, at any time, you can contact my supervisor, Michelle McCarthy by email m.mccarthy@kent.ac.uk

Thank you very much for your time and I hope to hear back from you if you would like to take the opportunity of your students taking part in this study. Do contact me about any issues or questions you may have on jmp54@kent.ac.uk

Many thanks

Jacqueline Paterson

Link to University of Kent privacy notice: <https://cdn-researchkent.pressidium.com/ris-operations/wp-content/uploads/sites/2308/2020/06/GDPR-Privacy-Notice-Research.pdf>

Appendix G: Support services to give to YP

- The Mix: helpline phone: 0808 808 4994

Website: <https://www.themix.org.uk/get-support>

- Time to talk Next Steps: email: alice.mccoll@ndti.org.uk

Website: www.ndti.org.uk/projects/time-to-talk-next-steps

- If you are in a crisis situation contact the Samaritans:
phone: 116 123 or email jo@samaritans.org

Website: <https://www.samaritans.org/>

- Or the Anna Freud Centre: If you need crisis support, you can text AFC to 85258.

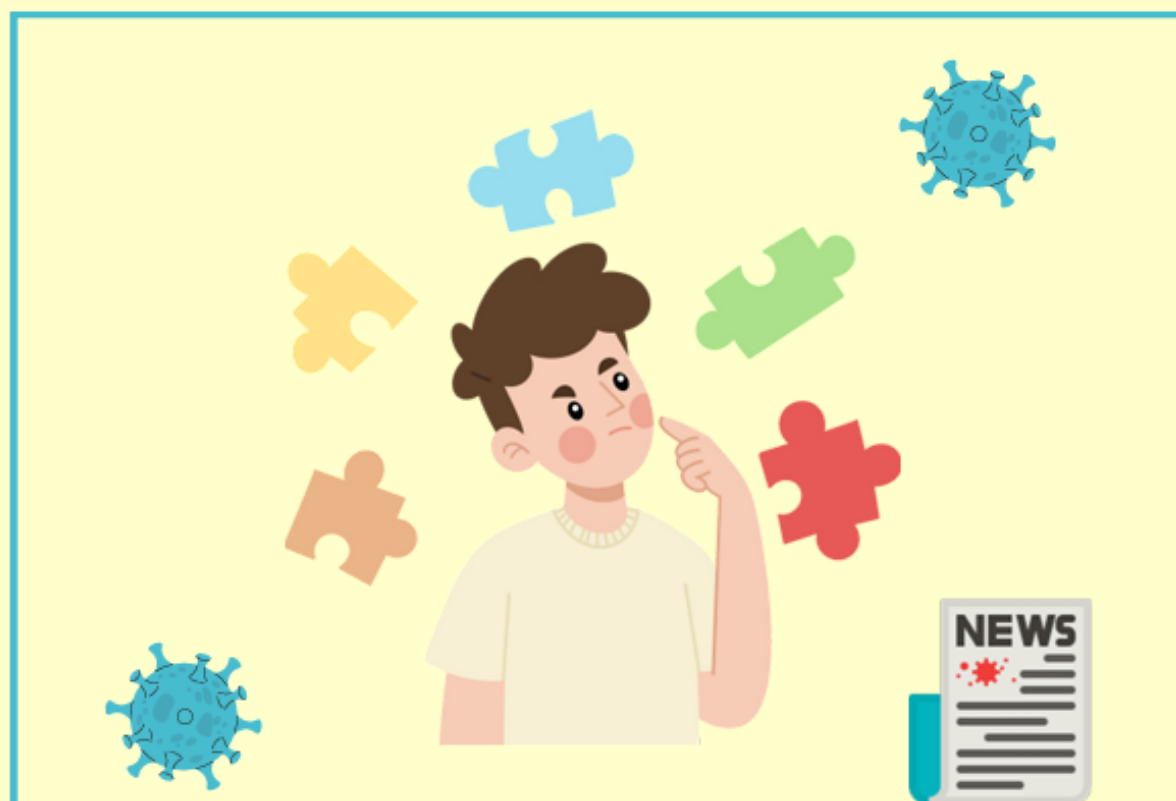
www.annafreud.org/on-my-mind/afc-crisis-messenger/

- Papyrus UK: email: pat@papyrus-uk.org phone: 0800 068 4141

Website: www.papyrus-uk.org

Two additional support services were listed for YP but these are not given here as their location could break confidentiality, as they were area specific.

Appendix H: report for YP participating in Study 1



The experience of young people with special educational needs or a disability during the Covid pandemic.

A summary report of interviews in 2023 with young people with special educational needs.

Jacqueline Paterson

The study

This study was the result of working with young people with special educational needs during the pandemic when I saw what impact the restrictions had on them. It felt important to capture the experiences of the young people themselves about how they had felt.

It was a delight and a privilege to speak to the young people who took part. This report is a snapshot of what I found out as part of a bigger project undertaken through the Tizard Centre, University of Kent.

Jacqueline Paterson

Who was interviewed?

46 young people:
15 female
29 male
2 other



All the young people said they had special educational needs

The young people had been at school, college or university during Covid

The young people were between 16 and 26 years of age

The young people attended schools or colleges in the South East and 3 were interviewed online.

What did the young people (YP) say?

So everyone's in the same storm that we don't know how to get out. (Paul)

At the start.



Most YP at first thought COVID wouldn't come to the UK or would be short-lived. They were surprised when it came here.

Most YP found out what was happening from the news on TV or social media. Finding out from their caregivers was the second most common way.

Everything happened really fast. Schools closed, you had to wear masks and make sure you were social distancing. You had to stay at home during the lockdowns. This was all a shock for most YP.

There were some upsetting things shown about the pandemic on TV about people becoming ill and dying, so many YP stopped watching the news because of this.

"And we heard about it on the radio but then we never thought it was going to come to England" Kim



"It was on This Morning...I heard there was this new virus going around" George

Education

"So it was online and sometimes I didn't get the work completed but I had to work for ages and it was really stressful." Elias



"Err, well, some stuff was ok but some...doing stuff out of clay or something like that, couldn't really do much with that." Finley

Most YP did not like home learning and found it hard. If the YP attended a mainstream school or college, they did not think the work was adjusted for their needs. This made it more difficult or sometimes impossible to do the work. Family had to help much more but not everyone had family who could do this. It made learning at home stressful.

But there were a few who loved learning at home as they liked to learn quietly at their own pace. Some liked not having to go to school or college as they were not happy there.

Some subjects like science, drama or cooking were more difficult to do at home and YP felt they did not get the full experience of their course when it was more practical.

Not everyone had Wi-Fi or the right device to learn on, so some stopped learning at home completely.

Not knowing what was going to happen made YP anxious and they felt teachers did not always understand this. The YP did know that it was hard for the teachers as well and that they were doing their best in a difficult situation.

Looking at screens all day was tiring and it was a bit boring just listening, reading and writing. Some YP found online activities which helped their learning and made it more interesting.

YP appreciated the fun activities their schools put on for them such as quizzes, games and competitions.

The YP felt out of practice at socialising when they returned to school or college. Some YP would have liked to have talked about what had happened to them during the pandemic. Many would have liked more focus on their mental health and wellbeing and not just on academic work.

"I did find it harder, having written materials which just wasn't quite the same as being able to listen." Tilly

"The PE staff were great. They had a few like, who could do the most keepie uppies or things like that which were nice." Lisa



Friends and family.

Most YP missed meeting their friends in person. Some YP were lonely and bored at home during the lockdowns.

Family and caregivers were the most important source of companionship and support for YP. But some said there were arguments at home, sometimes about the Covid rules or vaccines.

"It was pretty difficult with my family as we don't have the healthiest family dynamic...there was a lot of screaming and a lot of praying!" Frankie

It was hard not seeing their relatives such as grandparents and some older people could not use technology.



"It was very hard, because I'll have to go FaceTime them all the time and it's very hard not to like actually hug them." Nessie

YP felt the use of social media increased during the pandemic as a good way of keeping in touch with others. Some started online groups to chat together. It wasn't as good as meeting in person but better than nothing. YP didn't always know what to talk about online though as nothing much was happening.

Wellbeing

Special events like birthdays and Christmas, proms and learning to drive were very different or cancelled which was upsetting. YP missed being able to say good bye to friends at the end of school or college, visit family or go to funerals.

Anxiety was worse for some YP and they would have liked more support at school/college for this. Phone support was not right for all YP if they struggled with communication or talking on the phone.

Many YP were very resilient and adapted to the changes over time, but some found it very difficult and struggled afterwards with getting back to school/college and learning.

"...me and my mum, we didn't really get much presents, it didn't feel Christmassy" Paul.



"Because of all the time I was spending at home and hearing about all the news surrounding the situation, kind of took a toll on my mental health for a while."
Steve

It was especially difficult for those who were shielding, those who did not have outside space or those with few social contacts outside school/college.

Some did less activity during the lockdowns and ate more junk food. But some found new ways to be active, like online exercise classes and found new hobbies to interest them.

Suggestions made by the young people if there was another pandemic

- ✦ If you test negative, then you should be allowed to carry on with in-person education if you wear a mask.
- ✦ Find some way for YP to have more personal contact during a lockdown.
- ✦ Teachers should teach YP to use the software and programmes before there is another pandemic and be able to use them themselves.
- ✦ All teachers should have the same expectations and approach to the work set.
- ✦ Allow YP to return home during a lockdown if they are in a residential setting, if they want to.
- ✦ More focus on mental health during a lockdown, and opportunities to talk about what had happened to them if they want to, on return to education.
- ✦ The government should find a simple communication method to give information to everyone in a crisis.
- ✦ The government should give clearer instructions on what people should do, with the reasons behind it.
- ✦ Politicians should listen to scientists and follow any rules they set.



With thanks to all the young people who took part in this research project, for their time and interest and to the staff who made it possible.

*Thank
You*

Appendix I: Example of flyer to advertise the study to YP

Variations of this flyer were sent to parent/carers, teachers, ethnic minority YP and YP groups and leaders.



The Impact of COVID on Young People with SEND.

Would you like to be part of a study and tell a researcher about your COVID experiences? Good or bad!



Are you a young person aged 16 – 25 with a special educational need or disability? Were you in education during the pandemic? I would like to hear from you!



What will happen?

You will be asked about your experiences during COVID and the lockdowns and afterwards.

It can be in a small group of 3 or 4 or individually.

You can have a friend or family member with you.

It can be online or in person.

You can meet me before we chat about the study and ask questions.



If you are interested, then please contact me on: jmp54@kent.ac.uk

Or text or What's App 07734 002717 (work phone)

Appendix J: Demographic information for Study 1 YP

Information about you.

This will be confidential and is only used for the researcher to see what range of young people have been involved with the research.

Age

Under 16 ☐ 16 -18 ☐ 19 -22 ☐ 23-25 ☐ 26+ ☐

Special need or disability – please tick all that apply

Autism	☐	ADHD or ADD	☐
Learning needs/disability	☐	Medical or health condition	☐
Physical disability	☐	Visual or hearing disability	☐
Down syndrome	☐	Other	☐
Learning difficulty (such as dyslexia or dyspraxia)			

Education now

Mainstream school or college	☐	Special school or college	☐
University or Higher education	☐	Not in education	☐

Other (please write what you are doing now)

Gender

Male ☐ Female ☐ Other ☐

Ethnicity: White: British, Irish ☐ Other white ☐ Black ☐ Asian ☐

More than one ethnicity ☐ Other (write it here) Prefer not to say ☐

Appendix K: certificate for YP participants



Appendix L: Interview questions for parent/carers

For confidentiality reasons, please don't use any names of CYP you are referring to in answering the questions.

1. How did you and your family manage during the pandemic?
 - Were you able to do anything as a family to support each other?
2. How did you and your YP find out what was going on during the pandemic?
 - Did the school/college inform you and the YP of what they should be doing?
 - Was this ok or not?
3. Did your YP continue to attend school/college?
 - Why or why not?
 - Do you think this was right for them or you?
4. How was school or home learning for you and your YP?
 - Enough tech, space, support, differentiation?
 - Who supported them? LSA or teacher?
 - Did they like doing it?
 - Was it the right amount of work?
 - Practical subjects?
 - Any advantages?
 - Contact with school?
5. How much support was there from school or other professionals during the lockdowns?
6. How did the YP react to the restrictions and guidelines the government put in place?
 - Staying at home – loneliness or boredom, anxiety /wellbeing/mood.
 - Behaviour.
 - Masks, social distancing etc – how was that?
 - Lack of routine
 - Sleeping, eating, activity levels.
 - Vaccinations
7. Did any services you usually use stop or change?
 - How were medical appointments/ speaking to people you needed to?
 - Physical and mental health.
8. How was returning to school/college?

- Was there any support or preparation?
9. Did they go to a new placement during the pandemic?
- How was this affected?
10. What do you think was the impact of the pandemic on the YP's learning?
- Did they catch up on return to education?
 - Do you think there are any lasting repercussions of the pandemic on the YP?
11. Did you think your YP was vulnerable or at risk during the pandemic?
- Do you consider them so normally?
12. Use of social media – how savvy is your YP now and did this change over the pandemic?
- How did the YP keep in touch with friends during the restrictions?
 - Did they use social media? Their phones? Or meet up with anyone?
13. How important do you think friendships are for your YP?
- Do you do anything to support or encourage socialising and making and keeping friends?
 - Does their school/college do anything?
14. Were there any difficult situations to deal with during the pandemic, like dealing with a death or illness?
15. Did they miss any special occasions during the pandemic?
16. How has the educational journey generally been for your YP?
- Do you think inclusion in education has worked for your YP?
17. Would you describe your YP as happy and thriving?
- Why/ why not?
 - Do you think they feel they belong at school/college?
 - Are they doing well there?
 - Do you think people listen to what they want?
18. Is there anything else you would like to tell me about your experience with your YP during the pandemic?

Appendix M: Ethical approval notification



24th July 2024

Ms J Paterson

Tizard Centre

University of Kent

Canterbury

Jmp54@kent.ac.uk

Dear Ms Paterson

The Impact of COVID-19 restrictions on Children and Young People with Special Educational Needs and/or Disabilities

Thank you for the amendments to this application (1064), sent on 19th July 2024. I am happy to agree these amendments to the ethics application, and so that the application receives a favourable ethical opinion from the Tizard Centre Ethics Committee.

Please notify the committee about any ethical problems or questions that arise during the project using the email lssjethics@kent.ac.uk

Yours sincerely

A handwritten signature in dark ink that reads "David Oliver". The signature is written in a cursive, flowing style.

Professor David Oliver

Acting Chair of Research Ethics Committee

Tizard Centre

University of Kent

ccLSSJEthics

Appendix N: Flyer for caregivers



The Impact of COVID on Young People with SEND.

Would they like to tell me how lockdown affected them? Good or bad.

Would your son or daughter like to be part of a study and tell a researcher about their COVID experiences?



If they have a disability or special educational need, are age 16 – 25 and were in education during the pandemic, I would like to hear from them!



What will happen?

They will be asked about their experiences during COVID and the lockdowns and afterwards.

It can be in a small group of 3 or 4 or individually.

They can have a friend or family member with them

It can be online or in person.

They can meet me before we chat about the study.

If they are interested, then please contact me on: jmp54@kent.ac.uk

Or text or What's App 07734 002717 (work phone)



Appendix O: information sheet for parent/carers

Information Sheet for parent/carers

Jacqueline Paterson PhD candidate. Email: jmp54@kent.ac.uk Phone: 07734 002717

Supervisors Michelle McCarthy m.mccarthy@kent.ac.uk and Paraskevi Triantafyllopoulou
p.triantafyllopoulou@kent.ac.uk

Tizard Centre, University of Kent, Canterbury, Kent, CT2 7LR

Hello and thank you for showing interest in this study.

I am Jacqueline Paterson, a PhD candidate at the Tizard Centre at the University of Kent. I used to be a teacher but now I work for a SEND information, advice and support service, providing support for young people with special needs and their families.

Purpose of the study: I am interested in finding out about the impact of COVID-19 on young people who have special educational needs and/or a disability (SEND) and who were in education during the pandemic and those who care for them. I have completed one study asking young people between the ages of 16 and 25 about their experiences and I would now like to talk to parents and carers of young people in this age group who were in an educational setting during the pandemic. I would like to ask you about your thoughts and experiences of what happened to you and your young person during the pandemic. The voice of young people with disabilities, and those who care for them, is not always heard and so this is a chance for your experiences to be heard to help young people and their families in the future.

What you will be asked to do:

- Meet with me online (or in person if you live in the Southeast of England) to answer some questions about your experiences and that of the young person you cared for during the pandemic. The interview should last about an hour.
- If you would like to, you can ask any questions about the interview before we meet up and you can have a list of the main topics to be discussed if that is helpful.
- All interviews will be recorded for accuracy, but all names and places will be anonymised so that no real names will appear in any reports or writing.
- You are free to withdraw from the study at any time up to when the data is analysed, without giving a reason.

What will happen to the information: All information from the interviews will be anonymised. The information will be stored securely and kept confidential, with recordings of the sessions being destroyed once the information has been transcribed. The only reason for not keeping information confidential would be in the unlikely event that a participant said they were either at risk of harm themselves or to others, when that particular piece of information would then need to be shared with the safeguarding lead in the participant's Local Authority.

What happens if you wish to make a make a complaint?

You will be given a form at the end of the interview so that you can give any feedback or make a complaint if you wish to. In addition, at any time, you can contact my supervisor, Michelle McCarthy by email m.mccarthy@kent.ac.uk

Thank you very much for your time and I look forward to hearing from you if you would like to take the opportunity of taking part in this study. Do contact me about any issues or questions you may have on jmp54@kent.ac.uk

Many thanks

Jacqueline Paterson

Link to University of Kent privacy notice: <https://cdn-researchkent.pressidium.com/ris-operations/wp-content/uploads/sites/2308/2020/06/GDPR-Privacy-Notice-Research.pdf>

Appendix P: Consent form for caregivers and professionals

The Impact of COVID-19 restrictions on Children and Young People with Special Educational Needs and/or Disabilities.

Researcher: Jacqueline Paterson

Email: jmp54@kent.ac.uk

Supervisor: Michelle McCarthy

E-mail and telephone contact: m.mccarthy@kent.ac.uk 01227 827997



	Please tick to confirm
• I confirm that I have read and understood the information sheet attached for this study.	☐
• I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	☐
• Any questions have been answered to my satisfaction.	☐
• I understand that information I give may be shared within the research team and that it will be kept securely.	☐
• I understand that my name will not be used in any publications or presentations arising from the research.	☐
• I understand that interviews will be recorded, but only the researcher is permitted to do this.	☐
• I give my permission for quotes to be used anonymously in publications.	☐
• I understand that if I am at risk of harm, then the researcher has a duty to report that to keep me safe.	☐
• I have read and understood the consent form and agree to participate in this study.	☐

Name of Participant: _____

Signature: _____

Date: _____

Appendix Q: demographic form for parent/carers

Information about your son/daughter.

This will be confidential and is only used for the researcher to see what range of people have been included in the research.

Please enable editing and highlight, mark or write your answers.

How many children are in your family?

How many children have special educational needs or a disability (SEND)?

Thinking about just one of your YP with SEND who was in year 10 or higher during the pandemic:

How old were they at the start of the pandemic (in 2020):

Under 16

16 -18

19 -22

23-25

26+

What type of special educational needs or disability do they have? Please mark/tick or highlight all that apply:

ADHD or ADD

Autism

Down syndrome

Learning difficulty (such as dyslexia or dyspraxia)

Medical or health condition

Mild/moderate learning disability

Physical disability

Profound and multiple disabilities

Severe learning disability

Visual or hearing disability

Social, emotional, mental health

Other (please state)

Where were they enrolled during the pandemic?

Please number them 1 for first placement then 2 for second if they moved during the main Covid years (2020 to 2022).

School College University

Other (please say where, e.g. alternative provision, hospital)

.....

What kind of setting was the placement (please number them if they moved during the pandemic)?

Mainstream Special Residential Special unit at mainstream school

Don't know Other (please say what kind)

What is the YP doing now?

At school At college Supported
internship

Voluntary work Paid work In a residential
educational setting

In a residential care setting Apprenticeship At university

Nothing Day care services

Something else – please say here:

.....

Gender of your young person:

Male Female Other

Ethnicity of your young person:

White: British, Irish Other white Black Asian

More than one ethnicity Other (write it here) Prefer not to
say

Information about you:

Were you employed during the pandemic? Yes No

What job were you doing?

Were you able to work from home?

Did you have other caring responsibilities

during the pandemic? Yes ☐ No ☐

What were these?

What part of the UK do you live in?

Appendix R: Support services for parents and professionals

If issues were raised in the interview which have been difficult for you and you wish to seek more support for these matters, you could try one of the services listed below or a service local to you that offers mental health support.

- **Your GP** can refer you to local mental health support services.
- **Every Mind Matters** – NHS: provides online support
<https://www.nhs.uk/every-mind-matters/>
- **MIND** is a charity that provides mental health support. You can contact them via 0300-123-3393 or email info@mind.org.uk
- If you are in a crisis situation contact the **Samaritans**: phone:116 123 or email jo@samaritans.org

Website: <https://www.samaritans.org/>

- Or the Anna Freud Centre: If you need crisis support, you can text AFC to 85258.

www.annafreud.org/on-my-mind/afc-crisis-messenger/

Appendix S: Questions for professionals

For confidentiality reasons, please do not use any names of cyp you are referring to in answering the questions. Thank you.

- 1. What do you remember about the pandemic and its impact on you and YP with SEND?**
- 2. How did you find out what was going on and what you needed to do as a professional?**
 - How did you let the families and YP know what was happening?
 - What information did you give to caregivers and the YP themselves?
did you call them -speak to P/C or YP themselves?
 - How did that go?
- 3. How was it decided who attended college/school/ placement?**
 - How did this work out in practice do you think?
 - What about vulnerable YP?
 - Did you think some YP were more vulnerable during the pandemic?
- 4. What changes did you have to make in how you work?**
 - How successful do you think these changes were?
 - Were all the YP able to access some sort of learning?
 - Were you aware of some YP struggling online or why they weren't engaging?
- 5. What was your own experience of work and home life during this time?**
 - Did you have other caring roles at the time?
 - Did you get enough support?
- 6. How did home learning work out for the YP and for you?**
 - Did you/they have enough tech and tech knowledge?
 - How did you get around any problems?
 - How did this work with more practical subjects?
 - Were you able to differentiate the learning?
 - Were there any advantages?
- 7. What happened for those who attended school/college as usual?**
 - Did you have to do both online and in-person work?
 - How did that go?
- 8. Do you think there was any impact on the YP's health and social care in this time?**

9. What happened about EHCP assessments and annual reviews?
- What was that like?
 - What was transition planning like?
10. What do you think was the impact of home learning/ attendance at school/college on the YP?
- Do you think they caught up afterwards?
11. What happened when they returned to school/college?
- Was anything done to ease them back?
12. Do you think there are any lasting repercussions of the pandemic on the YP?
- And on you?
13. How important do you think friendships and socialisation were (and are) for the YP with SEND?
- Do you or the school/college do anything to facilitate socialising and making friends?
14. Do you think the YP got enough support through the pandemic?
- Did you call them at home?
 - How do you judge how much support to give YP with SEND in their work and social lives usually?
15. What do you feel about inclusion in education and how well it is working for the YP you have worked with?
16. Is there anything else you would like to tell me about your experience with the YP during the pandemic?

Appendix T: Flyer for professionals.



The Impact of COVID on Young People with SEND

Do you work with young people with a disability or special educational need, who were 14 – 25 and in education during the pandemic?

Would you like to tell a researcher how lockdown affected them? Good or bad!



I would love to hear from you!



What will happen? 

You will be asked about their and your experiences during COVID, the lockdowns and afterwards.

It can be online or in person if you live in the South East.

I am happy to chat to you about the study if you have any questions.

If you are interested, then please contact me on:
jmp54@kent.ac.uk

Or text or What's App 07734 002717 (work phone)

Appendix U: Information Sheet for professionals

Jacqueline Paterson PhD candidate. Email: jmp54@kent.ac.uk Phone: 07734 002717

Supervisors Michelle McCarthy m.mccarthy@kent.ac.uk and Paraskevi Triantafyllopoulou
p.triantafyllopoulou@kent.ac.uk

Tizard Centre, University of Kent, Canterbury, Kent, CT2 7LR

Hello and thank you for showing an interest in this study.

I am Jacqueline Paterson, a PhD candidate at the Tizard Centre at the University of Kent. I used to be a teacher but now I work for a SEND information, advice and support service, providing support for young people with special needs and their families.

Purpose of the study: I am interested in finding out about the impact of COVID-19 on young people who have special educational needs and/or a disability (SEND) and who were in education during the pandemic and those who work with them. I have completed one study which asked young people between the ages of 16 and 25 about their experiences and I would now like to talk to teachers, tutors, teaching assistants, therapists and any other professionals who usually worked with young people in this age group in an educational setting and who continued either in-person or online during the pandemic. I would like to ask you about your thoughts and experiences of what happened to you and the young person during the pandemic. The voice of young people with disabilities, and those who work with them, is not always heard and so this is a chance for your experiences to be heard to help young people, their families and those who work with them in the future.

What you will be asked to do:

- Meet with me online (or in person if you live in the Southeast of England) to answer some questions about your experiences and that of the young people you worked with during the pandemic. The interview should last about an hour.
- If you would like to, you can ask any questions about the interview before we meet up and you can have a list of the main topics we will discuss if that is helpful.
- All interviews will be recorded for accuracy, but all names and places will be anonymised so that no real names will appear in any reports or writing.
- You are free to withdraw from the study at any time up to when the data is analysed, without giving a reason.

What will happen to the information: All information from the interviews will be anonymised. The information will be stored securely and kept confidential, with recordings of the sessions being destroyed once the information has been transcribed. The only reason for not keeping information confidential would be in the unlikely event that a participant said they were either at risk of harm themselves or to others, when that particular piece of information

would then need to be shared with the safeguarding lead at the participant's place of employment or their local authority safeguarding lead.

What happens if you wish to make a make a complaint?

You will be given a form at the end of the interview so that you can give any feedback or make a complaint if you wish to. In addition, at any time, you can contact my supervisor, Michelle McCarthy by email m.mccarthy@kent.ac.uk

Thank you very much for your time and I look forward to hearing from you if you would like to take the opportunity of taking part in this study. Do contact me about any issues or questions you may have on jmp54@kent.ac.uk

Many thanks

Jacqueline Paterson

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Appendix V: Demographic information for professionals

Information about the YP you work with.

This will be confidential and is only used for the researcher to see what range of people have been included in the research.

Please enable editing and highlight, mark or write your answers.

Age of YP you worked with during the pandemic:

Under 16 16 -18 19 -22 23-25 26+

Type of setting you worked in during the pandemic:

Special school Residential school/college

Specialist college Mainstream school

Special unit in a mainstream school Mainstream college

Higher education

Other (e.g. alternative provision, hospital, clinic, please state)

Education or services you provided during Covid:

Teaching or supporting in-person education only

Teaching or supporting with home learning only

A mix of home learning and in-person education

Providing therapy or other services to YP in-person

Providing therapy or other services to YP online

Management or Senior leadership role

Other – please specify

Your job title(s) at work during the pandemic (such as Learning support assistant, teacher, tutor, senior leadership team, headteacher, physiotherapist, speech therapist, administrative and so on):

How long have you worked with YP with SEND?

What type of special educational needs or disability do the YP have that you work with?

Please tick all that apply:

Autism

ADHD or ADD

Mild/moderate learning disability

Medical or health condition

Physical disability

Visual or hearing disability

Down syndrome

Profound and multiple disabilities

Learning difficulty (such as dyslexia or dyspraxia)

Social, emotional, mental health

Severe learning disability

Other (please state)

Your gender:

Male

Female

Other

Your ethnicity:

White: British, Irish

Other white

Black

Asian

More than one ethnicity

Other (write it here)

Prefer not to say

What part of the UK do you work in?

Did you have other roles apart from this work with YP?