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Then There Was Silence

The Impact of the Pandemic on Disabled
Children, Young People and their Families.

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About the Disabled Children's Partnership

The Disabled Children's Partnership is a major coalition of more than 90 organisations campaigning for improved health and social care for disabled children, young people and their families. We believe that disabled children, young people and their families should have access to the services they are entitled to, **when they need them.**

[Disabledchildrenspartnership.org.uk](https://disabledchildrenspartnership.org.uk)

Chapter One

Executive summary



Executive Summary

1.1 Background

Disabled children and young people were mainly absent from the narrative around the COVID-19 pandemic. The low risk reported to children assured they were mainly overlooked when considering the impact of the virus, containment measures and subsequent withdrawal of formal and informal support.

During times of emergency or disaster, it is known that people with disabilities are disproportionately affected during response and recovery phases. Therefore, although the disruption the pandemic brought was reported as “unprecedented”, the feelings described by disabled children and their families of being left behind, left out and locked out were not.

This research forms the response from the Pears Learning Hub at the Disabled Children's Partnership, to build the evidence base about the impact of the pandemic on disabled children, young people and their families and to identify what policy makers, funders and charities need to do next.



**Pears
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Pears Foundation

Pears Foundation is an independent British family foundation that focuses on understanding complex issues, engaging people in achieving social progress and promoting wellbeing.



**Disabled
Children's
Partnership**

Disabled Children's Partnership (DCP)

The DCP is a coalition of over 90 organisations that campaign for improved health and social care for disabled children, young people and their families.



The Pears Learning Hub

The Pears Learning Hub is a partnership between Pears Foundation and the Disabled Children's Partnership (DCP). The aim of the Pears Learning Hub is to develop the evidence base to understand the impact of the pandemic of disabled children and their families and how the third sector responded to it.

A mixed methodology approach to the research was adopted exploring three key areas:

- 1) The experiences of disabled children and their families to understand new and emerging need
- 2) An understanding of digital exclusion and digital disadvantage on the sector's provision for disabled children and young people.
- 3) The third sector response to the pandemic to aid the future planning and delivery of services.
- 4) An analysis of the policy context and opportunities for progress.

This report amalgamates the findings from the workstreams above. Research Methods are listed in Appendix I. Early chapters present the emerging needs of disabled children and their families, drawing on DCP primary research from successive parent panel surveys, parent / carer interviews and focus groups as well as national FOI requests. The review and analysis of open data sources, emerging studies and the policy context are also used to provide context to the families' perspective of the pandemic. Disabled children and families are not a homogenous group; findings presented consider experiences of various cohorts and demographic.

Independent research commissioned considers the accessibility of digital spaces, drawing on a focus group of disabled young people and interviews with 20 service providers, supported by a review of the academic literature and public documents.

The composition of DCP organisations are varied in terms of size, geography, children and families supported and how they are funded. Therefore, the response of organisations was wide ranging in terms of activities and experience. An independent evaluation of the sector response to the pandemic, undertaken with DCP member organisations, has combined learning from questionnaires, interviews and workshops, using a competency approach. This approach enables learning to be captured and taken forward, learning from how things were done rather than focusing on what was done. Five key lessons have been identified from the evaluation of the sector response.



1.2 The COVID-19 Pandemic

I've got to be clear, we've all got to be clear, that this is the worst public health crisis for a generation.

- Prime Minister Boris Johnson, 12th March 2020.

Worldwide at the time of writing, over 200 million cases of COVID-19 have been confirmed, with deaths approaching 4.5 million (WHO, August 2021). In England, there were just 18 days between the first confirmed death from COVID-19 and the announcement of national lockdown on 23rd March 2020. The initial stage of the pandemic was dominated by attempts to contain the new virus, with people with underlying health conditions widely reported as “vulnerable”. The older generation were swiftly deemed to be most at risk, along with people with certain clinical conditions, but there were many unknowns.

Once COVID-19 virus was widely circulating the strategy turned to control and mitigation, with the aim to reduce mortality and morbidity and disruption to society (WHO, 2020). To prevent the NHS system being overwhelmed a series of measures were announced to reduce social contact within the community. In addition to those deemed clinically vulnerable, it was soon apparent that there were groups of people and families more likely to be exposed to the virus due to the nature of their disabilities. Families had their usual support taken

away as services were diverted or paused. Therefore, the combination of the virus, subsequent containment measures and a reduction in support magnified the impact for disabled children and their families. Those relying on personal or supportive care in the home from others, or those who may not be able to understand or adhere to social distancing measures, appeared to be omitted from guidance issued.

This report acknowledges that it was frequent during the pandemic for the workforce of statutory and non-statutory organisations, voluntary or paid, to go above and beyond what was expected in their usual roles. The latter part of this report discusses the response from the third sector to the pandemic. Recommendations are provided in terms of how the sector can respond to the societal challenges COVID-19 has created. This report looks to the future, moving from the impact that COVID-19 pandemic had and continues to have on disabled children and their families in England, to how organisations can better support families in the future and provides recommendations for policy makers.

1.3 Disabled Children

The DCP campaigns for disabled children and young people (up to 25 years of age) and their families. DCP organisations advocate for children and young people with a wide range of disabilities, such as physical disabilities, learning disabilities, complex needs, sensory impairments, life limiting, rare or mental health conditions. The children and young people represented may attend mainstream schools, special needs provision, training or apprenticeships. They may require informal support from their family, formal support via school, statutory, independent or charitable services or a combination of both.

Disabled children and young people are frequently portrayed in the media and society as passive participants relying solely on support, rather than their ability and potential (UNICEF, 2018). Infrastructure such as transport, housing and public buildings in society reinforce barriers to disabled people, who have the right to the same opportunities as their non-disabled peers. For disabled children, with their needs identified at the right time, their opportunities for participation in society may be realised as opposed to the heightened risk of social exclusion being the alternative.

Disabled children may require support to communicate, understand, play, move, learn, eat, dress, socialise or interact. The type of need depends on the type and severity of their disability. Although some disabilities or conditions may be stable, as with all children their needs change as they develop and grow. For some this may mean equipment is updated, such as mobility aids, hearing aids or orthotics. Other disabilities may be intermittent and unpredictable. For example, those with epilepsy, manageable with drugs, may have periods of seizures with risk for hospitalisation and changes to medication. Autistic children may struggle with changes in routine and expectation, requiring support to manage that change. Disabled children with progressive conditions, such as

muscular dystrophy or cystic fibrosis, rely on effective combined support from multiple services across the range of health care, social care and education in order to participate in life.

In short, the quality of disabled children's lives relies heavily on the informal or formal support provided by multiple organisations within the community. Without such support, negating inaccessible barriers in society becomes an impossible task. Prior to the pandemic disabled children were not receiving the level of support needed. This leads us on to the experience of disabled children and their families during the COVID-19 pandemic. During usual times, the role families of disabled children play supporting their child to reach their goals cannot be understated. Families provide a nurturing home environment and they support their child to navigate the emotional challenges that their disability may bring while advocating for additional support. Parents play a vital role in supporting their child in overcoming obstacles that place them at risk of social exclusion. Siblings too play a role, not just in terms of the relationship or bond they have with their brother or sister. They may also support their sibling and wider family emotionally and help with practical tasks, experiencing difficult situations, feeling isolated from their peers.

1.4 Disabled children, young people and their families during COVID

Existing inequalities (social, economic and health) left particular groups vulnerable to the virus and containment measures introduced (Health Foundation, 2021, Marmot 2020). The Coronavirus Act (brought into law on 25th March 2020), suspended some of the duties of local authorities, replacing their obligations with “reasonable endeavours” for a period of time. This was to ease the burden for frontline staff by reducing administrative tasks and recognising covid restrictions might reduce their ability to provide some services. In practice, it allowed for the relaxation of certain legal requirements on local authorities, health care organisations and education settings. For example, if a local authority was unable to provide the provision required set out in an Education, Health and Care plan for a disabled child, it would not be penalised. The specification required in the Mental Health Act of 1983, for two doctors to detain an individual, was temporarily removed, with one doctor only required at this time. Local authority duties to conduct needs assessment, carer assessments or transition plans under the Care Act 2014 were also temporarily suspended.

In May 2020, the DCP conducted a survey of 4000 families with disabled children to assess the impact that lockdown was having. The Left in lockdown (DCP, 2020A) report highlighted that families felt abandoned by government and society, leaving parents feeling fearful about their own physical and mental health. 76% of families were no longer receiving vital services they relied on with parents and siblings taking on all caring responsibilities. During the pandemic, the suspension of statutory duties, redirection of resources and reduction in face to face support or care, restricted parents' capacity to cushion the impact of the pandemic on their disabled children, siblings or themselves.

1.5 Third Sector Response to the COVID-19 pandemic

The COVID-19 pandemic brought significant challenges for charities, many of whom saw demand for their services and costs increase whilst their income decreased. Many charities needed to adapt service models to deliver online, forge new partnerships, undertake operational restructures, respond to changing needs and find new ways to support and motivate staff and volunteers. An independent evaluation undertaken by Fivewaysnp and Discovery Research assesses the response from the sector and describes what is needed for the sector to move forward to meet the needs of disabled children and families.

1.6 Key findings: a snapshot of the impact of the pandemic on disabled children and their families

Children and families have been isolated and abandoned; and not been listened to

Despite restriction easing 55% of parents experienced the same level or a worsening of their isolation
9 in 10 disabled children were socially isolated, with three quarters (76%) seeing no improvement over the course of 2021 despite lockdown measures easing

Covid restrictions meant services were stopped or reduced; and many are still slow to return

Compared to Pre-Pandemic service levels, throughout the pandemic there was:

60% increase in referrals to paediatric emergency mental health services

Paediatric Pain Management clinics were reduced by 84%

67% of Trusts (FOI responses) completed fewer Physiotherapy assessments within 13 weeks target.

Almost half of Trusts completed fewer OT and SALT assessments

Less than 4 in 10 children with EHCPs attended school during Lockdown between January and March 2021

Mental health and wellbeing of all the family has deteriorated

Despite restrictions easing 60% of parents' mental wellbeing remained the same or worsened

Parents' level of depression was significantly higher than the general population during COVID

Over half of parents (56%) experienced the same level or worsening levels of stress over time

Parental anxiety is consistently high with more than 80% of parents having some form of anxiety

Level of isolation experienced by siblings of disabled children was high with 7 in 10 siblings still socially isolated despite restrictions easing

Children's conditions have worsened and needs become more complex; delays in assessments mean needs haven't been identified

71% of parents said that their child's progress regressed due to service delays

Compared to Pre-Pandemic service levels:

Over 40% reduction in Community Paediatric activity

40% reduction in paediatric surgery

63% of Local Authorities received fewer EHCP referrals than pre-pandemic

70% of Local Authorities completed fewer EHCP decisions to assess within the 6-week timeframe

6 in 10 Local Authorities not completing section 17 requests within timeframe

The charity sector demonstrates agility and flexibility and was able to extend its reach to help support families:

The role of the DCP is overwhelmingly deemed 'vital' both as a source of information and updates as the pandemic progressed and as a powerful lobbying body. Charities praise its ability to provide a unified front to raise awareness of the pressing needs of disabled children and their families, giving parents and carers a voice and providing evidence to secure funding bids – smaller individual charities would not have been able to focus on campaigning as all their time and resource was allocated to responding to the changing needs of children and their families. Organisations also praise the DCP's collaborative and all-encompassing approach, ensuring that all charities, big and small, could have a say and effectively influence policy change.

1.7 Recommendations

In light of the significant detrimental impacts disabled children and their families have experienced throughout the pandemic, all agencies need to step up and take action if they are to have the same opportunities for recovery as their peers.

Five steps for central and local government

1. Prioritise the needs for of disabled children and their families within covid recovery plans and programmes
2. Tackle the backlog in assessments and ensure that children's needs are re-assessed in light of missed support during the pandemic.
3. Ensure the right support is in place for all children and families, including education, health (including mental health), therapies and equipment
4. Take a whole family approach to assessments and support, including siblings. This should include the provision of respite/short breaks and opportunities for families to take part in activities to overcome the isolation felt by so many
5. Invest in services through the Comprehensive Spending Review

Five steps for charities

1. Charities should increase their capacity to be able to understand changing disabled children's and families' needs
2. Charities should increase their focus on delivering emotional and financial support to families
3. Charities should ensure that they maximise the benefits of online service delivery
4. Charities should adopt a more collaborative, holistic approach to meeting needs
5. Charities should adopt an agile approach to service design and implementation

Five steps for the Disabled Children's Partnership

1. The DCP should maintain a central repository of insight into the changing experiences of disabled children and families, for policy makers and charities to draw on to support their own work with families
2. The DCP should bring together charities to explore in more depth the practical application of the competencies identified in this report, including exploration of the barriers to good practice
3. The DCP should continue to work inclusively to harness opportunities for collaboration, including sharing and disseminating particular initiatives that have been effective in meeting the current and future needs of disabled children and families
4. The DCP should continue to draw on the expertise from its range of members to unite charities and families to raise awareness of the issues facing disabled children and their families and to lobby for change.
5. The DCP should encourage funders to take a holistic approach to support for the sector - by demonstrating the vital role different organisations play, how needs are currently met by the sector, and by highlighting the gaps in service provision experienced by disabled children and families.

Five steps for philanthropists, charitable foundations and funders

1. Support charitable programmes that take a whole family approach to preventing problems escalating into crisis and breakdown, for example support for respite, shorts breaks or support within the home recognising that that parents have taken on additional roles to support their child practically and emotionally without a break. Support partnerships that bring together organisations with different strengths and networks to best meet the needs of families.
2. Place an emphasis on programmes that provide emotional support and help families overcome the isolation they have suffered during the pandemic. These should range from peer to peer support through to therapeutic services, and include services that ease financial pressures.
3. Consider providing unrestricted funds to enable charities to be agile and flexible in responding to needs and working collaboratively with other organisations to secure the best outcomes for children and families. This could include providing 'test and learn' grants to enable charities to innovate and take risks on new approaches, as well as longer term support for well proven services.
4. Fund services that are developed in co-production with disabled children and their families; and allow flexibility for ongoing feedback from children and families to shape the service as it is delivered.
5. Support charities to develop blended approaches to services delivery; and invest in digital capacity, capability and confidence (within charities and within families).

I.8 Report structure

The findings of the research programme are presented in 4 sections (Chapters 2-5). As discussed, disabled children and their families require support and adjustments in order to negate barriers within society during their daily lives. Therefore, the first chapter “Then there was silence” discusses the findings in the context of support systems that disabled children and their families use. It looks at the impact of the COVID-19 pandemic on the support families may receive from education, health, social care and the financial consequences. It then reflects on informal support and impact of the pandemic on support received from family, friends and groups or activities in the community.

Parents acknowledged the early stages of the pandemic would bring disruption to the services they received. However, as time progressed they described feeling abandoned and forgotten (DCP, 2020A). Chapter 2 looks more closely at the consequences of reduced support on disabled children, with chapter 3 reviewing the experiences of the wider family including parents and disabled children’s siblings.

Chapter 5 presents the findings from the independent evaluation of the third sector response and looks to the future, with five key areas of learning, moving forward to ensure an effective response to the pandemic. Chapter 6 summarises findings from the Pears Learning Hub with next steps for policy makers and funders.



Then There Was Silence

- Parent of a disabled young person, April 2021

Chapter Two

The impact of the pandemic on the support accessed by disabled children, young people and their families.



Introduction

“We’re going to need to mobilise millions of people to help and support each other. And I just want you to know that the government will do all we can to help you and your family during this period”.

- Prime Minister, Boris Johnson, 12th March 2021

The COVID crisis has unique characteristics affecting economic, health and social phenomena, with responses such as school closures and home working placing additional burdens on families (Del Boca, Oggero, Profeta et al, 2020). This section looks at what happened to the support usually available to disabled children and their families during the pandemic. Supplementary evidence regarding the impact of COVID on support from education is supplied in Appendix 2.

“The complete loss of respite care was simply exhausting. We had formal, informal and family arrangements. We lost them all. Couple that with school closures and it’s been incredibly hard. We are physically and emotionally exhausted”. - Parent Carer.

The broad range of disability and needs of disabled children and their families mean that some families may require intermittent support from a small number of services with others requiring ongoing support from multiple organisations. As the older generations were highlighted as particularly at risk from COVID-19, disabled children were often overlooked in the narrative of those impacted by the sudden disruption to services. As before the pandemic, social care was framed in the media as a service to support older generations, rather than young adults or working age adults with disabilities, or children and families. Care homes and day services again were discussed as services only used by the older population rather than young people with disabilities.

For this reason, this chapter commences with a parent’s account of the impact restrictions had on the support received for a young person attending residential college (Case study 1). It provides an

example of a family relying on multiple organisations across multiple sectors and the cumulative effect that COVID and subsequent restrictions had and continue to have.

Achieving joined up support across education, social care, health and respite had its challenges before the pandemic for disabled children and young people. The pandemic has highlighted the fragmentation of support available. This section demonstrates the intertwining levels of support that disabled children and their families use to live their life.

“Respite provision amazingly carried on during lockdown one. It was literally a life saver - yes, I do mean ‘literally’. We struggled however with not only no school, but no after school club or holiday clubs. Provision in the autumn was better through school but respite care was not as frequent or beneficial. Since January, my daughter is back at school (when not having to self-isolate) but there is still no after school or holiday provision, and respite care has been further reduced”. - Parent Carer

Case Study I highlights the importance of support at home for families who have disabled children or young people. In this case, the family were unable to bring their child home from a residential setting as the 2-1 support available at the setting could not be replicated at home. In addition, the response to COVID appears to have undermined the rights of the young person to access their usual activities and previous expectations have diminished. The reduced role of the parent, as an integral part and source of knowledge within the care team too, has altered. This case study has been included as an example of such contentions, reported continually throughout the research across the various levels of support. *"Because of Covid"* agreed education support cannot be provided, health equipment will be delayed, access to short breaks has been paused. Following Case Study I, the first section of this chapter will review the impact of COVID on support received from education.



2.1 Case Study I

“My son has a human right to be kept safe but his rights seem to be overshadowed by the human rights of others. He has no choice over who supports him, no control over who walks into his home, his room; he cannot move away easily if he doesn’t want someone to be near him”.

Finn attends a college for 19-25 year olds with complex learning difficulties, special educational needs, communication needs and other disabilities. Students may attend as day students, weekly boarders, 38-week residential, or 52-week residential. There is also a school for pupils with similar profiles on the same site, some of whom are residential. The residential accommodation comprises approximately 18 separate houses, each with their own garden. There are four to six students in each house. In college, students may be in a different class from their housemates. Staff may also work in several different houses.

In March 2020 there was a minimum of six different staff on each day shift (more at certain times) and three night staff. Therefore, a minimum of 15 different staff coming into the house in a 24-hour period. Staff were a combination of full or part time, employed by the organisation, bank or agency. Before the pandemic, Finn went home approximately every six weeks for four or five nights. In addition, his parents would make occasional social visits and support him at all out-patient appointments with consultants, approximately

one visit a month for medical reasons. Despite a history of respiratory illness, Finn was not put on the clinically extremely vulnerable list until the change in government policy regarding Down Syndrome in November 2020. Parents made the decision to keep Finn safe at residential school rather than take him out of college, due to lack of essential support from care agencies. It was felt the residential college would be the safest. However, the government guidance created additional stress for the family.

“We were in the position of knowing what was needed to keep our son safe but the organisation was sticking strictly to government guidelines. We made the very, very difficult decision not to visit but there seemed to be other families that thought it was OK. Visits were not officially stopped until a good couple of weeks after lockdown”.

Despite the fact that family visits were halted, the anxiety about the risk from COVID-19 for vulnerable children and young adults continued due to the different status of students at the college.

“

My son has a human right to be kept safe but his rights seem to be overshadowed by the human rights of others.

"Finn also had a housemate who was going back and forth between their parental home and the residential house every weekend. This freaked me out as it created a channel for the virus to get into the house that could have been avoided. This was eventually stopped. But then we found out he was in a bubble with day students travelling between home and college every day".

The difficult decision not to visit and keep Finn at residential college was compounded by lack of communication and updates from staff. Family services had offered fortnightly phone calls but this agreement was not met.

"Then there was silence. I was struggling, when I called them after 6 weeks, I was told higher up in the organisation had said NOT to offer support to families of residential students. That felt really isolating".
- Parent

The priority appeared to be given to parents who had children and young people now at home and needed support. The isolation described was exacerbated when fears of the clinical threat from COVID were realised and lack of communication from the college enforced a feeling of a diminished parenting role.

"When Covid got into Finn's house there was an appalling lack of communication which created huge anxiety and genuine fear in me. It's as though lockdown sent them into their own little bubble, away from the wider world, now parents on the outside, no longer considered part of the team that support my son".

As a result of the pandemic there were staff changes due to isolation, relocation to other parts of the organisation, and new (temporary) staff introduced. The lack of family visits meant communications with new staff were often unproductive. Specialist understanding of Finn's needs were not appropriately understood. There are concerns that approaches used in the first months of the pandemic may become usual practice in the longer term.

"Before the pandemic there would usually be a two-week induction programme for new staff plus shadowing. The majority of that has gone with training now focused on behaviour support and health and safety rather than specialist training in communication of people with congenital deaf blindness and multisensory impairment. He is supposed to have Intervenor support at all times. This is in his EHC Plan. There have been so many staff changes, he is now supported by people who have started since March 2020, who have limited knowledge about congenital deaf blindness and have no access to training. However, because they have "managed" for months or, in some cases for over a year, it is now accepted".

The acceptance of approaches during the initial emergency lockdown of the pandemic has also led to a lowering of aspirations for Finn in terms of activities he has access to during the day.

"Since the pandemic Finn seems to spend his days doing the same old thing: got up late, had breakfast, went for a walk round site, listened to music, chilled out in his room (which often means he had nothing offered and resorted to self-stimulatory behaviours).....day after day, week after week, month after month. Lack of training, experience and insight is resulting in Finn having a largely dull, unstimulating, unexciting life with people underestimating what Finn is capable of and even what he enjoys".

Lack of communication between staff has resulted in prescribed pain medication not being ordered in time resulting in self-injurious behaviour. Very few activities and equipment sent by the family to support Finn during lockdown were used by staff.

"Decisions made by the organisation, attitudes that emerged, lack of support for myself and mostly lack of communication have resulted in me no longer trusting the organisation as a whole, or the individuals that support my son. And that is a very sad and scary place to be".

The parents feel their experience raises broader issues about how vulnerable people are looked after by society. There continues to be a lot of anxiety around organisational policies and making sure young people are protected and contention with working practices.

"I understand the rights of people to lead their lives as they want outside work but one staff member told me she was about to set off on holiday to an amber country and there seems to be a "there's nothing we can do.....we can't make staff take the tests" approach.

2.2 Education

The impact of the pandemic on children and young people's learning has been widely reported. As a key measure to protect against the spread of COVID-19 globally, it is estimated over 150 countries closed schools, affecting over 1 million children, representing 68% of enrolled learners worldwide (UNESCO, 2020). In England, schools were closed in March 2020, with advice to remain open for children of key workers, looked after children, children with an EHC plan or a social worker although in practice this wasn't always the case. There was a partial re-opening of schools in June 2020, but the full re-opening did not take place until September 2020.

Education is one of the most important indicators that contribute to outcomes later in life - in particular social mobility and employment - and leads to longer life. The emphasis on educational qualifications and attainment means that achievements form part of how people shape their own identity, either positively or negatively (ESRC 2021). Therefore, interruption to education is further reaching than the collection of qualifications achieved.

During the second national lockdown in November 2020, schools remained open, eventually closing on January 5th 2021. The schedule of school re-openings, whilst disruptive does not adequately illuminate the disruption to the lives of young people and their families. For example, over 12 months since the start of the pandemic in England, 1.13 million pupils in England were out of school on a single day (16th July 2021), due to a COVID-19 related issue (Lough, 2021). This section will explore the impact of the pandemic on the support disabled children would usually receive via their education placement. The evidence presented will outline how disabled children and young people were affected by such measures. There was concern that the closure of schools could deprive disabled children of dedicated activities, with them suffering further detriment in the future (Leocani et al., 2020).

This section will initially discuss the impact of COVID settings and attendance of disabled children (2.2.1). Section 2.2.2, will review how children with EHCPs or SEND support were affected. Section 2.2.3 reviews remote teaching and provision of education for those disabled children who received their education at home. In usual times, for disabled children attending specialist settings, access to additional services such as therapies and equipment to manage their disability condition are available. This is one area where crossover between education, health and social care exists. Therefore, access to therapies and equipment will be discussed in this section 2.2.4. Delays to health care appointments will be discussed later in section 3.4. A key aspect of COVID-19 pandemic policy was to "shield" individuals who were particularly vulnerable to the virus. A comparison for access to support of young children shielding with those who were not is discussed in section 2.2.5. Elective home education has always been an option for disabled children, and is discussed in section 2.2.6.

We will begin by providing an understanding of the settings available to disabled children including an outline of support that disabled children may have access to.

2.2.1 Educational Settings & Pupil Attendance

In England, 15.8% of pupils have identified additional needs, 3.7% have an Educational Health Care plan (EHCP) and 12.2% require Special Educational Needs (SEN) support, (a total of 1,408,701 children). An EHCP is for children and young people who need more support than is available through special educational needs support. It identifies the educational, health and care needs and sets out the additional support required to meet those needs (UK Government, 2021). The most common type of need for an EHC Plan is Autistic Spectrum Disorder and for those with SEN support a speech, language or communication need. Figure 1 illustrates the proportion of those with EHC plans or SEN needs by setting (2020/21).

Despite disabled children with EHC plans designated as pupils who were able to attend school, many did not attend. For example, in May 2020, a DCP survey (DCP, 2020A) of 4000 parents established that many of those with EHCPs were not in school. Almost half of these (43%) were concerned about their child's health at school or someone in the household was shielding and 20% of parents had been advised by school that their child should not attend. Further reasons are detailed in figure 2. Attendance figures reveal that just 1 in 5 disabled children registered at special schools attended their setting despite being eligible to attend (figure 3).

A series of surveys encompassing 9797 parents by Family Fund (2021) revealed that 3 in 10 disabled children attended school between March 2020 and the end of the school year. Although attendance improved in the new school year only 4 in 10 disabled children attended school during the lockdown at the start of January 2021 (figure 4).

Following the closure of schools in March, pupils attending the partial school re-opening in June 2020 was dependent on the age of children, with younger children and secondary school pupils in exam years prioritised for the return. Therefore, as will be discussed in section 4, the impact on children differs by age group. Although schools re-opened in September, increasing COVID-19 cases in particular regions had brought localised restrictions.

The government introduced a three tier system to standardise local rules in October 2020. Schools remained open during this time, however rising COVID cases, families isolating, variable staffing levels and lack of wrap around services (eg transport) affected pupil attendance. Attendance at special schools is usually lower than at mainstream schools, due to appointments and periods of poor health. Analysis of attendance data across all state provision by region (Figure 5) illustrates areas such as the Midlands and the North, placed in the Tiers with

higher levels of restrictions, as generally having lower levels of attendance. The Tier system was updated in December 2020 before being replaced by a national "stay at home order" in January 2021.

Analysis by Andrew, Cattan, Costa Dias et al (2020) compared attendance rates by wealth before lockdown and during lockdown, revealing rates of attendance were lowest for the poorest 20% of pupils and highest for the wealthiest 20%. This confirms multiple caveats across groups of students rather than merely whether schools are open. The association between disability, carers and poverty has been reported widely (JRF 2020A, Allcock 2019, Phillips et al 2018). Therefore, disabled children and their families are already at greater risk from inequalities prior to emerging inequalities in access to education. Research pertaining to digital disadvantage revealed that the pandemic has added to challenges disabled children experience in terms of academic challenges, with the gap between those digitally included and those excluded widening (Bradley, 2021).

Once in attendance, the threat of COVID-19 at the educational setting also caused anxiety at school for some children who then had time at school reduced to accommodate this. Changes in staffing as bubbles were introduced created anxiety for autistic pupils or those with emotional needs that required consistency:

They're not getting the space and keeping their routine and seeing people like the teacher that they are close to, so are unable to express themselves and when going out they are worried and anxious.

- Parent Carer

My daughter had a breakdown caused by anxiety of covid. College have reduced their input to 4 hours a week.

- Parent Carer

Not being able to have the same teachers each day. Not knowing a fixed timetable is causing anxiety. My daughter has not been socialising properly at school.

- Parent Carer

Therefore, where children and young people with SEND attended their settings the full curriculum may not have been accessible due to the introduction of part-time timetables, priority given to core subjects and COVID-19 guidance making some subjects difficult to deliver (CQC & Ofsted, 2020). The charts below demonstrate that the policy of prioritising those with EHCPs did not have the desired effect in practice on those with disabilities, requiring support from the perspective of their attendance.

During the autumn term the attendance of pupils with an EHCP was on average just under 6% lower than pupils without EHC plans. Inspections by CQC and Ofsted confirmed that children and young people with SEND were less likely to attend their schools and colleges than their peers. Problems accessing transport were included in their findings (OFSTED, 2020). DCP research in November 2020 reported that of those disabled children attending part-time, 43% were so due to a decision by school and 21% due to parent requests (DCP 2020B). At the start of 2021, schools once again closed to pupils other than those with social workers, EHCP or children of key workers. Despite this, the attendance for children with EHCPs was very low, with less than 50% of those with EHCPs in attendance (figure 8).

Schools returned on the 8th March 2021, with the proportion of children with EHCPs attending returning to pre-pandemic levels, on average 4.5% below pupils without EHCPs (between March and May 2021). However, despite schools providing face to face and learning for pupils at home, guidelines at the time resulted in staff shortages with not all staff able to attend their workplace. This resulted in many disabled children only able to attend their setting part time or at a reduced level. For those able to attend schools, physical distancing created barriers for teaching

methods used both in mainstream and specialised settings. Staff absences or smaller teaching groups meant that disabled children were not with their usual staff and created difficulties in support for those with additional needs, as quotes from parents below describes.

Social distancing prevents close engagement of support staff who are necessary to help scribe and for access of resources in lessons. Social isolation impacted too as unable to see friends.

On the days one of my children goes in, there is no one there to specifically support his needs or carry out interventions with him. - Parent Carer

My son's support has been affected but considering staff absence I think it's unrealistic to expect the same provision under the circumstances. It's not been a deliberative attempt to not provide support- but an inevitable state of play. School have done everything they can to try and keep going and provide everything my son needs but it's an uphill battle for them.
- Parent Carer

There were concerns from parents who had children requiring personal care involving body fluids or pupils who were unable to social distance or maintain hygiene routines (Skipp & Hopwood, 2020). Disabled children who required aerosol generating procedures throughout the day were met with a barrier. In September 2020, the date highlighted for all pupils to return, guidance highlighted the level of PPE required by staff delivering this procedure should be the same standard as that used on COVID-19 hospital wards (Ward, 2020). Therefore, many schools were unable to accept children back into the school environment until the source and supply for this recommendation was addressed.

2.2.2 EHCP & SEN Support

He has been offered 2 days a week in school, but won't have TA help there, so I see no point in him going in. Quite a lot of the support listed in his EHCP is not implemented, with school saying they have to provide the help to the best of their ability and not to the letter. This means, for instance, that he is not taught in a small quiet group in a calm environment, but in a busy classroom where students are allowed to move around and talk between desks. He prefers the quiet of home, but I don't know how much he is actually achieving in comparison with having full time TA help. - Parent Carer

This section looks at the impact COVID had on EHCP and SEN support, review processes and identification of additional needs or children with additional needs. As discussed earlier, the Coronavirus Act replaced the duty of local authorities with reasonable endeavours, meaning support described in EHCP was not guaranteed. During the lockdown in January 2021, 67% of those with an EHCP were not getting all of the support listed. 72% stated that their child's EHCP or SEN plan had been negatively affected by COVID-19 pandemic (DCP, 2021A). The impact of this on disabled children and their wider family is discussed further in sections 3 and 4.

The analysis of support provided by schools in England gives an insight into the type of needs children and young people may have. The primary needs of children with an EHC plan is most commonly due to a diagnosis of Autism, followed by speech, language and communication needs and social or emotional needs. The most common primary need for children with SEN support is speech, language and communication needs, moderate learning difficulties and social emotional and learning disability (Figure 9). Lockdown highlighted that provision of equipment was

not designated to the child but the setting, therefore equipment to aid communication and learning was not at home with the child.

The provision of support for disabled children whilst in education may be provided by staff at the provision or visitors attending on a sessional basis. In order to maintain the bubble system and minimise the footfall in schools and colleges, external professionals were unable to provide usual sessions for disabled students. Bubble systems were attributed to a back log of equipment and reassessments (Move Europe, 2021).

Teacher of the Deaf unable to visit although supports us by email/telephone.

Not being able to get in professionals to support physical and communication difficulties, mainly around equipment

Neither of the schools will allow visitors so SALT, CAMHs and OT have not been able to visit. Three of his regular staff have had to shield and he has mainly new staff. In the school his bubble has altered as well as staff so felt very anxious. - Parent Carers

In May 2020, 66% of parents responding to the DCP survey were experiencing delays to the EHCP assessment process and 43% reported that annual reviews had been delayed or put on hold.

Since diagnosis to be on SEN register we have been in a pandemic so nothing done yet to add support for my Child - Parent Carer

The legal deadline to complete the EHCP assessment is 20 weeks, however 27% of families waiting for EHCP assessments in January 2021 had been waiting for more than 6 months.

Across the age groups COVID-19 impacted on access to appropriately trained staff regarding interventions. Access to nursery education was affected, due to a reduction in training for nursery staff in equipment use such as hoists, with staff leading the training diverted to other services due to COVID. The dominant concern regarding this age group was the lack of access to speech, language and communication services.

Our 3 year old has been identified as needing hoisting for nappy changes etc and there is no one doing the moving and handling training for nursery provision because of COVID. She should have started January 2021 then it got pushed back to after April and still hasn't started

We have had 40 minutes zoom Speech and Language Therapy (SALT) since March 2020. Will not see face to face unless wearing mask and visor! This is a SALT!!! Impossible - Parent Carer

A third of parents of children in the school age groups reported that their disabled child's examination, assessment or transition was negatively affected by the pandemic. In particular parents reported school based anxiety, a dominant theme for autistic children who needed preparation and support with changing routines. 14% of parents reported that the return to school in March 2021 was worse than expected. Parents expressed concern that progress that had been made had been lost due to lower than usual confidence levels and a loss of communication skills. Disabled autistic children need to practise social skills regularly and without routine need additional support in re-learning skills.

Parents taking part in the survey panel highlighted a negative impact on life skills such as being out and about (53%), communicating with others (49%) and interacting with strangers (47%). Clearly this affects milestones for children moving through educational stages, in particular from primary to secondary school. Poor access to support for communication support or social communication skills had a knock on effect on confidence in usual settings and put transition into

new settings at risk. A poor transition to secondary school may result in increased anxiety to attend school, increased absence which in turn leads to high risk of isolation and lack of opportunity. In June 2021, 49% of parents reported that their child's transition had been negative, of those almost 70% had children in the 16+ age groups.

Parents also reported difficulties regarding support within the EHCP that had not been provided before the pandemic, with appeals and provision then not appropriated due to the pandemic. Parents were presented with a reality that overdue support would not be provided as agreed at appeals or tribunal.

Therapy provision not delivered. We had a decision given after 4 years of fight to make good missed opportunities/ therapies. What happens to that funding now because it's not been delivered? I haven't been able to get answers for it. Waste of 4 years worth of battle.

We had just been to tribunal and shown that we hadn't received the hours we should have and that was to be provided in addition to what we had been approved for from March onwards, but now we didn't just not get what we should usually get, we didn't receive the extra they said we had missed out on because everything has stopped. - Parent Carers

2.2.3 Remote Teaching at Home

No support for online learning, it's all left to me - now it's my work/deadlines. I've constantly told SENCO what is working & what isn't working - this week a TA was added to a chat group on TEAMS for SEN support - not much use when your child is incredibly slow at typing or struggles to spell. - Parent Carer

A government programme provided vulnerable pupils with laptops and computers. Research with parents and services concluded that providing devices only is an insufficient response to digital disadvantage. Other barriers are not considered such as the accessibility of design, support within the household and connectivity challenges (Bradley, 2021). At the start of the pandemic, families who stayed home and used remote teaching reported variable levels of support from schools or colleges. 1 in 4 parents reported good levels of support although 1 in 3 stated that they received no support from school. Although at the time of writing, school children are expected to attend school, disruption due to COVID-19 outbreaks is expected to continue with those not in school expected to learn at home. Despite the pausing of the shielding programme, where a child who is CEV has been advised by their doctor to not attend school, provision should still be provided at home (IPSEA, 2021).

Interventions at school have been cut in half, home learning pack was not differentiated.

My son is not attending face to face education as his younger brother is vulnerable so have kept him at home. He is blind so online learning can be quite difficult I have to spend a lot of time teaching him myself, audio describing work reading things out etc.

It disrupted everything. His mentoring stopped. No Speech and Language support was provided, counselling did not continue. Learning development lessons online were useless and did not follow up on the work the child submitted to see if they had understood, or learnt the skill being taught.

My child has severe physical and learning disabilities with complex health so remote learning is not applicable. She needs one to one care and teaching.

No schooling at all in first lockdown. Since then although place has been available at school my daughter has had to self-isolate for three separate periods and so missed schooling. Because of her PMLD and high energy levels she is unable to engage in online learning. - Parent Carers

The impact on parents is discussed in further detail in section 4. However, particular age groups were highlighted (figure 10) as losing out the time spent learning whilst schools were closed in lockdown 1 (Andrew, Cattan, Costa Dias, 2020). Families digitally disadvantaged find themselves in a vicious cycle of stress due to the detrimental impact on their education (Bradley, 2021) threatening their independence.

2.2.4 Therapies and Equipment

My son usually attends a conductive education school full time (he has quadriplegic cerebral palsy) so gets physical therapy all day every day but at home looking after 3 kids I don't have the capacity for this so he is mostly sitting in his chair all day. I am able to cope with teaching him from home and am confident in this but the physical therapy needs more than one person to assist him and I can't manage this on my own.

- Parent Carer

Disabled children attending an education setting may require additional support for their learning or therapy to support their disability. The educational placement provides access to therapies or activities to provide therapeutic, sensory, proprioceptive input. There may also be mental health support for those with anxiety or requiring support for social communication. In May 2020, 51% of parents told the DCP that they were no longer receiving therapies or support required for their child. During the third lockdown, in the DCP panel survey, parents reported that the support at school for their child's condition or disability was far from pre-pandemic levels. Although, as illustrated below (Table 1), this did improve as time progressed, the levels of support were still not back to pre-pandemic levels. In June 2021, 73% of families stated that therapies they were receiving were little or much less the level and quality compared to before the pandemic and 50% stated the same for support received by education services (DCP 2021D). 93% of SEN schools surveyed said lockdowns had adversely affected their students' mobility (Move Europe, 2021).

As with education equipment, equipment for physical therapy or to aid movement was shared at school. The school day would facilitate sessions and movement throughout the day would contribute to the physical therapy that children needed for their development, to strengthen muscles and relieve pain. Therefore, when the home became the setting and the child was spending all their time at home, socioeconomic differences affected if children could continue with such exercises: space to move,

equipment stored, time available with other children in the house. The impact that the lack of access to therapies has had on disabled children, physically and mentally, is discussed in more detail in section 3.

Deployment of children's occupational therapists to adult NHS services at the start of the pandemic meant fewer therapists were available to support children and young people with SEND. A survey by the Royal College of Occupational Therapists (2020) said that 1500 occupational therapists were deployed elsewhere. Therefore, capacity of therapy services to support families at home was reduced. Children's services also provide assessments that contribute to diagnosis and reports required for EHC applications and plans. In response to freedom of information requests, the level of disruption to NHS Trusts providing physiotherapy, occupational therapy and speech and language services was evident.

A comparison of the first 9 months (2020 Q1-Q3) of the pandemic and the same 9 months the year before (2019 Q1-Q3) revealed that disabled children who may access services for diagnosis, treatment or support face systematic barriers. Services are continuing to operate at pre-pandemic levels. Physiotherapy, Occupational Therapy and Speech and Language Therapy services are receiving few referrals as illustrated in figure 11. In addition, the proportion of Trusts providing a first appointment within 13 weeks remained at pre-pandemic levels, revealing a further barrier. 67% of Trusts that responded were providing fewer first physiotherapy appointments within 13 weeks than before the pandemic, 46% Occupational Therapy and 44% Speech and Language Therapy (figure 12). This was echoed in findings from DCP research with families of disabled children.

Table 1: Proportion of disabled children unable to access pre-pandemic level of therapies via school at 3 stages of the pandemic.

	Unable to use service All Responses Lockdown 1	Unable to Use Service All Responses Lockdown 3 (January 2021)	Unable to Use Service All Responses Lockdown 3 (January 2021)
Physical Therapy or Physiotherapy	85%	70%	51%
Speech and Language Therapy	84%	70%	54%
Music Therapy	82.5%	69%	19%
Play Therapy	84%	71%	17%
Hydrotherapy	95%	89%	36%
Occupational Therapy	81%	73%	56%
Talk Therapies (mental health)	71%	64%	24%

My son had an intensive physiotherapy programme 3 days a week and hydrotherapy once per week. He has had NONE of this taking place

School is short staffed. All NHS Physiotherapy and Speech and Language Therapy has been pulled.
- Parent Carers

The findings above are supported by research by Newlife (2021) that revealed over three quarters (77%) of families responding to a survey faced long delays in getting assessments for services such as physiotherapy, respite, speech and language and equipment. This brings us onto the impact of COVID-19 on equipment provision for disabled children and young people. Supportive aids or equipment may help a disabled child communicate, move, play and learn safely. However, staff redeployment and postponement of face to face appointments contributed to lack of equipment provision and maintenance. Although access to health care services will be discussed in more detail in section 2.4, it is important to review equipment provision here.

Services have a statutory duty to provide equipment for Disabled children as needs are identified. Disabled children grow, their needs change. Therefore the maintenance, calibration and renewal of equipment is imperative. DCP research in January 2021 revealed that just under a third (28%) of disabled children were experiencing delays receiving equipment and a fifth (21%) in the maintenance of equipment. Despite the easing of restrictions a third (28%) of families were still experiencing delays to equipment provision in June 2021 and although equipment maintenance had improved, 10% were still experiencing delays. One important point to note is that the majority of disabled children do not just use one piece of equipment. The use of multiple pieces of equipment means that delays may disadvantage disabled children multiple times. A delay with just one piece of equipment may have a knock-on effect on a young person's day to day life.

For example, a non-maintained hearing aid for an autistic child may cause problems for communication and understanding, leading to not just a loss of learning but increased anxiety and loss of confidence, that can take long periods of time and input to address. For a child waiting with cerebral palsy who needs replacement seating, pain may increase due to poor positioning, combined lack of therapy may increase muscle contractions resulting in loss of learning and socialisation, with a child experiencing further pain and isolation again requiring surgeries at a later date to rectify, as parent's comments exemplify.

His physical health (in particular) his scoliosis has been significantly adversely affected due to lack of support and access to equipment and appointments during the pandemic. We are now at the mercy of an extra long waiting list for surgery due to the pandemic and his condition is rapidly worsening.

Waiting for Wheelchair Services appointment. Was on waiting list in Feb 2020 pre-pandemic. Said wait was 4-5 months. Still waiting but have virtual appointment booked in next week. Fingers crossed my son gets a new wheelchair as he has totally outgrown it.

Child has not been able to access standing frame or walking frame so has lost ability to weight bear and needs leg splints. - Parent Carers

Research by Newlife (2021) revealed the scale of problems accessing equipment day to day. Almost 7 in 10 families (68%) said their child doesn't have the equipment they need, as listed below:

- 1 in 2 families in need of mobility equipment such as wheelchairs, buggies, walking frames
- 2 in every 5 families in need of an educational aid e.g. iPad to help children learn
- 1 in 3 families in need of a special bed/cot to keep child safe at night
- 1 in 3 families in need of a communication aid to help children talk, listen and see.

- 1 in 3 families in need of an essential living aid e.g. toileting/bathing equipment.
- 1 in 4 families in need of a special seat to provide comfort and support.
- 1 in 4 families in need of a special car seat to travel safely often to medical appointments.

2.2.5 Shielding

Disabled children, classed as clinically extremely vulnerable were unable to attend school and shielded at home. Shielding families taking part in the DCP parent panel attended a range of settings (figure 13), 52% attended day special needs or colleges and 29% attended a mainstream school or college but 1 in 10 did not have any school provision.

As with disabled children attending school during the pandemic or receiving education at home, those shielding were affected by the lack of access to support at school. Figure 10 illustrates the type of support those shielding previously had access to via their nursery, school or college before the pandemic. The level of access to those services during lockdown 1 and 3 is listed in the adjacent columns for the shielding group. The results of those shielding at home resulted in reduced access to the support that they would receive via the educational placement. For all services the proportion of those able to access support was lower (highlighted with shading) than for those families not shielding apart from occupational therapy which was comparable with the wider panel. Access to hydrotherapy, play therapy and talking therapies remained at low levels of pre-pandemic access at 10%, 16% and 19% respectively.

Table 2: Proportion of disabled children shielding accessing support via their educational placement during national lockdown.

	Using Service Shielding Lockdown 1	Using Service Shielding Lockdown 3
Physical Therapy or Physiotherapy	11%	23%
Speech and Language Therapy	15%	23%
Music Therapy	16%	22%
Play Therapy	14%	16%
Hydrotherapy	1%	10%
Occupational Therapy	20%*	24%
Talk Therapies (mental health)	19%	19%
Personal Care	24%	40%
Technological Devices	23%	30%
Communication Devices	20%	34%
Medicines	53%	63%
Medical Devices	38%	50%

78% of those shielding reported that they had an EHCP and 4% were in the process of applying for one. It was reported that 14% of those with an EHCP were getting all of the provision in the plan. 49% of families reported that they were getting some of it and 21% reported they were not getting any of it. 65% of families shielding reported that the support set out in their EHCP or SEN plan had been negatively affected by the pandemic. Less than half (41%) rated the quality of remote learning positively. Just over a quarter (28%) of families reported that their disabled child/ren exams or transition had been negatively affected by the pandemic.

2.2.6 Elective Home Education

Elective home education is when a child is not on a school roll and is educated at home. The impact of COVID on home education can be described in two parts: firstly relating to those children already home-schooled prior to COVID and secondly relating to those opting to be home-schooled on a permanent basis in response to COVID. Although parents take responsibility for home education, activities may be provided in the home by visiting tutors or by accessing activities outside the home. Therefore, those

home educating experienced similar interruptions as their peers in non-home settings. This group also experienced delays to the EHP process.

Although we home educate normally (due to unsuitable schools, it isn't really elective) we do so with input from others. My son has a Special Needs tutor who is continuing to visit during this lockdown (Jan 2021). Although she didn't during the first. Many of our other funded activities, swimming, forest school, horse riding aren't running though, and haven't since the 1st lockdown. In addition, none of the usual respite services we are funded for are running either, and all the social clubs which he would usually go to are only on line; which really doesn't work well for him. We are waiting for an up to date assessment from the EP so that the provision in his EHCP can be updated, and that too is affected by the pandemic. His EHCP should have been updated in October but we're still waiting. He's 12, so in a transition year but the provision in his EHCP dates from when he was 9... his needs are very different now! - Parent Carer

The annual elective home education survey (ADCS, 2020) indicated that there was a 38% increase between October 2019 and October 2020 in the number of children and young people home schooled. COVID-19 was the primary reason given by parents opting to home school, either due to health concerns at school or positive experiences of home schooling during lockdown.

2.3 Social Care

The pandemic has shown up the total fragility of our support network. The moment our son's (or daughter's) bubble goes down at school our PA does not want to come leaving us utterly on our own. - Parent Carer

2.3.1 Introduction

Disabled children are entitled to support on the basis of their disability. However before the pandemic only 4% of parents said they received the support they needed to care safely for their disabled child (DCP, 2019). Unfortunately, during the COVID-19 pandemic the word vulnerable has been used conflating a variety of needs. The use of the word vulnerable to identify somebody at greater need during COVID-19 has complicated the need of various children. For example, those who have an underlying condition and need support for their disability have different care needs than a child in need of protection. Therefore, the use of the word vulnerable for children who could attend school was perceived as children who may be at risk and need safeguarding (Blower, 2020). In addition, those not supported by social care for their disabled child's care needs are at risk of crisis and family breakdown, that may lead to safeguarding measures.

COVID-19 caused a large proportion of the workforce, including social workers, to work from home. Face to face contacts with children and families were limited, resulting in social care staff relying on other professionals such as families and teachers who were having more time with children (Baginsky & Manthorpe, 2021). The pandemic created challenges for those receiving support from social workers. A study by Ferguson, Pink and Kelly (2020) reported the challenges in particular for those working with small

children and the guidance around physical distancing brought difficulties when small children required comfort.

Initially this section (2.3.2) will discuss the impact of the pandemic for those children who receive personal care and the challenges posed by PPE provision and physical distancing measures. A dominant theme throughout our research with parents during the pandemic was the impact on respite and short break services. This is discussed in section 2.3.3. The wider impact on social care packages in section 2.3.4. The section is brought to a close by a discussion about the impact of the pandemic on safeguarding processes for families in crisis.

2.3.2 Personal Care

Families of disabled children may be eligible for social care support within the home to assist with personal care. It was reported that, due to the clinical risk and increasing cases at the start of the pandemic, that many families declined social care due to the concern of having care workers in the home (Bottery, 2020). DCP research carried out at the beginning of 2021 found that 56% of families reported a reduction in formal support with 66% of those shielding reporting a decrease in formal support since the pandemic began. The reduction in formal care was not short lived. In January 2021, parents previously receiving support for care before the pandemic reported a reduction in the following support:

- 48% of families previously accessing a PA no longer could.
- 56% of families previously accessing domiciliary support could not

Section 2.2.1 highlighted PPE guidance as a challenge within schools for children who used aerosol generating procedures. This was also the case for families who had support within the home.

We have had many problems with nurses from agencies not using face masks or PPE when caring for our son. Eating in his room with no mask, giving him personal care or medication with no mask. Even though he is shielding and extremely clinically vulnerable. This has been raised multiple times with the agency and we have been told to be flexible about this... Really. This is our son's life which is being put in jeopardy. We have been told that they don't need a mask in his room when they're more than 2 metres away. This isn't true if the person is extremely clinically vulnerable but they want us to put our son's life at risk to facilitate their nurses to not wear a mask in his bedroom and while eating in his room.... Absolutely unbelievable. - Parent Carer

In addition, a number of children require two to one support in the home with a parent acting as one of the two people supporting. Training for new procedures was available for some to understand risks and changes in processes. However, parents found that they were unable to access local training.

I'm listed in the care plan as his second carer but when I called to attend the training they said I couldn't access it because I'm not paid care staff. I've always attended the training but even though I'm here 24/7 and only been out the house twice in the last year, they don't think I'm worthy of training. I've always been the second carer. I can't get an answer I just can't get the training. - Parent Carer

For families with more than one disabled child requiring support, care workers entering the home may be from more than one agency especially if one child is supported by children's services and the other under adult's services.

It's just a constant stream of people into the home. I have to constantly check they are following the guidelines. We have to set up an area before people

come into the home to make sure they're not bringing COVID in. It's so scary. I'm terrified of them bringing COVID into the house. The boys won't survive it. - Parent Carer

2.3.3 Respite and Short Breaks

My son was due to start overnight stays with a view to moving into supported living but this did not happen and now after a year in isolation with me I feel he has been set back years. He is more dependent on me than ever before as all his activities have stopped and he has lost confidence. - Parent Carer

There was a difference between how care staff across various agencies and services implemented the guidance during the pandemic. There was concern again with short breaks away from the home, regarding appropriate use of PPE and how other families using services would adhere to guidance, making the decision to access respite where available a difficult one for families. Findings also indicate that the levels of support in the home and in the form of breaks away from home such as day care, overnight stays and residential stays had not returned to pre-pandemic levels even during the lockdown in January 2021.

- 85% of families previously accessing residential stays (more than 7 days) no longer could
- 80% of families previously accessing short breaks away from home, no longer could.
- 74% of families previously accessing short breaks within the home, no longer could
- 70% of families previously accessing overnight short term breaks, no longer could

As with personal care whilst at education settings, there were difficulties experienced by those attending care settings.

Son was shielding and PAs were also employed in frontline work, so high risk to him, so contact was very limited. Initially (and still now at day centre) staff would not do personal care/toileting due to COVID

It was discussed pre-pandemic that we would look into a PA for him. Heard nothing since. Respite was cut back a lot, but we did manage to have a couple of stays in the pandemic, especially when I had to go into hospital, they were really good to accommodate him. Social care closed initially. Not enough staff. After that we shielded until May 2021. Still waiting for a care assessment.

Short Breaks Care was available but I chose not to use it. Staff protocols were adequate but I could not trust behaviour of other families. - Parent Carers

As figure 14, confirms, for families shielding that received formal support before the pandemic, the top three services they could not access were care at home, support from a PA and support from a social worker. Support packages away from home, which were not delivered, were highlighted by parents of disabled young people seeking independence.

Responses from freedom of information requests enabled the impact of the pandemic on short breaks to be assessed. From the responses received comparative analysis between the pandemic and during the first 9 months of the pandemic revealed that:

- 40% provided fewer short breaks overall
- 50% provided fewer short breaks at home
- 78% provided fewer short breaks away from home
- 73% provided fewer overnight stays
- 60% provided fewer residential stays.

It is much more difficult to access overnight respite as the number of children they can look after at any one time has reduced since the pandemic. Pre-pandemic, children's hospices were already running at a bare minimum level (16 nights a year doesn't feel anywhere near enough).

My son was due to start overnight stays with a view to moving into supported living but this did not happen and now after a year in isolation with me I feel he has been set back years. He is more dependent on me than ever before as all his activities have stopped and he has lost confidence.

No short breaks during the pandemic due to his disability and due to lack of Local Authority funding and fundraising the only provider we use has reduced its service
- Parent Carers

2.3.4 Social Care Packages

Even though my child is not able to school, we have not been offered any additional hours of home care. The home care agency are also struggling to provide the current number of hours due to staff shortages.
- Parent Carer

Parents reported that despite changes in needs and levels of support, changes or increases in support within the home were not actioned. It has been reported that pressures in the system mean that care proceedings have taken longer to complete (DfE, 2021). There is evidence from the DCP parent panel that families receiving a social worker assessment have not had the recommended care implemented. Families shielding were waiting for a social work assessment with 36% waiting between 3 and 6 months and a further 50% were waiting for more than 6 months. 1 in 5 families shielding reported that they were awaiting for home adaptations to start.

We had an assessment started by the disability team (social services) in June last year as we were told our daughter should be receiving additional funding during the pandemic and while she's not in school. We are still waiting for the outcome - nearly 7 months later.

I have begged social services for help and they did an assessment and decided that I need some respite but nothing is forthcoming.

support assessment process has slowed down considerably and caused much extra stress
- Parent Carers

Families undergoing assessments or reviews reported difficulties with the procedures undertaken remotely.

Remote meetings ie by telephone have been difficult ie people talking over each other; not being able to identify who is speaking at times or hear clearly; no visual documentation of minutes of the meetings provided, misunderstanding of what is being said. – DCP parent during a social care review.

Section 17 of the Children's Act (1989) places the duty of local authorities to provide an assessment safeguard and promote the welfare of children who are in need. Section 17 requests can be made by social worker practitioners, parents or any other professional working with a child. In response to a referral, a decision is made whether to undertake an assessment under section 17. If an assessment takes place it should be concluded within 45 days of referral (Jarrett & Foster, 2020). The DCP submitted freedom of information requests to all local authorities in England to understand the impact the pandemic had had on section 17 referrals received. 73 local authorities provided valid FOI responses. Comparison of quarters 1-3, 2019/20 and 2020/21, reveal the impact of the pandemic on the social care referral system. 6 in 10 local authorities that responded were not receiving section 17 referrals at pre-pandemic levels. In addition less than half of local authorities that responded were completing assessments at pre-pandemic levels or within the 45 day mandatory timeframe (figure 15).

Therefore, responses to DCP requests demonstrate that disabled children and their families are not getting assessments for support for their disability.

2.3.5 Safeguarding

Prior to the pandemic there were already concerns about the robustness of multi-agency arrangements to safeguard children (Turner, 2020). The changes in support levels and the location of where support is needed have brought difficulties for families with disabled children during the pandemic.

For families who may experience crisis, the fragility of the system has created difficulties for those requesting support. It has been reported that there has been an increase in conversion from contacts with families to referrals to social care and from referrals to assessments (Blackwell, 2021). This has been accompanied by an increase in the complexity of children's social work cases (DfE, 2021). A retrospective observational study analysing data from child protection medical examinations (CPME) revealed there was a 37.3% reduction in referrals between 2019 and 2020, and referrals from school staff halved in that time. Of those CPME conducted 94% concluded there were significant safeguarding concerns, with the authors concluding school closure may have harmed children as abuse remained hidden (Garstang, Debelle, Anand, 2020).

2.4 Health Services

Complete lack of human contact, when I'm caring for a child with complex needs who is severely life limited, to only have support via phone and zoom meetings sometimes seemed inhuman. Yesterday I attended a hospital appointment where I was given very distressing news about my son's health by a doctor and nurse in full PPE standing 2 metres away from me. I understand why but again it seemed very harsh
- Parent Carer

2.4.1 Introduction

This section reviews the support disabled children and their families received from health services during the pandemic. A declaration of level 4 national incident was declared in response to the pandemic in England on 30th January 2020, with the NHS moving to incident response on the 17th March 2020. The aim of this section is to review the impact of the pandemic on the support families with disabled children received from health care services amidst these changes.

The global pandemic significantly impacted on all aspects of health care, with changes in working practices across all specialities (Maclean, Ashton, Garrick et al, 2020). Disabled children and their families require ongoing support and attention with health care and are in contact with a number of specialists to do this. There is overlap between health services provided in the clinics and hospitals, with disabled children also accessing therapies and equipment via their educational placement already discussed in section 2.2.4.

In order to respond to the first wave of the pandemic, hospitals rapidly discharged medically fit patients and postponed all non-urgent planned care and operations for at least three months. Remote consultations were rolled out at rapid speed with face to face appointments to only take place when “absolutely necessary”. The emphasis on providers was to create critical care capacity and free up resources and space to treat the surge in Covid-19 cases.

There have been longstanding concerns regarding the socio-economic distribution of the primary care workforce such as GPs, pharmacists or dentists (Asaria, Cookson, Fleetcroft, 2015). The most deprived areas have the fewest doctors contributing to health inequalities (Baker, Ware and Morgan, 2014). As services move towards remote working, the potential of another layer of obstacles for some families will need to be monitored. The difference in England across communities, regarding the availability of high quality internet connectivity, has limited the use of

some approved, data-secure platforms such as Attend Anywhere. The issue of health disparities, the gap in access and quality of care, is still present (Ashikkali, 2020).

This section commences with a review of the shielding process regarding health, before moving onto how measures affect access to treatment. Disabled children and young people access health care services such as diagnostics, with appointments and tests to review and monitor progress. Section 2.4.4 reviews the impact COVID-19 has had on this support and then reviews data pertaining to the backlog of services that disabled children need to access (section 2.4.5) and implications for mental health services (2.4.6). The section ends evaluating the impact that COVID continues to have on health care services going forward (section 2.4.7). The impact of such will be discussed in more detail in sections 3 and 4, regarding the effect this has had on disabled children and their families.

2.4.2 Shielding

As we take these steps we should be focusing on the most vulnerable...by this coming weekend – it will be necessary to go further and to ensure that those with the most serious health conditions are largely shielded from social contact for around 12 weeks. This is going to be very disruptive for people who have such conditions, and difficult for them, but, I believe, it's now necessary”.

- Prime Minister Boris Johnson, 16th March 2020.

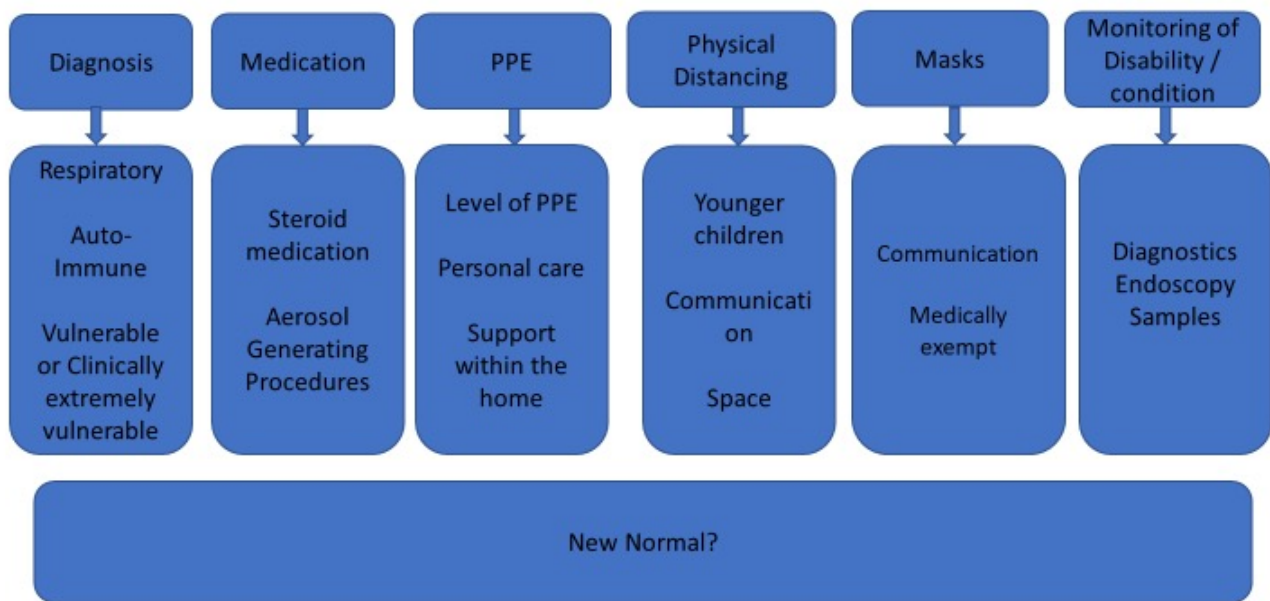
Shielding has become a common part of language around COVID-19 with regards to risk and support. In addition to people deemed to be vulnerable if exposed to COVID-19, people considered to be clinically extremely vulnerable were placed on a shielding patient list (SPL). In March 2020, 2,252,756 people were advised to shield. This included 56,027 children and young people aged between 0-17yrs, 2.5% of the total of those shielding. As the scientific understanding of COVID-19 grew there were amendments to the shielding list. During the second lockdown in November 2020, people over 18 with Down's Syndrome were advised to shield (NHS, 11/11/2020). In February 2021, there were additional changes with some conditions no longer considered as extremely vulnerable removed from the list.

The shielding scheme was paused on 1st April (UK Government, 2021), and those on the list instructed to minimise contact with people who are not vaccinated when COVID-19 cases are increasing in the community.

People listed as shielding received a letter from the NHS or the GP that they could use to access support via the government shielding programme (Ministry of Housing, Communities and Local Government, 2020). This was to ensure those who didn't have support from family or friends could receive shopping and

prescriptions. However, a diagnosis was not the only risk factor for disabled children and young people. As outlined below, there were many ways that a disabled child or young person could be vulnerable and impacted by COVID-19.

COVID-19 as a virus could infiltrate the lives of disabled children in multiple ways



The use of steroid medications was the highest risk to COVID-19. However, without steroid use children may experience disease flares, increased immunocompromise with the need for potential exposure to high-dose steroids with increased infection risk and subsequently the need for hospitalisation (Wisniewski A, Kirchgessner J)

Another outcome perhaps overlooked in the media was the impact of COVID-19 on those clinical trials. Clinically extremely vulnerable children with life-limiting and life-threatening conditions may have access to new and potential life-saving or life extending treatments via this route. However, in order to respond to the COVID-19 first wave, clinical trials were paused in order to ensure staff could be appropriately re-deployed where needed. As highlighted below (evidence from Duchenne UK, 2020), this included trials that children with progressive and degenerative diseases were involved in and in many cases trialling treatments they felt they benefited from.

My son is 14 years old and suffers with Duchenne Muscular Dystrophy. He is on the cusp of losing the ability to walk. He has been on a clinical trial for a new potential treatment for Duchenne for over a year. We were devastated when his trial was stopped due to COVID-19. Since stopping potential treatment the company has released interim positive data adding to our anguish that he can't access the treatment. The trial was stopped for 12 weeks because of COVID-19. This is time we don't have to sit and wait whilst we watch our son decline. (Duchenne UK, 2020).

- Parent Carer

The added anxiety in this case is that the delay in the trial also means that as a disabled child's condition progresses, when trials are resumed, they may no longer be eligible to novel treatments that may improve the quality of their life (able to walk for longer) and extend their life. As will be discussed in section 2.4.7 restrictions in health care have impacted research translational efforts, research within practice due to changes in patient flow, presenting a challenge to future research projects as non-covid studies re-start (Fleming, 2021).

A dominant theme from a study including children with cancer found that parents feared the response to COVID-19 would lead to suboptimal cancer care, with many experiencing postponed or cancelled clinic appointments, and several parents were concerned that relapses would be missed (Darlington, Mogan and Wagland, 2021). The following section reviews the evidence regarding access to treatment and healthcare in response to COVID-19.

2.4.3 Access to Treatment

It's terrifying to think people with health conditions could be denied treatment based on the idea that we might take longer to recover than other people. That we could die even though our condition could be treatable. (Jon Hastie, DMD Pathfinders, Duchenne UK 2020).

Disabled children and young people may require a multi-disciplinary team to manage complex needs. The pressure of COVID-19 on health services during the initial stages meant that protocols were reviewed for particular disease groups. Kubenz (2021) reported a range of barriers that disabled people experienced due the realignment of services to deal with COVID-19 cases. Many disability specific health services closed during lockdown, labelled as "non-essential" and many COVID-19 treatment centres were inaccessible to people with disabilities.

Inappropriate "do not resuscitate" (DNR) notices for people with learning disabilities were sent to individuals, with blanket DNR distributed (Tapper, 2021). This issue highlights the reliance on diagnosis and clinical data. The CQC reported that NICE guidance regarding a clinical frailty score, used to determine access to critical care, is also used by clinicians assessing needs of Learning Disabled people (Bloomer, 2021). This added to anxiety of people with learning disabilities and their families' access to care.

The role that diagnosis plays in the access to healthcare was also evident during the vaccine roll out. In priority groups there was a wide range of disparity across England as to who was able to access a vaccine as a carer for vulnerable people. The recording of a child or young person's disabilities on the primary care GP clinical system determined if their parent or unpaid carer could access a vaccine. This was later replicated when those with learning disabilities were omitted from the list of priority groups, despite estimations that they are six times more likely to die from COVID than the general population (Leder, 2021). In some areas whether a disabled person was recorded as having a mild, moderate or severe learning disability determined if they or their carer could have protection from COVID-19 using the vaccine. Parents as unpaid carers reported that they were providing care for their disabled child, alongside vaccinated paid carers.

Because of this controversy, families of children and young people with learning disabilities have increasingly become more aware of their rights. For example, a person over the age of 14 with a learning disability, on the learning disability register at their GP practice, can have an annual health check. Using data available for the 14-18 year group, a comparison of 2020/21 and 2019/20 data illustrates that the numbers on the learning disability register for that age group almost doubled. There was a 43% rise in the number of 14-18 year olds that had an annual health check in 2020/21 compared to the year before.

One area of the health services affected by the pandemic is the Emergency Department. Normally, in the UK the emergency services are reported as unnecessarily overused, leading to overcrowding and stretching of resources particularly during weekends and evenings. However, regional data suggests that there was a decrease of more than 30% in the cases of children presenting to the paediatric emergency department by March 2020 and this decline in activity was maintained into the summer of 2020 (Ashikkali, 2020). This reduction, especially in unnecessary visits,

may be viewed positively, however charities of disabled children and young people are concerned that necessary visits may also be reduced as a consequence of the fear created by reporting of hospital COVID cases and letters received by young people with learning disabilities.

For example, there are young people who may be more susceptible to respiratory infections due to weakened immune systems and at times may require additional respiratory support to recover from respiratory infections. Charities have raised concerns that patients and their families may avoid seeking treatment due to a fear of accessing hospital care at this time. There is a risk that respiratory patients may be put on wards with patients with COVID-19, increasing their exposure to the virus. Data from the NHS during wave 2 during Winter 2020/21 confirmed that 1 in 4 patients acquired COVID in hospital following admission for separate reasons (Oliver, 2021).

A further example of change in people with additional risk avoiding hospital is data regarding those shielding (as per clinical disease group). Before the pandemic they had a high rate of emergency admission. This, however, dropped in April 2020 by 46% for those on SPL and by 33% in the general population for all emergency admissions, not just those due to COVID.

For all emergency admissions across (all age groups there was a decline of 16% on the previous year with day case episodes down 36% (figure 16). For those aged 0-25 years there was a 33.7% reduction in emergency admissions and 38.3% reduction in day case episodes. Reduction in emergency admissions was greatest in the 0-4 age group (46.8%) and reduction in day case was greatest for the 5-9 age group (42%), see figure 17.

The DCP parent panel survey series investigated if families were experiencing delays to services that they would usually access. Table 3 shows the proportion of families (including those shielding) experiencing delays.

The hospital said no operations being carried out on children, found out they have been operating all the time, our son was top of the list before covid down to 35th last November -other children put before him, this operation will affect the rest of his life but we are being ignored
- Parent Carer

	Shielding Families	Total Families
Routine Appointments	78%	75%
Operations	16%	11%
Treatments	41%	31%
Equipment /support aid Provision	44%	28%
Equipment/support aid maintenance	36%	21%

Developed agonising complication/comorbid condition to his main disability, no specialists have been available to see him, left in agony for five weeks before the episode subsided, then finally received a scan 4 months later when the condition was no longer in flare

Medicine became unavailable and had to be changed mid lockdown. It didn't agree with him and he reacted badly, still affecting him now and other meds/conditions also affected". - Parent Carer

Section 2.2.4 discussed barriers to disabled children accessing services for diagnosis. For disabled children who required a first appointment with CAMHS or who were on the Autism Pathway, freedom of information responses revealed that there were barriers in gaining a first appointment within the 6 week guideline for these services. Of the Trusts that responded, just 1 in 5 Trusts were providing the same proportion of first CAMHS appointments within 6 weeks and 2 in 5 for Autism assessment (figure 18).

A further indicator of difficulties accessing health care is the issue around children unable to access mental health support in paediatric wards and therefore treated on adult wards. Analysis of the mental health dataset was conducted to assess the impact the pandemic had on access to mental health beds.

A comparison of 2020/21 (figure 19) and the previous year demonstrates that the number of bed days for children 17 years and under on adult wards increased as the restrictions for COVID-19 were implemented. As restrictions were eased, occupancy of adult beds fell below pre-pandemic levels for young people 16 years and under. However, bed days on adult wards for 17 years old in March 2021 have increased beyond the same level the year before (March 2020).

This section has reviewed the impact of COVID-19 for disabled children and young people accessing health care. The following section will look at this in relation to services that provide support to children in the way of the monitoring and review of their disability.

2.4.4 Diagnostics, monitoring, review

As discussed above, depending on their clinical conditions disabled children and their families could be classed as clinically extremely vulnerable or vulnerable. In addition to such children, many other conditions that were not deemed clinically vulnerable were affected due to the processes required to manage their disability. For many disabled children ongoing reviews within one or more clinical speciality are required in order to ensure any conditions they have remain stable or that potential changes to medication, therapies or surgical needs are reviewed.

This role is carried out by diagnostic services in the form of tests such as endoscopy or imaging, with clinicians making decisions on treatment protocols from results. In England endoscopy could only take place where the clinical management of the disabled child's condition could be influenced. Therefore, routine reviews did not take place during this time. Diagnostic tests that included stool samples for example put staff at risk from COVID (Maclean, 2020). For disabled children with digestive or bowel disorders, delayed diagnostics and investigations are associated with poorer outcomes and higher risk of surgery (Lee, 2017). Therefore, by delaying routine diagnostics, disabled children are at risk of further more serious conditions and interventions further down the line.

Although, it has been reported that most IBD specialist centres continued to provide surgical and radiological services during lockdown, the type of activity was reduced with planned non-emergency surgery delayed. Lower levels of access to radiological investigations at district general hospitals (smaller local hospitals) also had an impact on radiological investigations at this time (Ashton, Kammer 2020). For children with DMD, outpatient clinics were cancelled with telephone appointments offered instead. However, the need for physical assessment by physiotherapists, routine

tests used to monitor disease progress and inform the day to day care of patients meant this was not sufficient for those with progressive disease. Tests for this group of children and young people include blood tests, echocardiograms, electrocardiograms, bone densitometry (DEXA) scans, lateral spine x-rays, checks for scoliosis, respiratory function forced vital capacity (FVC) measurements and mental health screening (DMD, 2021).

For disabled children who experience pain due to their disability or condition, lack of regular appointments and medication reviews was difficult.

We've had no support from consultants for pain management as they have been redeployed to covid wards. No tests have been able to be carried out.

- Parent Carer

As per social care, there were additional difficulties for the younger age groups with new processes such as monitoring at home. For example, IBD home testing and monitoring kits showed 80% of parents felt it would improve disease management but practicality was difficult for over 50%. Piekala (2018) reported it was good for adolescents but difficult for younger children.

Concern has been raised by clinical specialists that diagnosis and monitoring investigations, normally widely available, were largely reserved for emergency use only, and this practice has continued as restrictions were eased (Ashton JJ, 2020). Paediatric teams face ongoing difficult decisions, including which patients require treatment initiation or a change in therapy, with limited access to specific tests that are usually imperative to making these choices (Maclean, 2020).

The following section will look at the backlog of sene referrals decrease by a larger margin than urgent decline in rates experienced during lockdown.

2.4.5 Backlog of services for disabled children and young people

As already discussed, families have faced delays with appointments, therapies and equipment. This section looks more closely at the impact of COVID on service provision. A comparison of health episode data analysis between 2019/20 and 20/21 provides a clear picture of barriers that disabled children experience. The image below (image 1) demonstrates the results of comparative analysis for paediatric surgical cases (routine and emergency), well below pre-pandemic levels. See figure 20 for non-surgical comparative data.

Lockdown restrictions impacted significantly on referral rates. Even with restrictions easing in summer 2020 rates remained between 15% and 37% lower than pre-pandemic times. The third national lockdown in January 2021 caused a similar pattern. Despite restrictions easing the increase in referrals does not represent the ongoing negative percentage decrease in over 12-months of NHS activity. What is visible is the difference between routine referrals and urgent referrals. Image 2 shows that routine referrals decrease by a larger margin than urgent referrals. However when reviewing data from March 2021 onwards, urgent referrals increase by a larger margin than routine. Therefore, demonstrating the case that routine issues have become more urgent issues as time progressed.

2.4.6 Mental health

A similar narrative emerges when reviewing data for mental health services for children and adolescents. Image 3 demonstrates a dip in accordance with the initial lockdown, and urgent mental health referrals returning at a higher rate than routine. The increase in all referrals, however, does not alleviate the decline in rates experienced during lockdown.

New referrals to CAMHS crisis team are illustrated in figure 21 and 22. The same pattern is demonstrated for young carers referred to mental health services

(figure 23). A point to consider is the increase in referrals for young people and the fact that young carers are new people. Therefore, new requests for mental health support have been made, confirming the mental health impact on disabled children and their siblings.

Image 1 – comparison of paediatric routine and emergency surgical cases

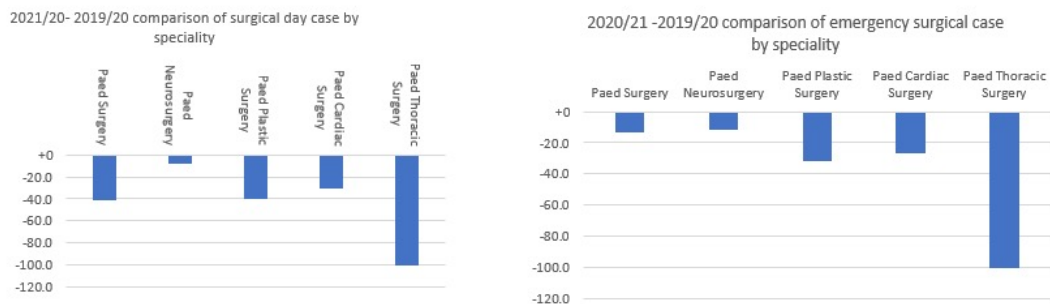
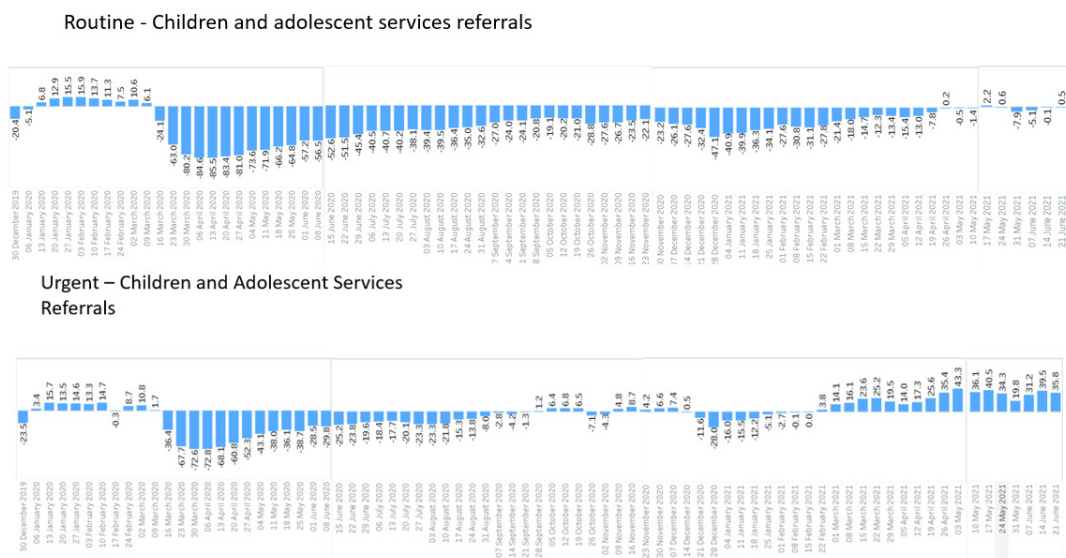


Image 2: Routine and emergency referrals, comparison data from pre-pandemic to April 2021



In addition, to the backlog of services that disabled children and their siblings access, it must be remembered that the backlog in health care is affecting the wider population. Parents who require treatment or appointments to manage their health or disability are also affected as is their capacity to support their families or, if in employment, work. 5.12 million people were waiting to start treatment in April 2021, with a 239 fold increase in the number waiting for more than 12 months (BMA, 2021). Parents in our DCP survey with disabilities reported the impact such waits had on their health and ability to provide the additional care required due to the loss of support since the pandemic began.

2.4.7 COVID Restrictions in health care

The backlog of services facing professionals is not the only issue that affects disabled children's access to health care. Physical distancing restricted the number of people allowed in waiting areas or wards leading to changes in how families access health care going forward. The introduction of remote consultations with specialists was welcomed by parents that previously would travel to regional specialist centres.

Before, we would have most of the day by the time we travelled 1-2 hours each way...then park...the move around the clinics waiting in between or go for tests...it was time out of school. Now we can spend more time together, not doing hospital things. There are some things we need to see them for but so much reviewing and discussion is better online.

- Parent Carer

Parents did highlight that remote sessions were not always productive, with the interface not appropriate for new paediatricians when discussing the disabled child's development. It was felt that in a room, face to face with a specialist was more beneficial.

They couldn't see him properly on the computer so as he was walking about she (doctor) was asking me to show her what he was doing but he was skipping about so much it didn't help, we needed to be in the room together. - Parent Carer

Parents felt that face to face support was required for therapies and although exercises were given to do at home, help face to face would have helped parents ask for advice. Lack of appointments in the home by mental health services meant that some children were admitted to hospital for assessments instead.

It's ok being given exercise and activities but sometimes when I'm doing it I think there might be a problem or need to know if it feels right and I can't see and they can't check to see if it feels right. When you're face to face they can manipulate her legs and muscles, checking what's happening....so paper copies of things to do at home are no good for such a long time. - Parent Carer

Child 2 doesn't like video/phone calls so receiving support from CAMHSs has been difficult. Also, the crisis team cannot assess at home so she's needed to stay in hospital - Parent Carer

The concern parents felt about potential barriers remote appointments created when clinicians would have previously observed children face to face raises an important consideration for disabled children with learning disabilities. Clinical overshadowing is when clinicians inadvertently find it harder to recognise symptoms as they are attributed to the child's learning disability (Langdon, P). Therefore, pain or agitation may be overlooked, causing serious problems with serious conditions remaining undiagnosed leading to acute episodes. Careful attention is needed as to how remote consultations are conducted in order to avoid the risk of clinical overshadowing.

Parents of disabled children with dual diagnosis or complex needs would usually meet multiple specialists on the same day. It was reported in the literature that people who required a team of multi-disciplinary experts struggled to meet or receive advice from the whole team. So for example a family may have an appointment with a neuromuscular consultant but could not access physiotherapists, endocrinologists, cardiologists and respiratory consultants. Parents taking part in interviews and focus groups also described this.

Before lockdown there we had a joint clinic with the respiratory consultant and the spinal consultant about operating to help improve his lung function and they were going to decide what needed to be done and how.....so the delays mean that that appointment didn't happen and when we chased it we got an appointment but it was just the respiratory consultant who wasn't the usual one and he just said we'd have to have a joint appointment.....so we weren't catching up we've gone backwardsthere's the worry that his lung function will get worse and he can't have the operation..... - Parent Carer

Parents of disabled children that were admitted to hospital reported difficulties due to lack of visiting one parent could stay with the child full time but had no respite. Restrictions were highlighted more widely across the NHS, that this guideline increased the pressures on the accompanying parent or carer (NHS, 2020) at an already stressful time.

Normally people come and go, bring stuff in, I would normally go for a break or a walk when my husband or mum came to visit but that wasn't allowed, so on my own on the ward just me and her was exhausting. It wasn't any good for either of us. - Parent Carer

The lack of face to face appointments was reported within primary and community care. Delays for dentists may cause a problem for children who have ongoing pain, therefore reducing nutritional intake and the presence of pain for some children may translate into unusual or self injurious behaviours.

We did get an appointment with dentist but only after 6 months after initial appointment.

The Ophthalmologist refused a face-to-face appointment twice we were only given one 10 months after initial appointment.

We have had decreased Homecare sessions from hospice and obviously during first lockdown no Carers in the house at all. I'm a single parent with no family so these sessions were our sole respite. He was unable to go back to school once lockdown finished due to him having a suction device and the government no clarifying guidelines for AGP so he was unable to go back to school before the 2/3 lockdown. We have been home now for 13.5 months given that he was extremely poorly in hospital Dec 2019/Jan 2020.
- Parent Carer

2.5 Finance

The economic impact of COVID-19 pandemic in England has been widely reported, with the size of the drop in Gross Domestic Product (GDP), the steepest decline since records began in 1948 (UK Parliament, 2021). In the decade before the pandemic there had been an increase in poor quality work, including part-time, insecure employment (Marmot, 2020). The pandemic has had an impact on family income (Andrew, Cattan and Costa Dias et al, 2021). However, the association between disability and low income existed before the pandemic. Poverty has been higher (on average 11% higher) for families with disabilities than those without disabilities (JRF 2021, DWP, 2021), across the last two decades.

Due to the practical aspects of caring, families with disabled children working are more likely to have a low income, in part time or insecure employment. Before the pandemic 87% of parents said their partner could not work as much as they would like due to caring responsibilities; 56% of parent said their disability benefits only partly cover the extra costs linked to their child; 33% had taken out a loan to pay for food, increasing from 4% a decade earlier (Contact 2018). 20% of lone parents have at least one disabled child (Bradley, 2020). In England, although Universal Credit increased during the pandemic, carers allowance did not.

39% of parents taking part in the DCP parent survey panel reported that their family income had dropped. However, 28% reported that the reduction in their family income was due to the loss of support received for their disabled child. As a consequence, parents had to give up or reduce their working hours (DCP, 2021D). More than half of responders to a survey by Carers UK (Carers UK, 2020A), had to reduce or give up work to enable them to meet the increased carer demands, caused by the withdrawal of vital services. The parent below described the cumulative effect of lack of educational and physical support for their son.

Usually has 1:1 support in the tutor rooms. No support in the beginning. Online class sometimes is too fast for my son to follow. He has CP and has processing issues. I had to fully support initially, whilst also trying to work a part time job from home. I've ended up being 21 hours behind (and my working week is 18.5), and now my GP has signed me off sick for the 5th week. I've never had time from work for mental ill health in my 31 years of working.

Managing to work remotely whilst home educating an autistic teen with severe and complex mental health issues continues to be a struggle. I have had to request flexible hours to manage both simultaneously - As a result, I have incurred a loss of income.

all (social care) services just ceased abruptly during the first lockdown and I have to take premature retirement a year early to support him.

- Parent Carers

Figure 24 illustrates the reduction in council spending before the pandemic, with analysis by deprivation demonstrating local authorities in areas of higher deprivation experiencing the highest level of spending reduction. Studies have shown that during the pandemic middle-class parents were more likely than working class parents to receive online support (Crew, 2020).

There were 2.5 million food parcels provided by the Trussell Trust network of food banks during the first year of the pandemic, 33% increase from the previous

year (The Trussell Trust, 2021). 17% of parents taking part in the survey panel reported that they had relied on food banks during the first year of the pandemic.

Parents reported an increase in their spending, increasing data packages, educational resources and increase in household bills with everyone at home. Some parents had to pursue privately funded support in response to lack of support from statutory services.

All of my children have SEN and 2 of them are unable to access the curriculum as it has been set out for home educating. I have had to buy books to fill this gap.

My son accessed his PA during the Pandemic but then towards the end of 2020, this ceased. He has only started seeing her again on very reduced hours and now privately funded. - Parent Carers

Disabled children being in school also enabled parents to work, exemplifying that attendance rates matter not just in terms of educational attainment but in wider opportunities for the family with economic resources from employment.

Having our child in school 3 days per week at least allows us some time to work and allows our child time with friends. - Parent Carer

90% of parents of young people aged 16+ taking part in the DCP panel that use personal budgets reported difficulties in using them. Parents also reported using their personal budgets to provide support that would usually be given in the educational setting.

Would have made use of personal social care budget but nothing to spend it on safely.

We have money from short breaks but very limited on what and how much I can use by the Borough.

Keeping our PA during this current lockdown has made all the difference. But this is all from our social care budget to make up for the lack of school. - Parent Carers

2.6 Family, Friends and Community

We have a friend who provided 1:1 informal support for us as a family by spending 1 - 1.5 hours with our daughter once a month at a weekend so that we could go out of the house together and have a conversation, walk or meal by ourselves but this has stopped. My Mum used to have our daughter to visit partly because she loved to see her and partly to give us a quick break - she also used to come here twice or 3 times a week - this has stopped. She is dearly missed as is our friend. - Parent Carer

The containment measures transformed and threatened people's interactions with their family, friends, community and employers. Individuals struggled to offset their new roles as key workers, carers, social care workers within the evolving landscape that now emerged. Section 3.3 will present evidence regarding the impact of COVID-19 on formal care. This section will analyse the impact of the pandemic on the informal network disabled children and their families rely on for support. It then reviews how the impact of changes within the community affect the lives of disabled children and their families.

2.6.1 Reduction in informal care

Societal assumptions tend to overlook parents of disabled children or adults from other aspects of life. For example, parents may be in employment, they may care for multiple children with special needs, in addition to the disabled children they care for they may also provide care for other members of their family, or they may be disabled themselves. The COVID-19 restrictions introduced meant that for parents of disabled children, friends or relatives who may have provided informal care ensuring short periods of respite were unable to support in the usual ways.

I also need to remind parents that, as we have already advised, children should not be left with older grandparents, or older relatives, who may be particularly

vulnerable or fall into some of the vulnerable groups and I know that will be difficult too.

- Prime Minister Boris Johnson, 16th March 2020.

In particular, older people over 70 years of age were identified as vulnerable to COVID-19, therefore restricting the support that families received from grandparents. The restrictions also increased caring needs for this population, with those previously living independently requiring support to collect shopping and medications. It wasn't until June 2020 that support bubbles were introduced meaning that people who lived alone could join up with another household for support. A report on children contacting Childline revealed children missed seeking emotional support from grandparents or other close relatives in their support network (NSPCC, 2020). DCP parent panel findings revealed that 86% of families reported a decrease in informal support from family, friends or neighbours due to the pandemic.

No friends or family visiting. Absolutely exhausted with 24/7 care and supervision needed to keep them safe. Have slept, locked in their room with them, for 6 months plus to avoid more accidents. Lots of disturbed nights with very challenging behaviour.

The lack of clarity with regard to family contact has been a nightmare. In addition to looking after my youngest son, my eldest son has epilepsy and is a key worker. If he doesn't rest this triggers seizures. In addition to working in excess of 70hrs per week he is up during the night with his young daughter. I need to look after my grand daughter to give them a break but worry about whether this would be seen as ok

We haven't been able to have nana or grandad in our house for months and I miss their practical and emotional support

We normally have a fantastic family support network, this has completely stopped due to older members being clinically vulnerable, this has left us completely on our own, nearly a year now with no respite or relief.
- Parent Carers

2.6.2 Parents caring for multiple people

A survey of 5000 carers in the UK at the start of the pandemic revealed that 70% of unpaid carers were providing care due to COVID-19 outbreak, with 35% providing more care due to the closure of or reduction in local services (Carers UK, 2020A). A follow up survey in September 2020 revealed that this had increased, with 81% of carers now providing more care due to the COVID-19 pandemic, 38% of which was due to the closure of or reduction in local services. (Carers UK, 2020B). Therefore, the impact of reduction in support from health and social care resulted in increased pressures on parents caring for their children but also caring for other members of their family.

Carers are more likely to be disabled themselves, with figure 25 demonstrating age groups where the proportion of disabled carers were significantly higher than those who were not carers.

My son is in the CEV group therefore we have been shielding for most of the time I also care for an elderly parent it has been very difficult as primary carer for my son to manage two caring roles without support

My own routine health appts and reviews have been hugely delayed, this obviously impacts on my children I being the carer of kids who normally would be expected to be independent by this age (22 and 17).
- Parent Carers

Therefore, covid restrictions were more likely to impact people who were carers themselves resulting in carers requiring additional support to what they may require during usual times. 42% of parents of disabled children indicated that they were an unpaid carer for someone other than their disabled child (DCP 2021D), this compares with 17% of all unpaid carers supporting more than one person (Carers UK, 2019). 79% of parents provided more than 20 daytime hours per week caring for their disabled child and 53% also provided night time hours.

The fact they are both at home full time and I'm trying to work from home and care for my husband

who's had 2 operations, since September hasn't helped. Having them in a provision during the day makes things easier but has not been an option in lockdown 3. Both need support to interact online and I can't always provide this support due to work/caring responsibilities.

I worry about my mum, she is having cancer treatment and she'd normally help me and I help her but we can't even do that. We're both so drained.
- Parent Carers

It is important to note that DCP research revealed that the network of support for parents with disabled children is limited. 27% of parents do not have family members and 33% do not have friends in their support networks, 15% had neither. Parents with disabled children indicated they would like their friends (56%) or family (54%) to check in on them more often than they do.

My mum who used to support us, is a key worker. So we are not able to have her support because of her line of work and lack of vaccinations

Due to not being able to visit family or friends. My daughter is very upset and thinks she will not get to see them which makes her very anxious.

Lack of support has meant that my son has not been able to continue to build on his independent learning and his learning on communication and interaction with his peers.

I receive a carer's break payment and when my son goes away with school for 5 days I use it to get away. Due to the pandemic he has not gone away and I have had no break since June 2019. Other support is provided by friends who we have not been able to see or stay with so we are pretty much left without any of our usual support. We do have a support bubble but they are in London - we had to move for my son to attend the school named in his EHCP for him to receive the help he needs - so our support group is all in London and we are now in Surrey, quite isolated anyway, but much worse in Lockdown. - Parent Carer

2.6.3 Community

Limitations placed on support from friends and family who may provide informal support was not the only loss of support. Disabled children and young people, as with other sections of society, were confronted with restrictions across all aspects of their lives. This section highlights how the pandemic impacts on this aspect of disabled children and their families' lives. As with the rest of the population, parents of disabled children required information to navigate changes affecting their families. Parents sought information from local charities or organisations (49%), from national helplines or charities (45%) and local SENDIAS services (28%). Figure 26 lists the topics that parents required advice about.

As with their non-disabled peers, disabled children and their families spend time in local communities at cafes, shops and leisure facilities. In some aspects, this may be for leisure but for some disabled children and young people, this may also facilitate skills requiring independence, address sensory needs, physical needs, reduce anxiety and poor mental health and support socialisation. Many disabled children require routine throughout their day. Without it anxiety may increase which in turn leads to distressful behaviours. Therefore, the rapid change to routines for disabled children and their families on a day to day basis was difficult to adjust to, especially given that the new reality was not clearly defined, interchangeable as guidance was updated.

The hospitality sector, such as cafes and bistros, were affected by the pandemic with 81% of the sector closing in the Spring of 2020. Despite the easing of restrictions in the summer of 2020, 54% of the sector closed during the third national lockdown. This brought difficulties for disabled children who may attend such venues as part of their routine or to socialise or learn life skills.

Indoor play centres such as soft play areas or trampoline centres were closed as part of the COVID restrictions and one of the last sectors to open following the first wave of the pandemic. Leisure

centres were closed, so were swimming pools and many parks. Play schemes, sports or activity clubs usually held after school, weekends or during school breaks were halted. Such activities, in addition to promoting physical or mental health of the young people attending, provide parents and siblings with respite. Therefore, with the community infrastructure now unavailable, the negative effect of COVID-19 restrictions permeated all aspects of the foundation that so many families relied on. As restrictions eased, the issues regarding support from PAs in section 3.3 also applied to disabled young people who had a PA to support them within the community.

No PA support has put a lot of pressure on me. My daughter misses her PA and all her groups. It is not good for her to be so socially isolated.

The children have not had access to their PA and have missed out on vital social training. - Parent Carers

The closure of community spaces did not just affect opportunities to socialise. For many disabled children activity plays a vital role in managing physical disabilities or conditions.

We saved up to get a jet bath to try to give the children some hydrotherapy. Not going swimming has been a massive impact on our family. Even when bookings went out for lifestyles to book a family swim it's impossible to get a session. Disability sessions should be available to book.

We used to access lots of services which helped our daughter for example swimming, hydrotherapy, private OT and private therapy and help from family members. None of that is allowed to happen now. Yet another punishment for having a child with needs.

She's not able to access sensory and physical activities like swimming, climbing and shopping

Our son has had less access to the settings he needs for his physio - less hydrotherapy, no rebound and not able to go outside into the community. - Parent Carers

Despite such activities opening as restrictions were easing, our research discovered the disabled community were overlooked and marginalised due to the priorities of local providers. For example, venues opened but without accessible sessions. Guidance on social distancing meant that reduced space available meant that many parent carers were told they could not attend to support their child or young person. Parents reported that new guidance was too confusing for the child and too stressful for the family to join in with and social distancing also reduced the opportunities available for young people to mix with their peers.

I saw they (swimming pool) was open again so I called up to find out what time the family sessions would be....they told me they hadn't started them and there was just lane swimming available. I explained my son had special needs so we used the family session so we could all go together just to have fun but they said they weren't running and had no plans to start them up again. It wasn't just one, I rang a few.

He goes to swimming lessons, he's always loved them and we couldn't wait to get back. Because of how he communicates I usually sit at the side of the pool so he is supervised while the lesson is going on. He comes over to me for breaks but they said because of the number of people now allowed by the pool I cannot do that anymore. That means we can't go to the lessons because he isn't safe.

In Lockdown 1 all provision was shut and we had to cope with my son without support at home. In Lockdown 3 he attends a service but has restricted opportunities and can't meet other service users due to social distancing. - Parent Carers

A number of larger venues such as the grounds of historic houses or buildings introduced a booking system in order to manage social distancing and reduced the numbers visiting. The majority of families talked about this positively. The lack of crowds reduced anxiety for many and provided more space for disabled children to access. However, for those

with medical or clinical conditions where their health peaked and dropped, the booking system prevented spontaneous trips that allowed families to take advantage of good periods of health.

Lack of retail and hospitality venues meant that young people who had support to learn life skills or were taking part in volunteering, training or employment schemes were limited to the opportunities available.

A lot of my son's targets are about independence as he will not take any exams, a lot of this has not been able to happen, eg trips to local shop and cafe to practise money and social skills.

Accessing work placements in the community was a major part of her timetable which she hasn't done since last March. She is confined to one room and doing "desk" work, getting no exercise and little social contact.

Part time provision and the closure of the hydrotherapy pool has reduced the amount of support. Plus the lack of community visits and outlets for the College "Enterprise scheme" has also had an effect on the wideness of the provision. - Parent Carers

As restrictions were eased the public were asked to continue working from home, only using public transport were necessary. Facemasks became mandatory in England in all shops in July 2020. Both announcements created difficulties for many families with disabled children. Community transport that many children relied on to take them to school was not fully available, with services prioritising particular children. Social distancing and the bubble systems meant that who and how many children could travel on a vehicle resulted in parents driving children to school.

My son went to a day centre for 4 days a week, this stopped then after the first lock down he went back one day, no transport was available so I have to take him, which I don't mind but what if I couldn't drive?

- Parent Carer

Masks were introduced for all children aged over 11 years of age in England unless eligible due to exemptions below:

People who cannot put on, wear or remove a face covering because of physical or mental illness or impairment or disability.

Where putting on wearing or removing a face covering will cause severe distress.

Instances where people are speaking to or providing assistance to someone who relied on lip reading, clear sound or facial expressions to communicate.

2.7 Summary

This section has outlined the impact of the pandemic for families with their disabled children in relation to services they may wish to access for support. It examined the changes to support and changes the introduction of restrictions had on the services disabled children and families use to live their lives. Disabled children were not just at risk of COVID-19 due to their diagnosis, such as respiratory disease or auto immune conditions. The type of medication

and processes involved in applying medication also introduced risk to disabled children. Sourcing of PPE and guidance around personal care and physical distancing created further barriers for disabled children wishing to attend school or needing health or social care within the home or community.

The section demonstrates the level of reduction in services for disabled children and young people. Services have not returned to pre-pandemic levels and a backlog places disabled children and their families at risk of breakdown and exclusion from opportunities in society. Mental health needs have increased for both those who need support before or due to the pandemic. However, as is described in case study 2, how services are provided present challenges in meeting the need of those with severe trauma.

For some disabled children with complex or life limiting conditions, they and their families may be supported to discuss palliative care needs or end of life plans, due to progressive conditions. The loss of a child with a life threatening or terminal condition did not pause when COVID-19 emerged. The experience of bereaved families too was affected by the changes discussed up to this point. Therefore, this chapter ends with a case study that highlights one family's bereavement of their disabled child during COVID-19. It exemplifies the intertwining support levels from various sources already discussed. The case study leads us onto the findings regarding the consequences of reduced support on disabled children and their wider family.

2.8 Case Study 2 – Child Bereavement During Covid-19

Holly was 18 years old when she died at home during the start of the pandemic in England. She lived at home with her mum, dad and her younger sibling Ruby. Holly loved being outdoors, she was very adventurous and would take on challenges like zip wires, abseiling and canoeing. She loved going to the theatre and watching musicals. She had complex needs since birth and a life plan had been in place for sometime, although flexible it was expected that Holly's end of life would take place at a hospice or at home. Holly died unexpectedly at home in March 2020. Her parents rang the hospice and were given support to keep Holly at home until the funeral.

This case study presents the impact of losing a child and sister during COVID from the perspective of Holly's mum. She describes the consequences that the restrictions implemented have had on their grief process. The lack of contact with family and friends or face to face support from services led to her parents and sister experiencing severe trauma. Holly died a few days before the government announced that schools in England would close.

At this point COVID was not in my brain at all. People were talking about toilet rolls and I thought what is going on outside? I was in so much shock with everything else going on. My family were trying to

not put anything else on me with everything that was going on outside. I wasn't going out of the house, so I had no idea the shelves were empty in supermarkets and all that stuff had started. Because of the government, there were no real parameters to work within, everybody was second guessing what they had to do.

The family had planned to access services locally through the children's hospice following Holly's death, that would support them to spend time together before Holly's funeral, making memories to help with their loss. This was not available.

Usually when children like Holly go to sleep there's a service where they do a hand print together and we could do all this memory making stuff and we couldn't do any of that. It's like everything was stolen away from us completely. By the second week everything had shut down, nobody was allowed to come to our home, so we were physically caring for Holly's body and everything else which was really, really traumatic

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From the minute she went to sleep, it's like our whole life got dropped off the edge of a cliff. We stopped and it was like someone pressing delete and we've gone.

The process for arranging her funeral started before the official lockdown was announced on 23rd March 2020. Guidance for arranging or attending a funeral or commemorative event during the pandemic was issued on 19th April. Holly's funeral took place on 27th March 2020.

The next day the funeral director got back to me and said, "we can't confirm anything, we can't even get a date in the crematorium at the moment". She said the only thing I can tell you is that you won't be having a service for her....Then the following day she said, "listen you're not going to be able to have any family or friends at the crematorium so I need to tell you this early. At this moment we've been guided...it will be eight people".

The numbers allowed at the funeral included a priest and anybody reading at the service, therefore the immediate family of three would only be accompanied by four other people. There were instructions for the family sitting separately from each other which meant that Holly's 13 year old sister was expected to sit on her own. The closure of schools meant that businesses that could operate struggled to, impacting how the funeral could be arranged.

I had to put my own order of service together. I had to sit and write it and print it off at home because every time I called everyone, they were like I'm sorry we've got no staff, I'm sorry 'cos of COVID we're closed, I'm sorry 'cos of COVID it's this. Then I think the straw that broke the camel's back was the coffin.

The family wanted Holly's coffin to be pink with unicorns. The funeral directors were told they were unable to do that and the family were told to pick a paint colour from a local hardware store. They then had to decorate the coffin at home the night before the funeral.

She was leaving us on the Friday and it (coffin) came to us on the Thursday and on Holly's last night with me. Me and her little sister had to sit and decorate it and personalise it. You know she did deserve so much more....way more than we could give her at the time.

The impact of the stark contrast to what the family had planned compared to what they were able to organise for the funeral caused severe stress. In addition, measures to contain COVID transmission meant that requests to alleviate some of the trauma of the funeral in particular for Holly's younger sister were not granted.

Beforehand, we asked if we can have the curtains open at the end. We said please don't shut them, Ruby was so really frightened, of that. They agreed to it but then the day before rang saying "because of COVID we can't leave the curtains open....we'd be in danger, because if anyone touches Holly's coffin at the end, you might give our staff COVID".

In addition to the trauma of the funeral preparation, the closure of schools meant that Holly's younger sister was at home when traumatic moments continued. Holly relied on equipment such as adapted bed, chairs, hoist and oxygen cylinders. All part of Holly's life had to be removed from the home following her death. They were collected intermittently over a number of weeks. As nobody was allowed to enter the home, her parents had to dismantle and manoeuvre equipment to leave outside be collected in a van and taken away on a specific day.

All Holly's equipment, her wheelchair got picked up, her bed was taken, her hoist the bath chair everythingso there were holes in our walls. Our home wasn't a home. Ruby had to witness everything being taken because we were in the house. We just had to leave them on the step. So rather than protecting her from going through that trauma because she wasn't at school, there was nowhere for her to go, so was going through all this with us.

Because of COVID, you see they needed her oxygen cylinders, they needed this machine– they weren't just things. They were part of her life. They were our home. So taking all of them from our homes, Ruby had to witness all that which was quite difficult.

The experience has led to Holly's younger sister being diagnosed with PTSD. School did however arrange for support due to her experience. Her mum thinks the isolation that lockdown brought to their grieving process has led to the diagnosis. Holly's sister was a young carer all her life and the impact of losing that identity brings with it challenges in pre-pandemic times but activities to support her were not available due to restrictions.

My daughter is still having flashbacks, she's still hearing Holly's alarms beeping. She broke down and wasn't coping very well and was breaking down in school. The school actually helped her get a counsellor in place that she could talk to each week. But she wasn't in school at this time but they said because she was in a vulnerable situation they would allow her to go to school to speak to the counsellor and have some lessons, so away from the home.

And I don't know whether what happened afterwards, because we were shut away from everyone. I don't know if we would have been able to access the help or support, would we be different now?

It's like she's now forgotten in terms of the person she was but she's still the same person, she still was a young carer and still has the after affects of it – it's hard enough for me to adjust, my identity, me as a person but for her who is a child – teenager transitioning in senior school – she'll lose a lot of her networks because all those networks that we were entwined with have all gone now, 'cos were not the family we were.

The isolation the family experienced commenced as Holly died and continued through from the funeral for several months afterwards, confounding their grief process and exacerbating their loss.

When we got there, the crematorium had put in a rule to say no cars were allowed to go in, so they stopped us about a quarter of a mile away from the crematorium. We had to get out and walk, there's no-one to hold onto and then we had to walk in but then, when I came out of there they wouldn't let the

car back in to pick me up so I had to walk out of there like I'd just been the shops

There was no afterwards. We couldn't be with our family straight afterwards so if you think about it, we went straight to the crematorium because we couldn't have people at our home beforehand and you know even though the family,we walked out of the house, dropped her off and then we got a lift dropped back outside the house.

Afterwards, we were isolated. During that isolation and that solitary period we didn't have anyone to talk to or interact with. So, if you imagine we had nobody to go through this amount of pain with. We weren't necessarily the best support for each other because we were in so much trauma in this moment. ...and so it just carried on and carried on and carried on.

Restrictions meant that formal and informal support was not available to Holly's family. Friends and family could not be in the house and services did not allow face to face appointments for information or support.

All the service provision just disappeared. So then there was like real stringent rules put on the networks around us. No-one could come near us, so my best friends were standing by their cars in the middle of the road it was so heart breaking because I just needed a hug.

Then the world just closed down. The loss of being able to do what we wanted to do for her, the loss of human contact, the loss of relationships, family support network.the world just closed down so we didn't have any access to any services ...the hospice was saying we'll phone you and things like that but at this time the phone calls weren't really cutting it for me.

Hayley describes the fact that the lack of memorial services, lack of friends being able to be together at the same time has distorted their grieving process. Communal gatherings enable friends and relatives to share memories together and support each other, the funeral being a psychological acknowledgement of the loss that has taken place and the start of the grieving process.

So before the pandemic, a certain amount of time would pass and you would achieve a certain amount of steps in your grieving process, whereas ours was paused – we didn't achieve any steps – we were just squashed in this moment. People get that closure moment at the funeral all at the same time but now we're getting that acknowledgement from different people all at different times. So now we're dealing with that as well. It was like it was paused. Hospices are speaking now about how different it is to counsel families who have lost children during the pandemic because it's so unique because it's so different to how they've done it before.

I'm very aware of the seriousness of the situation and we're very aware that we're not the only people who have suffered in terms of losing a loved one but I'm also very aware the aftermath and the trauma and long term effects of what happened to us will probably last a bit longer because of what we've been through.

The family's experience highlights the support needed for families losing a child, not just during COVID but beyond the pandemic. Support is needed for families who experienced the death of a child during COVID with their loss and trauma. Services need to recognise how isolation and loss of formal and informal support during lockdown restrictions added to trauma and pain for bereaved families.

Chapter Three

“My Child Is Becoming Invisible”

– the impact of the pandemic on disabled children and young people



3.1 Introduction

The previous section addressed the impact of the pandemic on the support that disabled children may use in order to have the same opportunities as their peers. This section investigates the consequences of this on disabled children and young people. As discussed earlier, the impact of COVID-19 can be broken down into key areas such as the impact from the virus itself and the implementation of restrictions, such as lockdowns, social distancing or remote working. Therefore, this section will address such components from the perspective of disabled children and young people.

Disabled children and young people are not a homogenous group. This section will look at the impact of the pandemic on disabled children, across a variety of age groups with a diverse range of disabilities. The disabled children and young people will have different aspirations to each other with varying levels of independence achieved later in their life.

3.2 Shielding

As discussed earlier, parents found themselves at an interface between government advice, clinical advice and their own parental knowledge of their disabled

child and their condition. The categories used to define those more susceptible to COVID-19 oversimplify the experiences of disabled children and their families. In particular, as results of our parent panel show (figure 27), more than 90% of disabled children shielding had more than one disability. Therefore guidance by diagnosis was not always helpful. The common conditions reported by families shielding were learning disability, followed by physical disability, speech, language and communication needs and complex health needs. As reported in chapter 2, a consequence of the pandemic was a series of delays to services. Results from the parent survey revealed that due to delays, disabled children who were shielding were more likely to experience a negative impact on their condition and development (see Table 4). In addition, more than half of parents reported their shielding child experienced problems with sleep, behaviour, anxiety or loneliness due to these delays, symptoms, of anxiety and stress. A third of families shielding reported that their disabled child displayed symptoms of depression.

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One minute life was good, then it wasn't, then we had a good bit in the middle, then we were back down again, and so it hasn't been stable.

– Young Disabled Person



Table 4: Proportion of parents reporting negative impact of delays to services on their shielding disabled child, February 2021.

	Proportion of Shielding Families -SI
Negative Impact of delays on child's condition*	60%*
Negative Impact on child's development*	54%*
Impact of delays on Sleep	57%
Impact of delays on Behaviour	56%
Impact of delays on Anxiety	54%
Impact of delays on Loneliness	58%
Impact of delays on Depression	32%

Further analysis revealed that when compared with their non-shielding peers, 89% of disabled children shielding were reported to be unable to see tasks through to the end (60% of non-shielding) and 81% did not think out before acting (76% of non-shielding). 44% of those shielding were easily distracted, 41% downhearted or tearful, 38% had more worries and 36% restless or overactive. It is clear to see how the impact of this affects their educational outcomes.

In June 2021, the impact of delays on the disabled child's condition and development was reviewed. Despite some improvements for those shielding, 46% of parents reported the delays to health services had a negative impact on their disabled children's conditions and 32% reported a negative impact on their development. Attributed to the delays was a deterioration in social communication (half of respondents), mental health (4 in 10) and physical health (3 in 10), see figure 26.

Although shielding was paused in April 2021, plus the

lateral flow testing and the roll out of the vaccine giving families more reassurances, this did not translate into improved levels of interaction from shielding families taking part in our parent panel. In March 2021, 91% of shielding disabled children were socially isolated (survey 2), reducing to 86% in June 2021 (survey 5). Therefore, only 5% of disabled children shielding felt less isolated. However, families did report that there were some benefits for children and young people at home with 17% of those shielding gaining confidence during the lockdown 2021.

They're anxious and scared, always needs me with him scared if other children walking past, loss of confidence very confused about everything

The inconsistency and uncertainty have made support almost impossible to continue during the lockdowns . tv messages saying to stay home caused anxiety and a refusal to want to attend their usual provision. professional help or doctor when in crisis has been over the phone advice and meds prescribed with no follow up. Transition to new educational year was managed by myself as services were unavailable

We are lucky that our disabled daughter loves being at home and we are able to support her well emotionally but her physical needs are suffering terribly.

We have continued to have one of our PA's in but the other works for an agency with multiple clients so we chose not to have her in during any of the National lockdowns due to the risk of infection. All my son's social activities have been moved online to zoom which doesn't interest him. We haven't been able to have nana or grandad in our house for months and I miss their practical and emotional support.

- Parent Carers

3.3 Social isolation

I think setting up peer relationships is really important. It's just being a friend essentially. That can be a means of checking on the family. - Young Disabled Person

As alluded to in section 3.2, as restrictions were lifted it was expected that the level of isolation disabled children experienced would improve. However, analysis of disabled children's social isolation scores for those whom follow up data was available showed that just 26% of disabled children's isolation improved and just 2% of those moved category from socially isolated to not isolated. Further analysis was conducted to investigate if particular conditions or geographical characteristics were associated with declining social isolation using statistical tests. This revealed that a

diagnosis of ADHD or ASD was associated with the level of social isolation remaining the same or declining despite the easing of restrictions. Disabled children in rural areas were significantly more isolated than disabled children living in urban areas.

In June 2021, analysis by diagnosis (image 4) revealed that at least 8 out of 10 disabled children were still socially isolated, with 9 out of 10 children with complex needs, hearing impairment and life limiting conditions.

The social isolation measure used for the parent panel survey comprises 6 questions separated into 2 sub sections, one regarding family and the other regarding friends. Parents indicated contacts that their disabled child had had in the previous month outside of their household. The threshold for being socially isolated is on average 2 or less per question.

Despite the lifting of restrictions the June survey revealed (image 5) 65% of disabled children saw two or fewer relatives in the previous month and 57% saw two or fewer friend (31% saw no friends). The picture is repeated when parents indicated the types of support their disabled children had outside the household to discuss private matters. 66% of disabled children relied on two or fewer relatives and 64% relied on two or fewer friends (image 6). 64% of disabled children have fewer than two relatives and 66% have fewer than two friends to call on for help outside the household (image 7).

Image 4

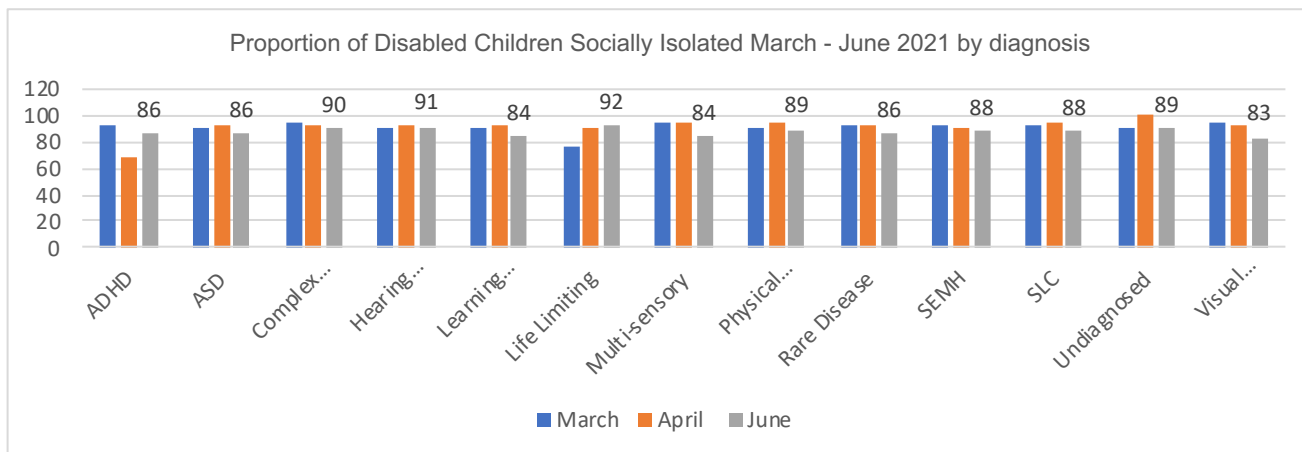


Image 5

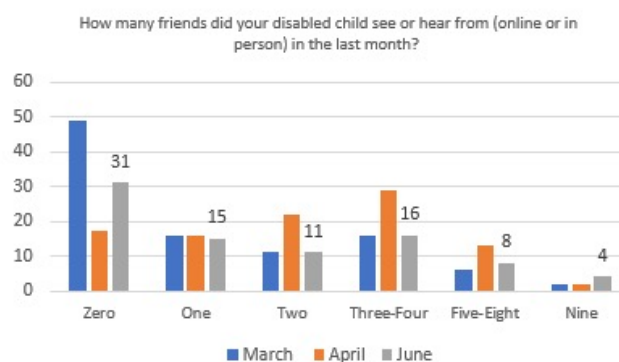
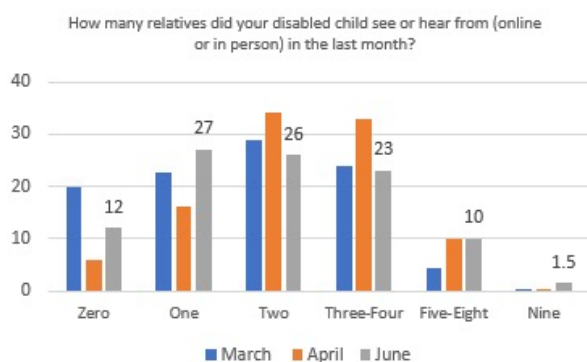


Image 6

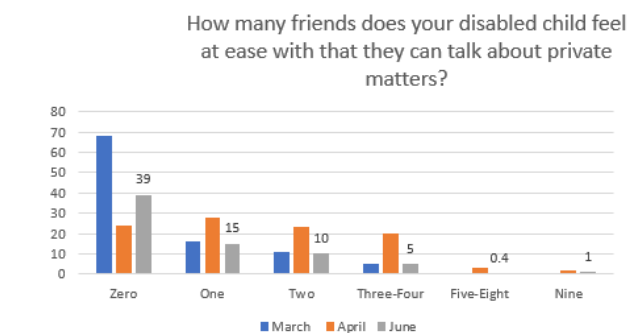
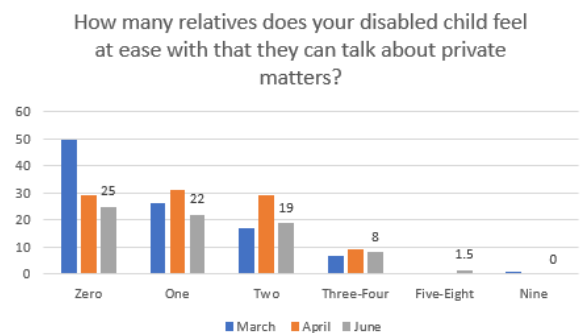
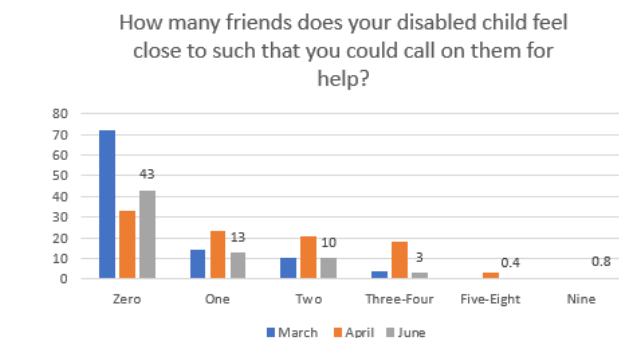
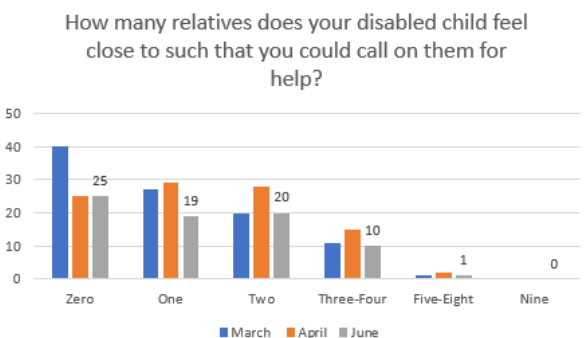


Image 7



Statistical analysis by ethnicity revealed that there was a strong association between ethnicity and social isolation with black or asian disabled children more likely to be socially isolated than white disabled children. Longitudinal analysis by ethnicity revealed that only 26% of white disabled children and 24% of disabled children from BAME ethnicity were less isolated as restrictions eased. However, 8% of white disabled children with an improvement in isolation score moved to the category of not socially isolated, but no disabled children from BAME background moved to the category of not socially isolated.

Parents were concerned that limited communication may increase isolation in the future. Research has highlighted that digital experiences with a relational focus aid access to support, fun experiences and information (Bradley, 2021), that could buffer isolation. Longitudinal analysis was undertaken to assess if particular age groups were more or less likely to experience improved levels of social isolation as restrictions were eased. There was no difference in age groups for the proportion of disabled children with a level of social isolation getting worse. Across all age groups around 75% of disabled children's level of social isolation stayed the same or got worse (figure 30).



3.4 Impact on Health and Development

The loss of support from services that should enable disabled children to lead healthy lives has been addressed in chapter 2. In addition to severe levels of isolation, loss of services had a detrimental effect on their health and development. 71% of parents reported that their child's progress had regressed due to delays to service caused by the pandemic. Almost three quarters (73%) state that this is the case for their disabled children's communication and half (58%) for their mental health. There was an increase in children with black and asian ethnicity contacting Kooth (NHS mental health support provider), with 26.6% increase in contact of black and asian children compared with 18.1% white children.

Constantly needs watching - escaped twice - one serious accident as a result with massive Injury needing surgery. Three accidents requiring A&E. all because they don't understand why they are being kept a prisoner inside their own home and all their daily activities have ceased. No friends or family visiting. Absolutely exhausted with 24/7 care and supervision needed to keep them safe. Have slept, locked in their room with them, for 6 months plus to avoid more accidents. Lots of disturbed nights with very challenging behaviour.

There have been some positive changes: some charities have been able to offer services/groups via Zoom which my child wouldn't have been otherwise able to join in person, pre-pandemic. However, we haven't been available to access any CAMHS services.

My child has always had issues around food, limited diet, this has become much worse and we will be seeking support from our GP soon.

My son had been out of school for 15 months due to anxiety due to school trauma Covid has made getting him back into school or education very difficult, he is attending online hospital school for 45 mins a day and we are currently waiting to finalise his EHCP naming a specialist school. - Parent Carers

73% of parents of disabled children reported that their disabled child was not getting enough exercise (January 2021), with 64% stating that the reduction in levels had affected their child's health negatively. As discussed in chapter 2, lack of access to therapies, activities and equipment resulted in children's conditions worsening with increased pain. Disruptions to medicines to address flare ups were not easily accessible. Avenue to address problems too were impeded, leaving families in limbo.

Medicine became unavailable and had to be changed mid lockdown. It didn't agree with him and he reacted badly, still affecting him now and other meds/conditions also affected

Physical pain from stiffness due to longer periods in same chair.

A child who was active everyday 7 days a week now is cooped up at home. Only able to go out for exercise.

There has been no OT support at all since January 2021 even when my child has OT provision on his EHCP. Raised formal complaints to LA but still no response and ongoing". - Parent Carers

A survey of grant holders for children in need projects reported heightened challenges, making challenges more complex to deal with, reduction in support that would impact on children and young people's outcomes and regression in progress for children and young people (Children in Need, 2020).

There has been no support available due to Covid - lack of available support staff and lack of open provision e.g. playscheme venues and regular 1:1 therapy sessions. All of this has had a huge impact on my son's development.

My child has regressed irretrievably, I despair he will ever be able to catch up. - Parent Carers

Parents who had one child in the early years group found it difficult to assess if delays in development were expected, related to their disability, or a consequence of COVID-19. Analysis of DCP panel survey data revealed that a higher proportion of disabled children in this age group experienced delays to health services. Figure 29 illustrates the delays to particular services for those five and under.

Transitions

For older children, a transition process should commence for children aged 14 with a view to creating a transitional plan, for post 16 education or training and transitions to adult health and social care. However, more than half of parents responding to a survey on transitions did not have a transition in place, with a third indicating that their child would now finish education sooner or later than expected. 65% of parents expected their child to continue living in the family home, as a third of families reported challenges transitioning to adult social care.

I know that I'm going to be coming of age soon, as I'm one of the older people, and there is no transition for people who are 26-30. I could have a conversation with someone, but I don't think there is actually anything to join, so...A bit of sign posting would be better than nothing. - Young Disabled Person

All children with special needs throughout their early life into adulthood around age 25 need consistency and support in all settings. They need a person that makes sure everything is in order, funding in place, provision in school, college. Parents are holding on by a thread trying to organise these things for their children, often with little or no support and no one to advise them what they can or can't do. - Parent Carer

A comparison of young disabled people aged 16-21 and their non-disabled peers reveals a difference in how disabled young people feel about their lives. This is highlighted as the data is pre-covid (between June 2019 – June 2020). Disabled young people are less likely to be as happy, satisfied with their life or consider it worthwhile and be more anxious. Policy makers have set out catch up plans but parents of autistic young people expressed concern about how this would be done.

Before the pandemic he was expected to continue with education part of the week, and training the other part and living at home here with us for support with a view to independent living in a few years because he is getting support for life skills. He's been unsettled because we're all at home together so mainly spends time alone in his room. He wants to move out sooner now and so to get him into a new training place, a new educational setting and now a new home with a new routine all the support he'll need, what do we do first. I'm worried if he does it all at the same time it'll just be too much and he'll give everything up and be back in his own room on his own. - Parent Carer

The deterioration of disabled children's physical and mental health and regression and development affect their relationships with their peers and others. Access to their counsellor less frequent so they feel on their own apart from talking to me, luckily we are close.

Access to their counsellor less frequent so they feel on their own apart from talking to me, luckily we are close. - Parent Carer

3.5 Attainment and Life Chances

As reported in section 2.2, education is one of the most important indicators that contribute to outcomes later in life. People with lower levels of literacy have poorer health outcomes. Therefore, poor health creates a barrier to future life goals. As discussed in 2.6.3, disabled children and their families spend time in local communities at cafes, shops and community centres during leisure time. However, this may also facilitate skills requiring independence, address sensory needs, physical needs, reduce anxiety and poor mental health and support socialisation. All key in supporting disabled children live the lives that they want to as they transition into adulthood. Therefore, worries about regaining the lost momentum COVID-19 pandemic had brought was a dominant theme with parents of disabled children and young people. Worried about their future due to the implications COVID-19 had brought for children's physical and mental health.

Just down to the fact that for a child who is so routine led, either not going to school or only going part time is detrimental to his happiness and structure and progress

No schooling at all in first lockdown. Since then although place has been available at school my daughter has had to self-isolate for three separate periods and so missed schooling. Because of her PMLD and high energy levels she is unable to engage in online learning.

My son won't ask for help in college, it is done by sight by the teachers, they know the signs when he is struggling. Remote learning is proving hard as the teachers cannot see my son, so he is getting frustrated, angry and thinks he is failing.

Child I has not be able to access any therapies regularly used within school to regulate and feed his senses which had led to unusual behaviours from him.
- Parent Carers

I ended up developing long COVID, and I had to leave Uni, with the option originally to return in October if I want to, I don't really want to. going to university was

something I was very attached to, in terms of like, like one of those ideas of what it means to be successful, especially as an autistic person, who's got like a bunch of other things going on as well. So, I was really depressed, and didn't really want to do anything for myself for a while. - Young Disabled Person

3.6 Summary

The withdrawal of support for disabled children increased isolation for a group already at risk. The impact of disruption to the intertwining support levels (discussed in chapter 2), from various sources that disabled children and their families use to live their life, had a significant impact on their mental health and physical health putting their attainment and life chances at risk. A high proportion (4 out of 5) of disabled children remain isolated, even with the lifting of restrictions. Delays in accessing appointments, therapies and operations resulted in pain, further disability and trauma for a large proportion of disabled children. This in turn impacted on their ability to attend school or take part in opportunities through their educational placement such as social occasions, life skill or vocational training. Delays in provision of equipment such as wheelchairs compound the impact on pain level, mobility and development subsequently leading to associated mental health decline. It is therefore not surprising that the most dominant theme from the analysis of qualitative data was the impact on disabled children's mental health.

The following section will present findings regarding the impact of the lack of support on the wider family, parents and siblings.

Chapter Four

“There are more times now where we as a family are broken”

– The impact on the Wider Family



4.1 Introduction

We all have to sleep in same room with mattresses on floor (only thing that works tried and tested over 6 years). If one twin wakes due to a bowel movement he smears to remove discomfort and the big clean up means the night timeroutine must begin again. I may be awake till 6am but if its a weekend, my partner holds the forte whilst I sleep between 6-9am and I'm good to carry on. Some nights I'm up most of the night working on twins admin and I'll do the 3 hours sleep whilst hubby again attends to both twins. This represents a positive day in the life due to Covid.

- Parent Carer

The impact of the pandemic on the formal and informal support families with disabled children may use was outlined in section 2. Support for families reduced drastically leaving families in a precarious situation. This section reviews the impact the loss of support had on disabled children's parents and siblings. It commences with a case study from a mother with a disabled child. It describes her thoughts and feelings towards the lack of support from society. The chapter then presents evidence regarding longitudinal data from our research programme regarding mental wellbeing, anxiety, stress and isolation of parents. It assesses the impact from families with particular characteristics such as single parents and parents with multiple disabled children. Additional characteristics are considered during the analysis, such as the impact of urban or rural environments, deprivation levels or ethnicity on parent and siblings experiences.

In order to keep her safe I've had to take on the role of providing ALL adapted curriculum education and ALL therapies (physio/OT/SALT) The quality of the teaching I'm able to provide and especially the therapies is vastly below what she needs! My disabled child is one of three children. My other children are

6 and 18 months old. My 6 year old has a full time school timetable none of which is delivered virtually, all needs supervising. My 18 month old has all the care and entertainment requirements of a lively toddler. I am overwhelmed by guilt that I cannot balance all of their needs even with a very supportive/involved working husband. School are really doing their best I don't blame them at all. They asked if we wanted a place but my fear for her health outweighs other concerns.

My confidence has diminished. I feel annoyed that there is no forward planning enabling family support. Trying to maintain and juggle so many demands ie ehcp, health apts zoom all requiring new skills. Everyone takes a piece of you and the child has more issues as routine changed as they are bored at home.

- Parent Carer

The quote above highlights the pressures placed on parents during the pandemic. Some parents did report positives due to them being at home in a more relaxed environment.

The children are actually more relaxed at home (I'm probably one of the few). They are learning more about themselves, and so are we as parents. The informal support has decreased because of shielding, and trying to keep our family members safe.

4.2 Case Study 3: No-one was clapping for me

The whole of the UK went out on a Thursday night and clapped for NHS, for key workers and all the people that are doing amazing jobs. But no-one was clapping for me.

All the other carers the other mums like me, actually do the roles of nurse. I do what qualified nurses do, but no one was clapping for me. No-one was thinking of me. No-one was supporting me.

No-one was explaining to me why my daughter had to shield in lockdown one and now doesn't have to shield in lockdown three. No-one was telling me how I can get PPE and help protect my family.

No-one in lockdown one thought about the impact of not having a social bubble when you're single, shielding and can't go out of the grounds of your house. Three months completely on my own 24/7, taking care of a child who cannot walk, cannot talk.

She has the mental age of a baby and she is 11 years old. Every pad change, every medicine, Syringe down gastric tube, feeding machines, baths, getting dressed, getting undressed, entertaining, playing.

Then there's all the other things that have to happen running a household all of it completely on my own. And to see her get so upset, distressed, angry and frustrated for three months, because she couldn't go past the end of the drive, She doesn't understand. We weren't even allowed to go out for a walk.

No-one has any idea what I went through with those three months and continue to feel that she was going to die from Covid. That I had to do everything to protect her. No-one explained to me why she didn't have to shield in lockdown 2. No one explained to

me why she didn't get a shielding letter this time. I've been hanging on waiting for a letter to come through the letterbox that never came.

They couldn't even be bothered to tell me we're not going to have to shield this time. I had to go and do all that research and contact the consultant myself. The stress they've put me through, the anxiety, the worry but it's okay because I'm not important enough.

And now she is able to go back to school. So all of last year what happened was a waste of time. Not one person has thought about explaining that to me. Then to be told last week that I am not important enough to have the vaccine along with other carers who are "paid". I've never felt so undervalued and worthless in all my life and what I have done this past 10 months.

I've even been told that the people working in charities, a food bank for example are entitled to have the vaccine right now along with over 70s because they are important enough. Not a single mother who is looking after a severely disabled child and the impact that might have on that disabled child if that mother doesn't get the vaccination. Nah she has to wait. Why?

Because she's not important enough!

4.3 Isolation

Social isolation is associated with poor health and risk of premature death (Holt-Lunstad, 2020). There is consistent evidence that links social isolation to poor cardiovascular and mental health outcomes (Leigh-Hunt, Bagguley, Bash et al 2017). Therefore, it is important to identify and address social isolation in order to prevent poor outcomes in the future. Social isolation is an objective measure indicated by the number of social contacts a person has. Parents taking part in the DCP parent panel indicated the number of social contacts they had had in the previous month from survey 2 onwards. The Lubben social network score was adapted to include online social networks. The measure is used by services to identify people at risk of social isolation, with a score of 12 or less highlighting a person at risk.

More than half of parents were socially isolated and would be identified as requiring support in usual times during February 2021. Despite restrictions easing, 6 in 10 parents remained isolated at the end of the survey series, (figure 31). Further analysis was undertaken to review if parents' scores may have improved over time. 55% of parents experienced the same level or a worsening of their isolation and of the 45% of parents improving their isolation score, 64% of those remained within the ranges of social isolation.

Analysis was undertaken to investigate if particular groups were more likely to experience social isolation. Longitudinally, 68% of black or asian parents had the same or worsening levels of social isolation compared to 53% of white parents.

4.4 Stress

Staff and therapists at school have been brilliant and very supportive but at the end of the day I am not a teacher, not a SEN specialist and not a therapist, and I cannot provide the same level of educational support to my child as they can. - Parent Carer

Stress is the term applied to the physical and emotional response experienced by individuals when they perceive the ability to manage their environment as challenging or exceeding their resources, endangering their wellbeing (Lazarus and Folkman, 1984 cited in Spaderna H and Hellwig S, 2015). Stress may be acute (a reaction to a one-off event) or chronic (ongoing cumulative stress), however in the literature the focus is often on episodic stress with a clear beginning or an end (Hamman, Kim and Eberhart, 2009). When stress occurs as a one-off event the body receives a signal to return to normal functioning. However, chronic stress affects the functioning of immune, digestive, cardiovascular and sleep systems meaning that over time serious health problems may occur (NIMH, 2021).

We are exhausted from having all three of our children at home and being in a constant state of high alert due to ongoing fears about our daughter's health.
- Parent Carer

As discussed in section 2.5 COVID-19 brought additional problems for families. The withdrawal of services led to additional caring for families, limiting their capacity to work. Therefore, families are at risk of reduced income, leading to financial strains on the household income creating additional stress on families already under pressure. The physical impact of supporting children who cannot access hoists, bath seats and other equipment that help parents move their children safely was highlighted by parents experiencing delays for equipment. Inaccessible education or public health information also created extra stress for families (Bradley, 2021).

The DCP panel survey measured the levels of stress parents were experiencing from January 2021 to June 2021. The short form Perceived Stress Scale was used to measure the level of stress (see Appendix 1). The initial survey demonstrated that parents' stress levels were higher than the general population. As this survey took place during the third national lockdown in England, this may have been a one-off response to lockdown. However, the subsequent surveys took place as the easing of restrictions progressed but stress levels remained significantly higher than the general population.

Longitudinal analysis reveals that compared with the national lockdown (January 2021) over half of parents (56%), experienced the same level or worsening levels of stress over time, despite restrictions easing.

Further statistical analysis was undertaken to assess if there were particular groups of families experiencing higher levels of stress. Parents with a disability themselves were significantly more likely to have higher levels of stress. Those living in the north were more likely to experience increasing levels of stress (61%) than those in the south (53%) and parents living in rural areas (38%) were more likely to have increasing stress levels than those in urban areas (34%).

Living in overcrowded council flat no space affects everything. - Parent Carer

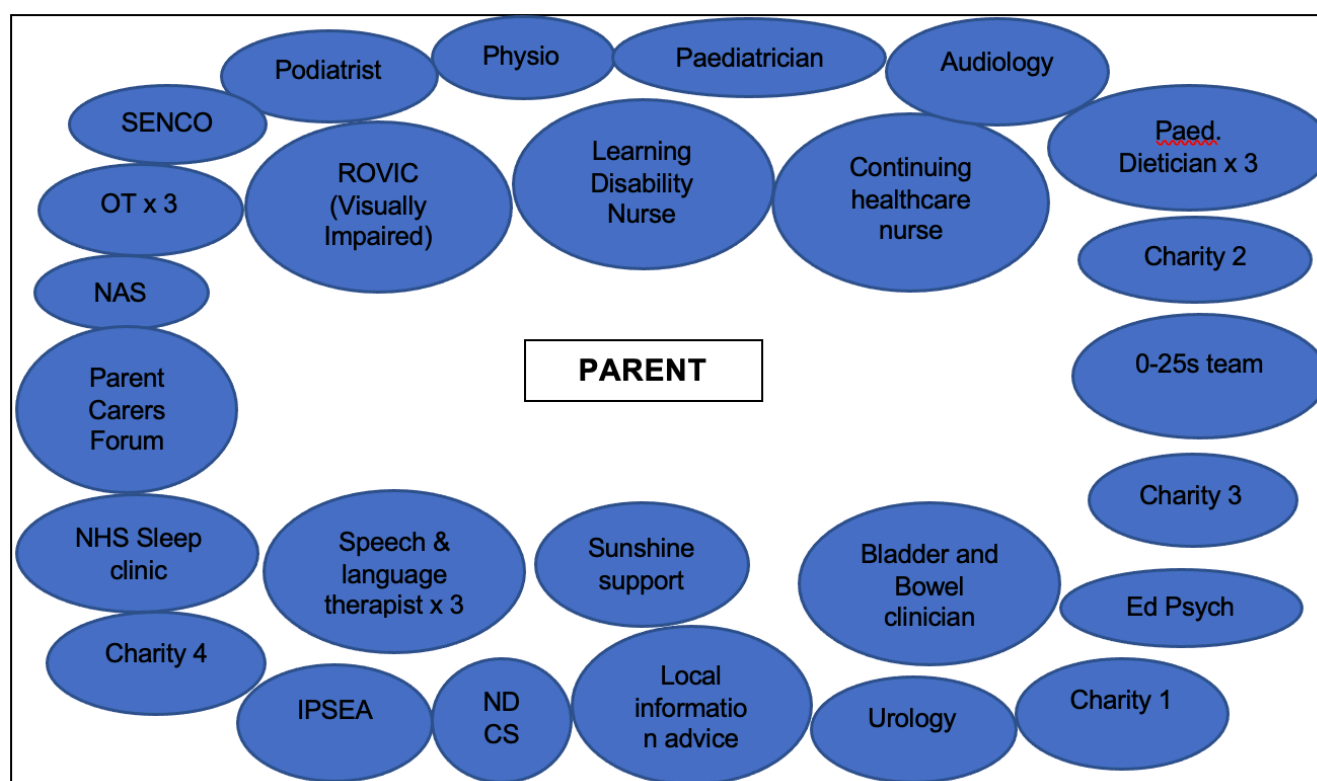
Therefore, it is clear that parents of disabled children are experiencing chronic levels of stress putting them at risk of developing further physical and mental health problems. Parents living in areas of higher deprivation were significantly more likely to be socially isolated than parents living in lower levels of deprivation. Ethnicity was also a key indicator for worsening levels of social isolation as time moved on. Black and Asian Parents (63%) were more likely to have the same or worsening levels of social isolation compared to 53% of parents who were white.

Just feel lonely as I'm a single parent looking after my complex needs son. Feel even more isolated than before which has always been the case. But now it's a 100 times worse. Miss my friends as cannot leave home only for a short time but too heavy to push in wheelchair uphill and I live on a hill.

- Parent Carer

As image 8 demonstrates for parents with more than one disabled child, the interaction with services takes up a large proportion of their time, leaving little quality time to spend together as a family.

Image 8: Parent contact with services for two disabled children



4.5 Mental Wellbeing

All my support groups have ceased, therefore I am not getting my own health boosted which is naturally impacting how I deal with family members and every day situations.

As mentioned above it is known that chronic stress may lead to poor mental health and conditions such as anxiety and depression. COVID-19 has exacerbated factors that can influence prevalence of parental depression (Shaw, 2020). As quote above illustrates parents with strategies to manage stress or worries, may have found themselves without their usual avenues of support. Parents with disabled children with life-limiting conditions describe the loss of support encroaching on their ability to process the

mental health challenges that come with supporting a child with a terminal diagnosis.

I've said, we've had all this and we forget that we're in a constant state of grief for what we could have, we're grieving every day

Although hubby works from home now, its not at all possible to put in the hours needed. Was under so much pressure from work that he suffered burnout and has been off work for 2 months as every single day during past year we have not had 1 day rest as one child never returned to SEN school due to them admitting they could not meet need. - Parent Carers

The DCP panel survey used the Edinburgh-Warwick Mental Wellbeing Scale to measure the level of mental wellbeing parents were experiencing. The scale enables a comparison to be drawn with the general population during usual times. Throughout the series of surveys, parents' mental wellbeing was significantly lower than the general population. Studies using the Edinburgh-Warwick Mental Wellbeing Scale during the COVID-19 pandemic were also reviewed to compare general population scores at this time. Parents of disabled children's scores were still significantly higher than those of the general population during COVID-19 pandemic.

The scale enables an indication of possible or probable depression to be made. A large proportion of the parent panel score was within the range for possible or probable depression.

Longitudinal analysis established that despite restrictions easing, 60% of parents' wellbeing remained the same or worsened. This equates to 40% of the panel scores improving over time. However, 57% of those with improved scores remained within the threshold of possible or probable depression.

Further analysis between groups revealed that ethnicity was associated with worse levels of mental wellbeing. 53% of black or asian parents were experiencing lower levels of mental wellbeing compared with just 18% of white parents.

Previously, this report has addressed the impact of the shielding process on health and education and specifically the experience of disabled children. A third of the DCP parent panel were shielding, 42% of whom indicated that they also had a disability or health condition themselves. The list below illustrates the characteristics of the parent panel who were shielding:

- 90% were mothers
- 9% were fathers
- 1% were grandmothers
- 29% were single parents
- 88.3% identified as white
- 9% identified as BAME
- 79% had one child, 18% had two children and 3% had three or more children.

Longitudinal analysis specifically investigating the level of mental wellbeing experienced by parents who were shielding revealed that they were more likely to experience (54%) worsening mental health than parents who were not shielding (46%).

Statistical analysis revealed that single parents with disabled children had significantly lower levels of mental wellbeing than parents with a partner. They were also more likely to have probable or possible depression when compared to parents with a partner.

Sometimes I just cry myself to sleep at night as I'm shielding so as a lone parent the kids pretty much do too. - Parent Carer

4.6 Anxiety

Anxiety is defined as a feeling of unease, worry or fear (NHS, 2018), that as with stress may be a reaction to a one off event or more prolonged. General anxiety disorder is long term anxiety in response to a wide range of issues with people experiencing it most days.

The DCP parent panel indicated their level of anxiety during the survey series. The General Anxiety Disorder (GAD) questionnaire was used (Spitzer, Kroenke & Williams, 2006). The scores obtained can be categorised into four categories corresponding to the severity of anxiety (no anxiety, mild, moderate or severe anxiety). The initial survey in January 2021 revealed that parents' level of anxiety was significantly higher than the general population. The average score for parents of disabled children was 10.4, within the threshold of moderate anxiety. Parental anxiety was consistently high for the further three surveys, with more than 80% of parents having some form of anxiety despite the easing of restrictions (86%, 80% and 84% respectively).

Further analysis was undertaken to assess the association between particular factors and the level of anxiety experienced. Parents with a disability or health condition were significantly more likely to experience higher levels of anxiety than parents without disabilities. Longitudinally black and asian parents were more likely than white parents to experience worsening anxiety over time (38%, 31% respectively).

Where people lived also had an impact on their level of anxiety. A comparison of parents living in the 20% of the most deprived and least deprived local authorities in England revealed those living in more deprived areas were significantly more likely to have higher levels of anxiety than those living in the least deprived areas. In addition, a regional trend was discovered with parents living in the north having higher levels of anxiety than parents living in the south. Over time parents in the north were more likely to experience their anxiety staying the same or increasing (39%) than those in the south (35%).

4.7 Impact on Siblings

As with previous sections of this report it is clear that reduction in services and changes in family life during the pandemic has affected siblings of young children. Almost half of parents reported siblings were providing more care during the pandemic (Kasa & Pavlopolou, 2021). Research by Carers UK revealed that 11% of young carers and 19.7% of young adult

carers were providing 30 more hours of care per week due to the pandemic (Carers UK, 2021). As reported earlier, families experienced a reduction in the level of care provided within the home, therefore siblings provided additional support:

My other child is giving more care to her disabled sibling. I have no respite but truthfully no trust in bringing in outside carers. Many paid carers in my area are unwilling to get vaccinated and have made that clear to me. So there I think of the risk.

- Parent Carer

Research by Family Fund in 2020 with almost 2000 parents illustrated that 90% of families reported that the sibling of their disabled child had been negatively affected. The DCP research in early 2021 established that 83% of parents felt that this was still the case. The most common problems reported included dealing with more challenging behaviour from their disabled sibling, fewer opportunities to have fun and fewer breaks (Family Fund, 2021).

Figure 31, demonstrates the level of isolation experienced by siblings of disabled children with 7 in 10 siblings still socially isolated despite restrictions easing. Parents reported the types of anxiety and stress related behaviours that their children were exhibiting:

- Sleep 67%
- Anxiety 59%
- Concentration 51%
- Physical Health 48%
- Behaviour 42%

Very little contact with other children. She has had less than most children anyway as we were protecting her sister by not letting her in big nursery settings, but now was meant to be her time starting school, but she hasn't spent as much time at school or been able to go to friend's houses due to the pandemic.

- Parent Carer

The quote above demonstrates that in addition to filling the gaps of reduced services, siblings also missed out on other life events as with their peers. 57% of parents reported that siblings were unable to find a quiet place to concentrate on school work.

Sibling one has missed friends and was always so active and attended lots of classes as well as school but feels like missing out and missed the social side of things especially.

Their friendships have disappeared completely.

- Parent Carers

It is known that siblings of disabled children are more at risk of emotional or mental health problems than their peers (Caliendo, Lanzara, Vetri, 2020). The culmination of loss during the pandemic of friendship groups, social activities and difficulties accessing education has led to a decline in the mental health of siblings (Carers UK, 2020). This is demonstrated in section 2.4 as the mental health data set revealed that referrals for young carers declined at the start of the pandemic, later increasing by over 50% services compared with pre-pandemic levels. Research by Sibs UK revealed that mental health was the most common impact of the pandemic, with 81% of parents reporting that siblings' mental health had been negatively impacted.

Section 2 reported that family relationships were under increased pressure due to the reduction in support. 40% of parents reported that the relationships between siblings had got worse during the pandemic (Kasa & Pavlopoulou, 2021). Parents reported that siblings were increasingly anxious with frequent worries about the impact of the virus on their disabled brother or sister.

Her life has definitely been impacted upon by the fact my son was shielding initially and him being home more. She also has massive anxiety around my son getting the virus

They have had to absorb the increasingly erratic and angry behaviour of their older sibling with disabilities, and she is only just 4. - Parent Carers

As reported in earlier sections, the effect of the pandemic has impacted disabled children from various angles, and this is indeed the case for siblings. They experienced and observed the impact of pressures on their family due to loss of support and changes to routine. However, lockdown removed the outlets for support to siblings such as respite, school and outings with disabled brother / sisters or friends. Instead siblings experienced cumulative pressure along with the rest of their family, as demonstrated by the quote below:

My non-SEN children have had to deal with the physical tantrums, aggression from their sister, sadness seeing their parents attacked, anxiety seeing their parents row about how best to cope, and they've overheard discussions about lack of money.

- Parent Carer

Parents with more than one child expressed added anxiety about meeting the needs of disabled children and their other children. Support from statutory organisations was not forthcoming and it was a common narrative that parents felt at risk of making incorrect decisions. As the parent below describes, with no support on occasion any decision is associated with potential risk.

My daughter's mental health can be so bad, that she spends most of it in her room. A good day is if she comes out to use the toilet. So when she's like that I get into trouble for not taking her younger sibling to school. I can't leave her and they don't help me so either way I can't get it right. If I left her and took him to school and get back and she's harmed herself then I've failed her, if I stay at home to watch her then I'm told off because he's not at school. There's no help, I just can't win.

Formal support has changed. I'm not a very social person by nature so our local support group can sometimes be quite overwhelming. They now do online support groups which are a lot more accessible for me as they are generally a lot smaller. I don't have to speak, I don't have to have my camera on. The council however threatened me with social care near the end of 2020 because my eldest is refusing to attend the placement named. Then ignored me for several months, & are now threatening prosecution. My other child's school told me his absence would be unauthorised even though it is down to anxiety (diagnosed) and then told me I could face a fine. The support from those that should be trying to help, and actually hold the power to do so, is seriously lacking.

- Parent Carers

The authoritative, punitive perception of services was spoken about by parents. The administration and management of care and support for disabled children was a dominant theme. This chapter commenced with an example of parents' tasks to deal with the loss of support due to COVID. It ends with a parent describing the impact of the system to appeal for support that doesn't enable their family to have more time together.

What I don't understand is, I have to have someone watch my children in the garden while I sit and work through the admin tasks that are needed to co-ordinate their care and to appeal decisions made or highlight where the care we should have isn't being provided. It's making me ill but it has to be done. So what they offer is, we'll give you a break and take your kids out for the day or there's respite so you can have a break, so they can help me by getting someone else to look after my kids but they can't help me have more time with my kids by sorting what they should get anyway? They won't take all that admin off me and that makes no sense....I want to have more time to be with my kids and do stuff as a family not more time to get admin done. It makes no sense.

- Parent Carer

4.8 Summary

This chapter has demonstrated that the lack of respite, short breaks or support within the home resulted in parents increasing their roles to support their child practically and emotionally. Parents experienced high levels of anxiety, stress and poor mental health at a time when informal support from family, friends or access to services within the community such as parks, leisure or retail venues that may bring some distraction from a stressful environment were limited. This was significantly higher when compared with the general population during pre-pandemic and during COVID-19 pandemic. Parents dealt with children in pain, with deteriorating conditions, exhibiting unusual behaviours or dealing with loss or upsetting news in seclusion. Siblings too took on extra caring responsibilities and in turn are exhibiting symptoms of anxiety and poor mental health. A high proportion remain isolated despite restrictions easing.

The pressure on families of disabled children has not been short-lived. Our research shows that they are ongoing with little change despite the easing of restrictions. Continuation of the current situation increases more urgent support from health services and breakdown in educational and social care placements, creating a high risk of family breakdown due to the cumulative impact of the loss of support.

The following chapter presents findings as to how the sector can support families in the future. It details competencies required.

Chapter Five

Sector response to
the pandemic



5.1 Introduction

The previous chapters demonstrated that the COVID-19 pandemic has hit families with disabled children and young people hard. Families have not been able to access therapeutic services; they have coped with supporting their disabled children at home 24/7, and the anxiety created by the possibility of catching COVID all took, and continue to take, a heavy toll on families. This chapter presents the findings from the independent evaluation of the third sector response to the COVID-19 pandemic and describes the methods used to explore the response from the sector. This chapter identifies what can be learnt for the future in terms of planning and delivering services for disabled children, young people and their families.

There is a unanimous perception from charities that disabled children and their families have been largely forgotten by the statutory sector since the start of the pandemic. Consistent with findings in chapter 2, most charities mention that all resources were diverted to the COVID response early on, with families of disabled children having to deal with a sudden withdrawal of services and therapies and a lack of access to GPs.

“So many of the families that we support have multiple agencies involved in working with them. And 60% of them said, ‘only Dingley had supported us through this’. I find that really disturbing, because these are people who have physiotherapy, occupational therapy, speech and language therapy, and may be in touch with educational psychologists or so many different people involved. And it just stopped for so many of them.” – Dingleys Promise [Medium, balanced funding, CYP and carer services].¹

Many also comment on the difficulty of navigating constantly changing guidelines that were designed for the NHS and schools but did not consider charities doing similar therapeutic work. What that meant in practice was that organisations had to find their own ways of securing PPE and reinvent service delivery in ways that ensured the safety of children and staff. This meant organisations had to establish their own

pathways interpreting how the legislation applied to them. This often included reconciling contradictions between the guidelines issued by PHE and the DfE around shielding and educational settings. Driven by a strong desire to maintain their support and not to let families down, charities quickly developed and adapted services, challenging processes and ways of working that have been established, effective and appreciated for many years.

Organisations were also themselves affected by the pandemic having to furlough staff, or having other staff become ill needing to shield with vulnerable family members, or cover childcare and home-schooling responsibilities. Universally, the organisations participating in this research put effective steps in place to support the mental and physical wellbeing of staff.

Parents participating in the focus groups spoke of the “battle” to access statutory services even before the pandemic – however, as we have seen above, those services “just disappeared overnight” with parents feeling providers “didn’t give a damn”.

Parents contrasted charities’ response with that of the statutory sector. They already considered charities to be “on their side”, caring, proactive, driven by families’ needs and accessible. Parents felt this was particularly true of small charities but some felt that large, national organisations demonstrated some of the same inflexibility as local authorities.

“Sense have been doing everything, I mean they went virtual overnight, supported me and my mental health, supported my children by giving them some entertainment a couple of times a week ... and all the proper services ... they all stopped. We were just left in the dark.”

– Parent, focus group

Parents had almost only praise for the way charities reacted to lockdown and tended to feel that charities, when they were at their best, were already demonstrating many of the “competencies” we will explore below. During the pandemic and lockdown, charities became even more flexible, responsive, empathetic and supportive than they had been pre-pandemic. For parents, the fact that charities “stepped up” during the pandemic was welcome, but not surprising.

However, parents are also worried that when life goes “back to normal” budgets for statutory provision will be cut and services will not return even to the less-than-ideal level they were before the pandemic and the fight for support will start again. They anticipate that charities will be called on to cover what they see as “core” therapeutic services. Therefore, although the new, practical activities implemented by charities to support families during lockdown are desirable and needed, parents feel they should be in addition to the charities’ core service delivery work.

The role of the DCP is overwhelmingly deemed ‘vital’ both as a source of information and updates as the pandemic progressed and as a powerful lobbying body. Charities praise its ability to provide a unified front to raise awareness of the pressing needs of disabled children and their families, giving parents and carers a voice and providing evidence to secure funding bids – smaller individual charities would not have been able to focus on campaigning as all their time and resource was allocated to responding to the changing needs of children and their families. Organisations also praise the DCP’s collaborative and all-encompassing approach, ensuring that all charities, big and small, could have a say and effectively influence policy change.

The DCP membership (of over 90 organisations) is united by the belief that disabled children, young people and their families should have access to the services they are entitled to, when they need them. However, the composition of DCP organisations is hugely varied in terms of size, geography, clients supported, and sources of funding. As a result, the specific activities that participating organisations adopted during the pandemic were very wide ranging in execution and experience.

Therefore, the evaluation of the sector response has focussed on competencies: what was learnt about how to do things, rather than tactics: what was learnt about what we did. By taking this approach we hope that organisations will find the conclusions easier to apply to their work more generally, not solely when they are required to respond to emergencies.

Finding can be summarised by five guiding organisational approaches or “competencies” that most participants found useful during the pandemic and many wish to continue to implement going forward.

Those guiding competencies were:

- Being able to understand changing disabled children’s and families needs (5.2)
- Having an increased focus on emotional support (5.3)
- Maximising the benefits of online service delivery (5.4)
- Adopting a more collaborative, holistic approach to meeting needs (Chapter 5.5)
- Adopting an agile approach to service design and implementation (Chapter 5.6)

Although these approaches support each other and overlap in places, each is explored in more detail in the following chapters which outline the charities' experience and learning in that area and provide considerations for continued implementation.

5.2 Understanding the changing needs of children and families and increasing reach

5.2.1 Generating new insight

Charities pride themselves on understanding the needs of their client groups. This is a strength that parents and young people feel charities have compared with statutory providers. However, the assumption that charities knew their disabled children's and families' needs was tested during the pandemic, with many charities reporting needing to deepen their understanding of what support disabled children and families now require.

There's definitely been a real sea change in what the needs of parents and carers are now in comparison to what they were pre pandemic. The pandemic has made people really reassess their own circumstances, their own positions. When your priorities change, your need for support changes.

– Scope, [Large, vol funded, carer services]

"I really think that we had to sit back and say what do we do that is going to make the biggest difference to our members. There was a lot of soul searching and thought 'let's look at the whole package of what we provide and what our families need.' The pandemic has absolutely made that happen. Everything else has fallen away and it's been 'what do our families need?' There's definitely been a coalescing of activity around need."

– The Fragile X Society [Small, vol funded, carer services].

56% of respondents to the survey (39) agreed with the statement "During the pandemic, my organisation was better able to understand families' needs" with only 10% disagreeing.²

Charities were able to generate this insight due to more frequent engagement with disabled children and families across more communication channels. This engagement was both reactive (e.g. increased calls to helplines and information services) and proactive (e.g. ringing people up to see if they were okay, setting up Facebook or WhatsApp groups, or sending surveys to identify needs).

"We had more regular, structured communications with families to ensure that the constantly evolving projects we were delivering were going to meet their needs. We also had more 'chats' with families to ask how they were generally and learnt of their needs in this way." – KEEN London [Small, vol funded, CYP services].

5.2.2 The extent of the need

The key realisation reported by charities was the complexity of need experienced by many of their clients – beyond the particular need that their organisation supported them with. Many participants in the research, even those with many years' experience of providing social care, were taken aback by how resilient and adaptable families were, and by the precariousness of many of their families' situations.

"[We saw] how tenuous some families' situations are and how much they had put up with for so long (inappropriate housing, insufficient or non-existent care packages, financial pressures). The cracks that were always there are now chasms, and we can only try and fill in the gaps."

– Shine [Medium, vol funding, CYP and carer services].

In addition, charities revealed the high demand for emotional support amongst parents (particularly from peers in a similar position) to maintain wellbeing and address mental health problems such as anxiety and isolation. These needs were present prior to the pandemic, but COVID-19 exacerbated and amplified them to the extent that several charities adapted their services in response (see 6.3).

Revealing increased and changing needs requires different resources and skills to meet them. It also requires an acceptance of where an organisation's strengths and weaknesses lie. This will be covered later in the collaboration competency (5.5).

"It's important to match audience needs to the capabilities an organisation really has - we need to be honest about what our strengths are. We are more likely to overstate what we can do as organisations - and we need to be honest about where other partners are stronger."

– Workshop participant

5.2.3 Key learning: Understanding the changing needs of children and family needs and increasing reach

Continue to gather and share insight

Most charities wished to develop this competency and maintain a closer, ongoing understanding of families' needs to ensure they were delivering the most impactful services. To help them do this charities mentioned the need to: ask and listen more, share insight within their organisation more effectively, allow time to analyse information (making sense of diverse feedback and identifying trends), evolve evaluation methods and be open to adapting approaches (discussed further in section 6.6)

Hear the voice of the young person

Most of (but not all) the young people interviewed felt that the charities they interacted with understood their needs. The age of the young people that we spoke to (20-25yrs) possibly led them to feeling

charities should commit to understanding the young person's needs first and foremost, as opposed to the families' needs.

"I feel like the priority should be about committing to really understanding the disabled person's needs, because I think if you understand those needs better, then that will automatically involve the family. Obviously, families are affected, but the person who is affected the most is always the disabled person" – CYP interview 1

Consider who you are not hearing from

Although not an issue particular to the pandemic, workshop participants commented on groups where it was harder to generate the required insight (e.g. BAME groups, and young people themselves rather than their families) and running the risk of always hearing from a similar profile of service users. To do so may require additional resources or innovative research methods.

Consider survey fatigue

In the workshops, some participants raised the concern that families may be feeling "survey fatigue" and that it is important to be able to demonstrate how insight gained has been used to deliver positive change. This would be a concern to address whenever research is taking place, and it may also be an issue for gathering monitoring data required for the agile ("test, learn and adapt") competency (see section 6.6).

"We have to feedback too - we can't just keep asking families for their thoughts on our services and expect them to come up with new things all the time. Eventually they will stop wanting to contribute unless we give something back."

– Newlife [Large, vol funding, CYP and carer services].

This may be more of an issue of how the insight is being gathered. In the focus groups, parents spoke of how charity staff and volunteers had conversations with them. Their recommendation would be that charities continue to have these conversations around their child's condition, related and possible co-conditions and needs, what services and support they're getting, and how they can support the whole family. These conversations tend to be very welcome and are not seen as prying or as box ticking. Parents and carers feel their circumstances are "very individual" and so conversations based on understanding their needs make sense to them and validate their knowledge of their own family and child.

There is perhaps a distinction to be drawn between insight aimed at understanding and clarifying need (which is generally welcomed) and monitoring feedback to collect impact data to measure if services are effective which may be more at risk of survey fatigue (covered 5.5).

Co-ordinate knowledge that already exists

Several organisations mentioned doing their own research during the pandemic (perhaps contributing to a feeling of "survey fatigue") and the workshops generated a discussion on whether it was possible to co-ordinate, review and share that insight. Some saw this as a role for the DCP.

"During the pandemic, things were so manic, and surveys were going out left right and centre because things were changing all the time. Families are exhausted from talking to organisations all the time and they are mentally overloaded, but we do need information from them in order to help them...so organisations like the DCP who bring together charities representing disabled people could be a good vehicle for bringing [that] information together."

- Shine [Medium, vol funding, CYP and carer services].

5.2.3 Conclusion: Being able to understand the changing needs of disabled children and families

Having a clear picture of children and family needs is vital for charities to ensure their services are effectively meeting those needs. During the pandemic, DCP charities have responded quickly and kept in touch with their clients to understand their needs – but what many discovered was the full extent and complexity of the needs families and disabled children face, and that their services would need to adapt as a result (some of these adaptations are covered in subsequent chapters).

That insight gathering experience has provided some useful considerations for how best charities can generate insight on children and family need including adopting a conversational approach, considering innovative research methods to hear from under-represented groups, and having a central repository of insight to draw on.

5.3 Have an increased focus on emotional support

As seen above, charities picked up very quickly on the emotional impact of the pandemic on the families they supported. Although emotional support would have been an important element of service provision prior to the pandemic, the situation families found themselves in required many organisations to expand their provision in this area.

"I think it was devastating. Those parents that had children who were being homeschooled on top of the disabled child, or with teens who were shielding and couldn't get therapy. Their stress levels were astronomically high."

– The National Bobath Cerebral Palsy Centre [Medium, vol funded, CYP and carer services].

"[In our survey] we always ask the children 'if you had a magic wand, what would you change?' And normally we get some brilliant responses like 'I would turn my doctor into a frog', or 'I would make the world out of chocolate cake'. This year the answers were much more depressing, 'I would make my mum and dad have enough money to buy us food,' and 'I would stop people dying.' I don't think we've even scratched the surface of what the impact on children's emotional wellbeing is going to be."

- Rainbow Trust [Medium, vol funded, CYP and carer services].

74% of respondents to the survey (38) agreed with the statement "During the pandemic, my organisation adapted its work to focus more on the emotional needs of families" with only 10% disagreeing.

"There was a huge swing to emotional support above all other types of support during the pandemic."

- Dingley's Promise [Medium, balanced funding, CYP and carer services].

"What we found six months in is that a lot of people wanted someone to speak to as they were stressed, angry, and upset. And our service became a bit of an emotional counselling exercise... and that was what ultimately informed the change to having a wellbeing focus."

- KEEN London [Small, vol funded, CYP services].

This increase, and particularly the dramatic increase in peer support for fathers, was noticed by the parents in the focus groups.

"I have to say thank God for them because, you know, they were at the end of the phone, you know, if I had a very bad day, I knew I could call them and talk to them about anything, but from social services, [I had] no help whatsoever"

- Parent, focus group.

5.3.1 Supporting emotional wellbeing

The research revealed that DCP charities developed

many innovative and creative ways to support their families' mental health and wellbeing – from developing new services (virtual groups and events, podcasts, being outside in nature, having "walk and talk" sessions with support workers) to providing therapy sessions and developing peer support opportunities.

"We created a listening ear telephone service to support parents struggling emotionally and looking for strategies to cope. Or maybe they just need to talk to someone who understands the extra challenges they face and who can point them in the right direction to get the support they need for their family."

- Contact [Medium, balanced funding, Carer services].

Young people also felt that emotional support was addressed by charities continuing to provide services (particularly online peer support) and providing engaging activities.

"They started off with Zoom, by doing a Bingo Night and a quiz night. And then they sent this thing through the post like craft activities, scavenger hunt to do out and about when we were allowed our one hour exercise a day."

- CYP interview 2

Another approach was to provide practical support to alleviate emotional distress and anxiety. For some organisations this manifested itself in a desire to ensure existing services were kept open with minimal disruption. For others this meant providing support and resources to resolve tangible problems that would lead to emotional distress if they were not solved. There were many examples of this commitment to provide practical support taking charities and services beyond what they would have considered their "remit", or indeed "comfort zone" – such as shopping, topping up pre-paid gas cards, delivering breast milk to hospitals, and delivering food parcels and medicine.

“We continued our face to face services through the pandemic so for many of our families little changed. There were a few families that fed back that we were the only place they felt supported, so I guess that was extra emotional support.”

– White Lodge [Medium, statutory funding, CYP services].

5.3.2 Financial support

In a similar way to the practical actions described above, helping families in dire financial difficulties would be another way for organisations to alleviate emotional distress. However only 19% of respondents (38) agreed with the statement “During the pandemic, my organisation adapted its work to focus more on the financial needs of families” – 54% disagreed.

Those charities that did provide services in this area distributed emergency relief funds and food parcels, provided services for free and supported families to access benefits and apply for grants – but for many charities supporting financially was considered to be “outside of our remit” whereas other types of support described above and aimed at achieving a similar outcome (alleviating emotional distress) were perhaps more acceptable to provide.

5.3.4 Measuring the impact of emotional support

Unless organisations were already routinely gathering indicators of emotional wellbeing, the research did not reveal much evidence of charities being able to measure the impact of this increased focus on emotional support. Several factors may explain this including the changed context in which the support was being provided and measured, and that some organisations may have lacked the relevant monitoring tools (although there was mention of the Warwick Edinburgh Wellbeing Scale and The Five Ways to Wellbeing toolkit).

“Previously we have monitored outcomes around reducing isolation. Well, those went out the window because everybody was isolated. Our isolation measures went up with online support, because

families were feeling at least it's somebody else coming into the room.”

– Rainbow Trust [Medium, vol funded, CYP and carer services]

5.3.5 Key learning: Providing increased emotional support

Most organisations wish to retain an enhanced focus on emotional support and continue many of the services and activities introduced during the pandemic, not least because many see a prolonged, adverse impact of the pandemic on families of disabled children.

“We are currently looking at how we can take forward family peer support in a sustainable way and we're also looking at developing a new dedicated counselling service to provide more in-depth support.”

– Together For Short Lives [Medium, vol funded, carer services]

Interestingly, the emotional impact of financial pressures and poverty was cited as a growing concern for the medium term, perhaps indicating a need for some charities to review their remit or approach when it comes to responding to financial need.

“The demand for this (financial) service has skyrocketed as we see families and young people needing support to apply for benefits whereas they might have avoided doing so in the past - but they are now desperate. We are seeing increasing financial poverty needs of families.”

– Amaze [Medium, balanced funding, CYP and carer services]

Some charities also recognise they need to improve how they measure their impact on emotional wellbeing. Outcomes monitoring may need to become more person centred – focussing on the goals the individual wants to achieve rather than those determined by the charity or service.

One piece of feedback from parents for charities to consider when offering emotional support was that it might not be for everyone, and parents may wish to choose their level of engagement. At times of intense pressure, some parents felt too personally fragile to actively engage with the offer of emotional support, for fear of not being able to continue to support their child and family.

“Personally I’ve avoided it. I feel I’ve got to keep it together. Because I thought if I open this up, my concern is that my feelings, you know it’s going to overflow”

– Parent, focus group

5.3.6 Conclusion: Having an increased focus on emotional support

DCP charities responded very well to the evident need for emotional support by providing a range of support options – from opportunities to talk and share, counselling and peer support to providing practical support to tackle some of the causes of emotional distress - including just keeping their services open.

Whereas charities are very comfortable adapting their work to support families emotionally, there is less appetite to support families financially, despite the fact that the pandemic has, and will continue to increase the financial burden on families with disabled children and is clearly a source of emotional distress.

If charities do want to be truly responsive to children and family need, the stance that financial support “is out of our remit” may need to be revisited by some.

5.4 Maximising the benefits of online

service delivery

Moving online was the main way that most charities were able to provide some element of support during lockdown and when families and young people were shielding, or unable or unwilling to access physical venues. 81% of charities responding to the survey (36) moved some aspect of their services online during the pandemic – 19% did not.

In many ways this pivoting to online support was something that charities had been planning but its implementation was vastly accelerated by the urgency of the pandemic. Several organisations were proud of just how quickly they were able to develop an online service offer, and many organisations have gained new service delivery skills as a result. Some charities reported being able to reduce costs (e.g. travel costs and venue hire) by migrating certain services online.

5.4.1 The benefits of moving online

Keeping in touch

It is perhaps important to remember the context that, with the unavailability of other support, parents and young people would have been very receptive to any kind of help and support.

Young people reported that online provision had helped their mental health and provided them with a chance to stay in touch with friends (especially new friendships made due to the extended reach of online services), who they would otherwise be geographically isolated from.

Parents in the focus groups were also positive about their online experience – it gave them some respite if their child was occupied with an activity, it reduced their feelings of isolation to see others in similar positions to them, and the effort charities made to put things in place reassured them that they were “not just forgotten about.”

For organisations, as we have seen above (5.2), online communication was one of the ways they were able to contact families more frequently and fully understand their needs.

Increased flexibility and personalisation

46% of organisations who did move online (29) agreed with the statement “Moving our work online allowed my organisation to deliver a more tailored, personalised service to our families” – 18% disagreed.

Several organisations found it easier and quicker to develop new content and services online responding to children and family needs more promptly. Others replaced face to face group work with one-to-one online support allowing more space and time to explore issues on an individual basis.

“We delivered an online project that paired a CYP with a volunteer. Having that sole contact, 1:1 support meant that every session was tailored to the needs of that individual child, which is more difficult to do at a group session. Working with the same volunteer every week also enabled a relationship to build and more successful solutions to challenges were found as a result.”

– KEEN London [Small, vol funded, CYP services]

Other examples of services being adapted online included activities (such as keep fit, cooking, arts and crafts and music), advocacy and legal services and behaviour workshops.

This flexibility and personalisation are highly valued by parents and carers. For example, the mood (and therefore receptiveness) of their child at the time of the online contact is a crucial factor; meaning choice and flexibility about when the service takes place is extremely important to parents and carers. Some mentioned this also applied to their own mood as parents.

Parents also value online sessions where things can be slowed down enough so every child participating can follow and contribute at their own pace. Importantly, parents preferred online sessions to be shorter two-way conversations rather than being too long, complicated, therapeutic or didactic.

“The fact we provided them [our sessions] flexibly at different times of the day and for shorter periods, meant more families could attend”.

– SIBS [Small, vol funding, CYP and carer services]

Increased reach and engagement

The flexibility and convenience of online provision enabled DCP charities to reach more families. 83% (29) agreed with the statement “Moving our work online allowed my organisation to reach groups of people we hadn’t reached to the same extent before.” Only 10% disagreed.

Those groups included those living in areas not previously covered by face to face services, working parents (who were working from home), fathers (with couples engaging more than previously), families with more complex needs, and those living in remote areas or who find travel difficult (i.e. those who were isolated before the pandemic). This extended reach was noted by parents in the groups who felt that because the charities were “In their home” the whole family – including siblings and fathers - was receiving support.

“We were really pleased that we were able to reach those families and spoil them. We also had families that we didn’t know about. So there were a number of children, young people who were absolutely Sense families, and we thought, ‘how do we not know about these children?’ So this was a really effective way of increasing our reach and improving our engagement.”

– Sense [Large, vol funded, CYP and carer services]

“[We reached] families whose children had more complex needs, who often can’t make it to sessions when they are poorly or unwell. This is also for the parents who wouldn’t be able to attend parent training, counselling sessions, or Face to face advice as they would need to care for their child. We have also reached families who find travel difficult, due to the needs of their child, and so can’t access the Centre.”

– SNAP [Medium, vol funding, CYP and carer services]

5.4.2 Challenges with online provision

Alongside the benefits above, there were also drawbacks to online provision.

Online doesn't suit all groups

As with face to face delivery, online delivery is not necessarily for everyone. 81% of survey respondents who moved online (27) agreed there were some groups they couldn't reach as well online. Families need reliable internet, digital skills, accessible content and platforms, guidance on supporting children and young people (Bradley, 2021) include families without professional digital experience, minority culture or linguistic groups, and rural communities who have adapted to patchy connectivity.

These included families with more chaotic lifestyles, and those for whom English is a second language, those in "digital poverty" (either with no equipment, sharing devices, or concerned about the cost of data), those in areas with poor internet connection (such as rural communities, Bradley 2021) those who felt they were online too much (with working from home, home schooling etc), some older people, very young children, some people with multi-sensory impairment and those who just chose not to engage that way. Materiality and touch are important aspects of connection, that are even more essential for some people. Physical components within digital services can improve engagement and combat screen fatigue (Bradley, 2021).

There was one particular family that when we were doing the setup call with them and testing, it became clear quite quickly that they were actually in a library and accessing IT there which, obviously, wasn't appropriate."

– Brainwave [Medium, vol funded, CYP services]

In addition, parents noted that sessions with too many participants could be too overwhelming for some children, especially when it was important for them to clearly see faces to communicate. This point was echoed by the young people interviewed.

[We] had a Zoom with a massive group of people, over 15 people on a screen and that was quite hard. It was quite a lot to take in. If you're going to use Zoom then you might have to think about like splitting groups and narrowing it down not having one great group."

– CYP interview 2

Organisations were resourceful in how they maintained a service to these groups who found it harder to engage online with some providing equipment and training to use it, creating pre-recorded sessions to play at a more suitable time, continuing to support through phone and mail, and returning to face to face services as soon as possible (for those who wanted to).

Online doesn't suit all types of service

Services that required being outdoors, physical therapy, close observation or palliative care were more challenging to transfer online – some charities decided to continue with face to face, others found innovative ways to keep some delivery in place.

"Each of our parents said, 'online is not going to work for us, we need respite. The primary reason why I use your service is to have a meaningful break from my child. And so if you do an online session, I'm still going to have to be there with them. It just isn't going to work.' So it didn't make sense to put the effort into online, it made more sense to put the effort into keeping us open and jumping across the hurdles and barriers that were in front of us. And it worked."

- Cherry Trees [Medium, stat funded, CYP services]

"One of our family support workers has done some incredible work with a little boy with a puppet. The worker is not visible, it's the puppet who's done it all and the worker said that would never have worked before. Now she's beginning to see this boy face to face again. She's had to come up with a story that the puppet gets car sick so the puppet can't come. The little boy knows it's a puppet, of course he does, but there's a different element of magic that you can have when it's online."

- Rainbow Trust [Medium, vol funded, CYP and carer services]

In some cases parents had been supported remotely to conduct physio sessions for their children – this was seen by some as a positive with parents learning new skills. Although some therapists initially questioned the efficiency and thoroughness of the approach, over time they have accepted that it has a place in the child's support.

Online is not necessarily cheaper

Workshop participants were keen to challenge the perception (perhaps held by funders) that online provision is cheap. With increased reach (5.1.3) comes increased demand for services – whilst the short-term cost of this has, for some, been covered by emergency COVID grants, charities expect the demand to continue into the medium and long term.

By introducing online services charities are expanding their delivery model – adding online components where they can best meet children and family needs

and providing service to more people. So there is a cost (time, process development, staffing and technology) in implementing a new online approach. Many respondents also highlight that charities need to demonstrate a good grasp of the legislation and strong protocols around online safeguarding to ensure that they have the capability to deliver services safely in ever-changing circumstances.

"We will still have to work as hard as we are. Normally in a sensorial session, I've got a couple of members of staff in a session, but now I've got to have someone else on Zoom, interacting with those families. So it's going to take a lot more staff."

- SNAP [Medium, vol funding, CYP and carer services]

Measuring the impact of online provision

At the time of the research, few charities were able to articulate how the outcomes generated by services delivered online compared with the outcomes generated when the same services were delivered offline. Going forward it will be important to be able to answer the question – in what circumstances do the benefits of online implementation translate into quality outcomes for families? Some organisations mentioned that their existing measurement processes were not yet adapted to the new online provision.

"We actually didn't gather much evidence at all because our evaluation was set up for somebody attending a six-week training and so the baseline and exit surveys that we give them weren't actually relevant to someone that's coming to a two hour online workshop"

– Scope, [Large, vol funded, carer services]

When it comes to increased personalisation or reaching new children and family need most charities were not yet able to describe whether these new approaches or supporting these new groups had affected the charities' ability to achieve their desired outcomes, although anecdotal feedback received was generally positive.

"Feedback from families has been excellent - they have liked the online format and flexibility of the approach. They have appreciated the regular contact and have felt more connected and better supported as a result."

– Sense [Large, vol funded, CYP and carer services]

"Dads felt they were less isolated and that they had a connection with other dads that understood them. They could share their worries, which they often had to hide."

– Together for Short Lives [Medium, vol funded, carer services]

5.4.3 Key learning: a blended or hybrid approach

A well-supported approach as it provides increased choice

Most participating charities had the sense that families want organisations to continue with online support and most wish to retain the benefits of online provision (flexibility, accessibility) alongside some of their face to face work – this is described as a “blended” or “hybrid” approach. For most this means supplementing existing face to face services with digital support and/or developing a digital offer that may (or may not) be supported by face to face delivery.

"Hybrid delivery will ensure our services are as accessible as possible, supporting more disabled children and their families both in the UK and globally."

– Flamingo Chicks [Small, vol funded, CYP services]

"I think the hybrid approach is good if it is done well. Hybrid is hopefully the future of doing stuff, and generally one of my mottos is that people should be able to work and access services in a way that suits them. So, I think hybrid and the fluidity is good."

– CYP interview 3

Young people were concerned that online support may stop once life returns to a more normal state and would like to know charities' plans so they can prepare themselves. The young people interviewed also wanted to have a say about what services are online or face to face. Ideally, they would appreciate a combination of online and face to face as most acknowledged that attending regular face to face sessions is not always possible if they need to get a lift there or it is far away. Therefore, running weekly online sessions and monthly face to face ones means they would be able to plan the in-person sessions into their schedule – as there is strong desire to retain them.

"Absolutely, we should have a say in it, as just because it might be easier for the organisation it might not fit the group. Not everybody likes online, some people only like face to face, it's very important that you should ask your group members."

– CYP interview 2

Almost all the parents in the groups were very positive about a blended approach as online delivery had given them flexibility, more control, and reduced “hassle”. The key issue for parents is choice. They know their child and family circumstances best and they know that online provision might be better one day and face to face might be better the next. That isn't to say that they expect charities to provide a choice of accessing services every time. Parents and young people are realistic and know that isn't feasible and they are reluctant to demand too much from charities in terms of customisation. In short, parents and young people want online provision to continue as it adds to their options for accessing services.

"Parents have said to us whatever happens when you're back in the Centre [face to face], please we need an online element to this group, because nine times out of ten our kids are too ill to come. It is great knowing we can Zoom in from a hospital bed, and still see friends and see the team that we know."

- SNAP [Medium, vol funding, CYP and carer services]

"It depends on (my daughter's) mood. For me it doesn't matter if we have to take the child to a centre, it's fine. If you want to do a Zoom, I mean it saves a lot of time actually to be fair, but I think that interaction is important as well"

– Parent, focus group

"Some families were very keen to come back into the house. Others didn't feel confident, they are too anxious and they ask 'can we keep online for a bit longer?' And that's where I think this blended approach is going to work. It's good we potentially have an option, so it's not face to face or nothing."

- Rainbow Trust [Medium, vol funded, CYP and carer services]

Consider online fatigue

Some organisations warned against "online fatigue" commenting that some families were growing tired of it, opting for face to face interaction when opportunities to access it were increasing. Some parents did mention that sometimes the 'event' of getting out of the house - although it could be a hassle - was a benefit in and of itself, in addition to the reward of accessing face to face interaction.

However the concern about "online fatigue" was not shared by the parents in the groups (although these were a group of parents who had agreed to take part in a Zoom interview). They saw online provision as inevitable both in lockdown and for the foreseeable future, and they are happy to cope with any fatigue or frustration as they felt it was just "part and parcel" of being able to access support and services in the current environment.

Consider whether what worked in an emergency will work going forward

In the workshops, some organisations raised the concern that an emergency online offering, put in place so something could be offered rather than nothing, may not be the same as a more considered online offering – so charities should take the time to review and not simply continue "as is". Some of this concern was also reflected by young people. This may well be a topic for the "test, adapt and learn" competency described below (section 6.6).

"We have launched a strategy around how digital is front and centre of the way that we are going to continue to support families and reach families, but we haven't tested that properly yet. So we have come up with a hypothesis and we've seen increased engagement, activities have been received well and positively, but that is in the middle of a pandemic with families who are still social distancing...I feel nervous and uneasy that we haven't tested it in the longer term, and whether there will still be the reliance and expectation around digital support."

- Sense [Large, vol funded, CYP and carer services].

"My main piece of advice for any charity, to be honest, is don't try to go hybrid just because that's the trend, if it doesn't actually make sense for your organisation."

– CYP, interview 1

Workshop participants were also keen that funders know that the online provision charities have put in place shouldn't be considered the norm simply because it was well implemented to fill gaps in other provision.

“A lot of the things we’ve talked about today, charities have picked up because government services have failed. How do we ensure that this doesn’t become the norm? Just because we’ve had to step in doesn’t mean we have the funding or the expertise or the remit to do this in the future.”

– Ambitious About Autism [Large, stat funded, CYP and carer services]

5.4.4 Conclusion: A blended or hybrid approach

Charities, parents and young people all welcome the introduction of online channels into service delivery albeit for slightly different reasons. Organisations value the opportunity to offer tailored services and reach more people. They also demonstrated some tremendously creative approaches to adapting offline services online. Parents welcome the choice it gives them to access services if circumstances change. Young people also value the flexibility and the chance to retain social contact with peers more easily. However, there is some work to do to effectively measure the true impact of online services.

Online provision doesn’t suit all services or all service users – so a blended approach is recommended rather than transposing what was done face to face online. Therefore, it is an expansion of service provision rather than a cheap replacement and it requires funding and more development seeing it was, in the main, introduced when face to face services weren’t available.

Parents and young people are pragmatic enough to know that not every service offer will be able to be accessed online and face to face – and young people especially would welcome some close involvement in developing how the blended service develops.

5.5 A more collaborative, holistic approach to meeting needs

We saw above (section 5.2) that through increased communications, charities understood families’ wider needs even more clearly.

“What has been coming through to us has been the really multi layered complex things where people just can’t solve because everywhere they look there’s a problem. So you know people in a domestic abuse situation that have a disabled child. Where the housing is poor, where they can’t get the necessary NHS treatment because they keep having to move around because of their partner, where it’s just too much to fight on your own.”

- Shine [Medium, vol funding, CYP and carer services]

In the focus groups, each parent mentioned at least two other charities they were involved with. Their overarching assumption is that it’s their responsibility to ‘join up’ services and support for their child. For parents, the most helpful and “pioneering” charities are those that, rather than just focusing on the core service they deliver, prompt families to consider other needs their family might have and facilitate them to source additional support from elsewhere.

“Disabled people are more likely to end up in a host of different vulnerable situations, such as homelessness, educational problems, exploitation, so I think any charity that doesn’t have links to organisations that help with these things, is failing.”

- CYP interview 1

To offer more holistic support, charities needed to work with others. 74% (34) of respondents agreed with the statement “The pandemic led to increased collaboration between my organisation and other organisations”. Only 12% disagreed. This collaboration involved DCP members joining networks and consortia, developing new delivery partnerships and staff being able (through online working) to attend national meetings.

5.5.1 The benefits of increased collaboration

The impact of this collaboration was, in some cases, profound – as charities, taken aback by the complex needs of families (see 3.2), realised that working on a single issue (however serious) was not necessarily going to guarantee positive outcomes for children and families and more holistic, family centred solutions were needed. Many charities reported accessing other skills and resources, developing strong referral and signposting processes and conserving resources by reducing duplication.

“I think working with other organisations could help prevent duplication of the offer or a more consistent delivery, but I guess it is about if it makes sense and there is a tangible benefit for us, then it is worth exploring.”

- CYP interview 3

“We collaborated with other LD and autism focused charities to make sure families got the support they needed from the organisation that could help them most.”

- Contact [Medium, balanced funding, Carer services]

“Our workers tend to be home based but they have big patches to cover, so if we are working with another organisation and they are able to go and visit a family face to face and we can't, then we will use that opportunity to give a service to a family that we couldn't provide.”

- Shine [Medium, vol funding, CYP and carer services]

The need for this approach was echoed in the workshop and by young people who commented that being more flexible and turning to partners was considered the “smart” response and an indication of an organisation “doing their job properly.”

“Organisations do need to try to be less protective of their own work and be more open to finding [other]

organisations best placed to help with a particular issue. If you're protective then collaboration will be challenging, but if you think about being family centred, then it shouldn't be about competing in the funding market as it always needs to be about providing the best service for the family.”

- Rett UK [Small, vol funded, carer services]

“I think moving from a fixed ‘this is what we offer’ to being more about keeping in mind what people want themselves going forward is important.”

– CYP interview 3

5.5.2 Barriers to increased collaboration

Those unable to forge new collaborations during the pandemic cited having to focus on their own fight for survival and/or seeing potential partners close their doors. Others mentioned the senior management time it takes to develop trusted partnerships, which was in short supply during the pandemic.

Funding

Several organisations mentioned funding structures not facilitating effective collaboration. When organisations are funded to achieve certain outcomes, they are motivated to ensure they take credit for them.

“I think there's lots of very siloed funding by government and local authorities – ‘you deliver this service for us in this way, and that's all you do.’ When I think the third sector works at its best is when funders say, ‘this is the problem to solve, tell me how you're going to solve it’ and we come together.”

– Shine [Medium, vol funding, CYP and carer services]

Culture

In the workshops more fundamental barriers were raised, including the tendency for some organisations to prioritise the delivery of their own plans over spotting opportunities to provide more holistic solutions with others. Participants spoke of the need to move from charities referring to clients as “our families” and thinking of them instead as families that receive services from them (as well as others).

“With all the new issues that emerged because of Covid and that you want to respond to, you want to collaborate where you can, but you’ve got a strategic plan and you are held to account when it comes to it, you’ve got your governance structures and trustees. So, you might have really good ideas from the bottom up and start to think about who to partner with, but by the time you’ve tried to work through your internal systems and move it up, there are blockers along the way that get in the way of the need and responding to it.”

– Unnamed [Large, vol funded, carer services]

“This requires a change in culture so that partnership working is hard wired into the organisation’s ways of working even more.”

– Ambitious About Autism [Large, stat funded, CYP and carer services]

Getting referrals right

From a parent’s perspective, increased collaboration has to come with clear, simple and smooth referral processes so that busy, stressed parents and carers don’t get confused and waste precious time contacting the wrong people. For example parents and carers talked about being very intimidated when given a list of organisations to contact on their own. Having a trusted and known charity taking some of that load off them (e.g. providing guidance on who to contact, what to say, or even arranging a call from the relevant person) is very highly valued.

In a related point, organisations themselves need to

identify others who are best placed to help and work together to assess the overall state of provision which may include both duplication and gaps.

“Lots of people are doing the same thing and there is no coordination of that. And we know that families are overwhelmed as it is. There is such a crossover of services. There is loads of good work going on. But I think there is also duplication and, at the same time, gaps in services”

– {KIDS, large, statutory funded, CYP and career services]

5.5.3 Key learning: A collaborative approach

The workshops develop a concept around DCP members sharing their top (say) three skills or strengths with the DCP – who could then share the results with members, who would then know who to approach when they recognised their children and family required certain support that they were unable to give.

Ideally this concept would be developed beyond DCP organisations as members encountered several non-disability related issues that affected the quality of life of the disabled child (e.g. housing, legal expertise, poverty etc).

5.5.4 Conclusion: A collaborative approach

The DCP is representative of the range of needs and support across the disabled children’s sector, working across health, social care and education. It can play a role in continuing to share and disseminate specific initiatives that have been effective in meeting the needs of disabled children and families and in sharing good practice and resources of how services, run by DCP organisations, are reconfigured to meet current and future needs.

The complexity of need uncovered by the pandemic requires a holistic approach led by children and families. This is an approach desired by families, young people and charities but it is very hard to realise.

Funding structures, organisational cultures and the time required to develop relationships and assess the quality of others' services are all obstacles in the way of effective collaboration.

5.6 An agile approach to service design and implementation

When applying for funding, charities often need to describe what they are going to do, what outcomes they will achieve, who they are going to work with and how much it will cost. This is to give the funder confidence their money will be spent as intended. To increase their chances of receiving funds, charities often turn to "tried and tested" methods that can demonstrate good outcomes.

This funding process relies on circumstances remaining the same throughout the project, which may be multi-year. What COVID has made clear is that circumstances change, and unforeseen barriers can stymie planned delivery. It also demonstrated that charities are highly proficient in adapting to change whilst maintaining positive outcomes for families.

The new landscape demands more of this agile approach to service design and delivery with more innovative and risky services being tested and adapted following regular formative input from users.

The workshops revealed that smaller organisations found it easier to adapt and change and become more customer-focussed whereas some larger organisations with more rigid processes and approaches to service delivery found it harder to be as agile.

"Because of the Covid situation we have had to experiment – before that we would have never, across the sector, moved in this direction. What do they say,

necessity is the mother of invention – that's probably a good analogy of what we've all had to do."

– [Workshop participant – Afasic]

"So it's now about what our families need, and central services need to support our services to deliver that. IT were being very focused on 'these are the systems you have to use', but you know, actually, our families don't want to use Microsoft Teams, they want to use Zoom – that was a bit of a battle but there has been a real culture shift."

– KIDS [Large, Stat funded, CYP and carer services]

5.6.1 The requirements for an agile approach

Involvement of service users in designing the service

Most charities were able to do some (although limited) consultation with users when they developed their COVID response services. Clearly effective input from users is vital at the outset of any service design. Young people in particular feel strongly that they should be co-creators in the design and delivery of services that affect them.

"I like the service because we get to have our voice in it, we get to have our say in sessions, and we get to say what we like to do, and, if we don't want to do things that's fine. There's no pressure, it's all very chill and no stress. We get a say in how we want our information delivered to us." – CYP interview 2

Monitoring to “test, learn and adapt”

To implement an agile “test, learn, adapt” approach, ongoing active monitoring of both outcomes and processes is key – services need to hear promptly what is working, or not, and for whom. As noted previously, securing feedback may, in some cases, be challenging and it requires resource.

In the interviews young people offered charities advice for how to request their feedback:

- Be more explicit about why you are asking for feedback
- Explain “what is in it for me?” - how will I or other young disabled people benefit?
- What positive changes will come about because of my feedback?
- Share the results around outcomes
- Don't ask me to explain something I've already explained – it feels like you are not listening to me
- Make it accessible – not just a text-heavy survey, ask for verbal or video feedback too
- Use volunteers with the condition to do the research

“My advice (for organisations) would be to keep asking us about how it's going, how are we finding [the service]? Are there any changes that they do to make it better? But keep asking us - just because they asked us at the beginning of the pandemic, we might not like it now.” - CYP interview 2

Flexible funding

Before the pandemic charities and funders were accustomed to a structured approach to service design and delivery, founded on a robust evidence base and validated measurement tools. This approach gave funders and charities a “safety blanket” that enabled them to justify that money is being spent responsibly and effectively. This formality probably

applied more to larger charities than smaller ones, who generally find it easier to be agile.

A more agile, “test, learn and adapt” approach to service delivery doesn't suit that more formalised approach. With a changing context and more complex and changing needs, charities may not have the upfront evidence funders require for what intervention would work best, and there may not be enough time to develop things to such a detailed extent.

If a funder wants to support projects that are well-researched, evidence-based and with certain outcomes, then charities will not be able to propose more agile “test, learn, adapt” service development approaches. This is also true of the need to collaborate above (6.2.1). The workshops revealed some examples of a lack of flexibility from funders.

A key issue here is the level of evidence a funder is willing to accept to give them confidence the project is progressing well. Clearly “academic” style randomised control trials or systematic reviews are less useful in the context of an agile approach. More rapid review style, formative, empirical and experiential methodologies including customer journey mapping, online research communities and journaling through video or verbal dairies are going to be more appropriate sources of data to make decisions.

“What tends to happen with funders is that you have to decide who your partners are at the beginning. This doesn't allow for much flexibility.”
– Scope, Large, vol funded, carer services]

Some organisations had had experiences of flexible approaches by funders during the pandemic, although some wondered if this would continue as we come out of the pandemic.

“If you’re part way into a piece of work and something comes up, then it’s about talking to the funder. We’ve found our funders have been really flexible throughout the pandemic, as long as you communicate with them.”

- Rett UK [Small, vol funded, carer services]

A key issue here is the level of evidence a funder is willing to accept to give them confidence the project is progressing well. Clearly “academic” style randomised control trials or systematic reviews are not possible in the context of an agile approach. More rapid review style, formative methodologies including customer journey mapping, online research communities and journaling through video or verbal diaries are going to be more appropriate sources of data to make decisions.

More acceptance of risk

The ability to take risks, work quickly, gather data, accept failure, change approach, redeploy resources, and motivate staff are all important skills for a manager implementing the agile “test, learn and adapt” approach.

“So the government would announce mandatory wearing face masks, we then need to get an easy read document together on that. In normal circumstances, we might take a couple of weeks to write it and various people would submit comments, and we’d plan it and review it. But it needed to be out on our website by the end of the day. So something that might have taken a fortnight to produce we got done and dusted in three hours.”

- Downs Syndrome Association [Medium, vol funded, CYP and carer services]

I know that if I had suggested doing the sessions that we do now to my team, and it wasn’t a pandemic, they would have been, like, absolutely no chance at all. You know, we just had to try it, we did things that were riskier, to our organisation - things that we have held back on doing in the past,

because we were too afraid. I’ve learned a huge amount as a manager. People have been way more open minded about how change can work. You know, because it was, ‘okay, we’re going to try doing this thing, and you’ve only going to have a couple of weeks to decide if it works or not.’ So you’ve got to put a lot of energy into it to find that out.

– KEEN London [Small, vol funded, CYP services]

5.6.2 Key learning: An agile approach

Having seen it work in the pandemic, organisations would like to adopt a more agile approach to service delivery more often. In broad terms they lay the blame on not being able to do so on funders, revealing another potential role for the DCP, impressing on funders that funding arrangements need to allow organisations to be agile and that funders may need to accept different types of evidence to fund projects and demonstrate project effectiveness.

There is also a possibility that evaluation teams within charities themselves may also need to be more comfortable using more user-friendly data collection methods as opposed to more academic validated scales which can “confuse” clients.

5.6.3 Conclusion: An agile approach

The pandemic saw the disability sector at its agile best – realising a need, quickly implementing solutions and reviewing them to check they worked. Organisations overwhelmingly want to retain this approach of continuous improvement by testing, learning and adapting. This will require organisations to be more comfortable taking risks and basing decisions on less than complete data sets. However, the advantage will be continuously improving services, relevant to the changing needs of disabled children and families.

Chapter Six

Conclusion and
next steps



6.1 Key findings

- Children and families have been isolated and abandoned; and not listened to
- COVID restrictions meant services were stopped or reduced; and many are still slow to return
- Mental health and wellbeing of all the family has deteriorated
- Children's conditions have worsened and needs become more complex; delays in assessments mean needs haven't been identified
- Charity sector demonstrated agility and flexibility and was able to extend its reach to help support families

6.2 Call to Action: Recommendations for charities, funders and the Government

In light of the significant detrimental impacts disabled children and their families have experienced throughout the pandemic, all agencies need to step up and take action if they are to have the same opportunities for recovery as their peers.

This section sets out five steps for Government, Charities, the DCP and Funders to take to create a brighter future for disabled children and their families

6.2.1. Five Steps for Central and Local Government

Prioritise meeting the needs of disabled children and their families within covid recovery plans and programmes.

To achieve this:

Prime Minister to appoint a Minister with clear responsibility, accountability and power across departments to make sure that the right support from health, social care, education and other services is in place for disabled children and their families

Tackle the backlog in assessments and ensure that children's needs are re-assessed in light of missed support during the pandemic

To achieve this:

Department for Education to put in place a plan to support local areas to tackle the backlog of assessments, including funding and training, and to publish data on the number of overdue assessments

Ofsted/CQC inspections to consider local progress in tackling assessment backlogs and the quality of needs assessments

New Integrated Care Boards to ensure needs of disabled children and families are a specific element of Joint Strategic Needs Assessments and take into account the differing needs and circumstances of different families, including those from black, asian and minority ethnic backgrounds

Ensure the right support is in place for all children and families, including education, health (including mental health), therapies and equipment

To achieve this:

The SEND review must be clear about Government expectations in relation to meeting the needs of disabled children across education, health and care and how it sees these being implemented locally

This should include clear expectations for local areas to fully involve disabled children and their families in assessing whether the right support is in place

The Children and Young People's Transformation Board should take an oversight role in the provision of therapies for disabled children to ensure they return to pre pandemic levels and are sufficient to meet children and young people's needs in the future

Department for Education and NHS(E) should review the sufficiency, quality and sustainability of the workforce across public services for disabled children and their families

Ofsted/CQC inspections to hold local areas to account for quality of provision both for pandemic recovery and 'business as usual', with clearer and stronger intervention powers if there is insufficient progress following a Written Statement of Action

DfE/NHS(E) to develop and implement clear commissioning guidance and models for local areas, across education, health and social care

The Health and Care Act to strengthen both the health service role in, and accountability for, joint commissioning through - clear guidance to local Health and Care Boards; data collection and monitoring at a local level; and assurance measures at a national level

Take a whole family approach to assessments and support, including siblings. This should include the provision of respite/short breaks and opportunities for families to take part in activities to overcome the isolation felt by so many

To achieve this:

The Independent Review of Children's Social Care should make specific recommendations on how best to support the whole needs of families with disabled children

Councils and Clinical Commissioning Groups/Integrated Care Boards to ensure the range of short breaks/respite provision includes the specialist provision needed to meet the needs of disabled children and families

Government to introduce a programme for disabled children, young people and their families similar to the DCMS Digital Lifeline Fund so that they have the equipment, support and opportunity to use a digital service, to measurably grow their digital access and skills and to benefit from broader range of interventions and services both on-line and with blended model of support (across virtual and face-to-face) in the future

Invest in services through the Comprehensive Spending Review

To achieve this:

HM Treasury should address historic underfunding, and ensure funding is sufficient to meet the current and future needs of disabled children and their families, in particular focusing on areas of highest unmet needs such as short breaks and respite care.

Department for Education should prioritise disabled children and their families within Covid recovery programmes, in particular to address the impact of missed therapies and health support, and to overcome the emotional and mental health impacts of the pandemic on disabled children, their sibling and their parent carers.

Department for Education should create a dedicated Disabled Children's Innovation Fund, to support and develop best practice in cross service support to families and demonstrate the long-term cost effectiveness of providing the right support at the right time

6.2.2 Five Steps for charities

This research has identified five key competencies common to effective responses from charities during the pandemic. Charitable organisations should work to embed these approaches in how they work going forwards to best meet the emerging needs of disabled children and families. This will reflect a shift in working practices and culture for many and build on what has worked over the past year:

1. Charities should increase their capacity to be able to understand the changing needs of disabled children and families
2. Charities should increase their focus on delivering emotional and financial support to families
3. Charities should ensure that they maximise the benefits of online service delivery
4. Charities should adopt a more collaborative, holistic approach to meeting needs
5. Charities should adopt an agile approach to service design and implementation

6.2.3 Five Steps for the Disabled Children's Partnership

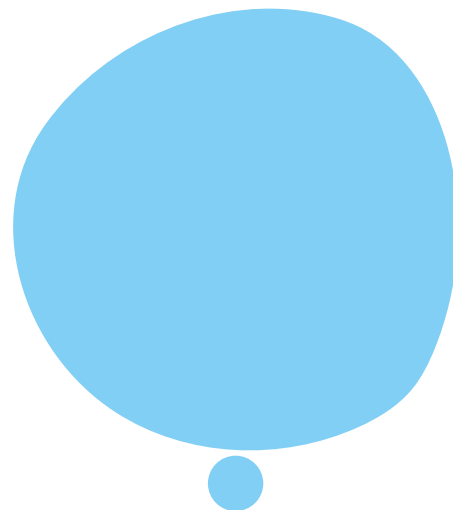
The sector evaluation highlighted the important role that the DCP played during the pandemic, as a source of information and updates and as a powerful lobbying body that was able to bring together the experience of its range of member organisations into a unified voice.

Going forward, the DCP should:

1. The DCP should maintain a central repository of insight into the changing experiences of disabled children and families, for policy makers and charities to draw on to support their own work with families
2. The DCP should bring together charities to explore in more depth the practical application of the competencies identified in this report, including exploration of the barriers to good practice
3. The DCP should continue to work inclusively to harness opportunities for collaboration, including sharing and disseminating particular initiatives that have been effective in meeting the current and future needs of disabled children and families
4. The DCP should continue to draw on the expertise from its range of members to unite charities and families to raise awareness of the issues facing disabled children and their families and to lobby for change
5. The DCP should encourage funders to take a holistic approach to support for the sector - by demonstrating the vital role different organisations play, how needs are currently met by the sector, and by highlighting the gaps in service provision experienced by disabled children and families.

6.2.4 Five Steps for philanthropists, charitable foundations and funders

The pandemic, and the resultant reductions in support for children and families, have led to an increased complexity in the support needs of disabled children and their families and high and increasing levels of unmet need. Philanthropic funders with an interest in 'levelling up' should include a focus on disabled children within their programmes. As should those aiming to reach out to groups disadvantaged through the pandemic, or to those experiencing poverty and inequality.



1. Support charitable programmes that take a whole family approach to preventing problems escalating into crisis and breakdown, for example support for respite, short breaks or support within the home recognising that that parents have taken on additional roles to support their child practically and emotionally without a break. Support partnerships that bring together organisations with different strengths and networks to best meet the needs of families.
2. Place an emphasis on programmes that provide emotional support and help families overcome the isolation they have suffered during the pandemic. These should range from peer to peer support through to therapeutic services, and include services that ease financial pressures.
3. Consider providing unrestricted funds to enable charities to be agile and flexible in responding to needs and working collaboratively with other organisations to secure the best outcomes for children and families. This could include providing 'test and learn' grants to enable charities to innovate and take risks on new approaches, as well as longer term support for well proven services.
4. Fund services that are developed in co-production with disabled children and their families; and allow flexibility for ongoing feedback from children and families to shape the service as it is delivered.
5. Support charities to develop blended approaches to services delivery; and invest in digital capacity, capability and confidence (within charities and within families).

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Appendix I – Methodology

As highlighted in the summary DCP research has included a research programme to look at the impact of the pandemic on disabled children, young people and their families, independent research into digital exclusion and disadvantage and an independent evaluation of the sector response. The Methods for the three approaches are outlined below:

Pears Learning Hub – Impact on disabled children, young people and their families

Parent Survey Panel

- 4 consecutive surveys with parent/carers of disabled children January – June 2021
- 1 survey with parent/carers of disabled young people (16+ years).

National FOI requests (England)

- Local authorities (education, short breaks and NHS Trusts)

Literature Review (Rapid Review)

- What is known about the impact of lockdown and other responses to Covid 19 on children with SEND and their families

3 Focus groups and Online, face to face and telephone semi-structured interviews with 32 parents of disabled children.

- Analysis of open datasets (health, education, social care and ONS)
- Analysis of policy content

Independent research into digital exclusion and disadvantage (KIDS London and DCP).

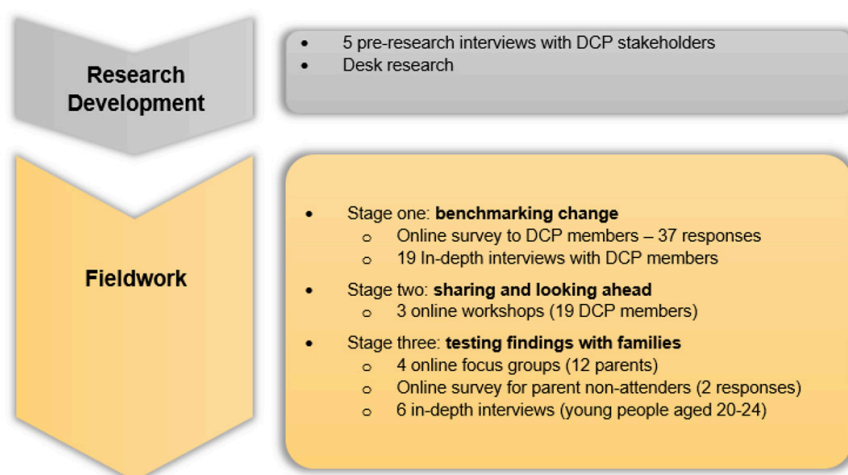
Review of published literature and third sector reports

Use of publicly available data and freedom of information requests

Learning from families with DCP Survey and from young people with a focus group

Learning from service-providers and parents with conversations

Independent evaluation of the sector response undertaken by Fivewaysnp and Discovery Research



DCP organisations participation in evaluation of sector response.

	DCP member	SURVEY (37)	INTERVIEW (19)	WORKSHOPS (19)
1	Activity Alliance	X		X
2	Afacis			X
3	Affinity Trust	X	X	
4	Amaze	X	X	
5	Ambitious about Autism	X		X
6	BACD British Academy of Childhood Disability	X	X	
7	Brainwave	X	X	
8	Cherry Trees	X	X	
9	Contact	X	X	X
10	Council for Disabled Children	X		
11	CPotential Trust	X	X	
12	Dingley's Promise	X	X	
13	Family Fund (incomplete)	X		
14	Flamingo Chicks CIO	X		
15	Go Kids Go (incomplete)	X		
16	I-Can			X
17	KEEN London	X	X	X
18	KIDS	X	X	
19	MOVE Europe (incomplete)	X		
20	NCB			X
21	National Autistic Society	X		
22	Newlife the Charity for Disabled Children	X		X
23	Non-Verbal Affective Care (NAC)	X		X
24	Rainbow Trust Children's Charity	X	X	X
25	Rett UK	X		X
26	Scope	X	X	X
27	SeeAbility	X		
28	Sense	X	X	X
29	SHINE	X	X	X
30	Sibs	X		X
31	Special Needs And Parents (SNAP)	X	X	
32	Spinal Muscular Atrophy UK	X		
33	Swings & Smiles	X		
34	The Amber Trust	X		
35	The Children's Trust	X		X
36	The Down's Syndrome Association	X	X	
37	The Fragile X Society	X	X	
38	The National Bobath Cerebral Palsy Centre	X	X	X
39	Together for Short Lives	X	X	X
40	White Lodge Centre	X		

Appendix 2 – evidence of impact of COVID on families with disabled children

Education

Figure 1: Support for disability at schools by settings

Setting	EHC at setting (%)	SEN support at setting (%)
State Funding Nursery	1.4	13.3
State funding primary	2.1	12.6
State funded secondary	2	11.5
State funded special school	98.6	1.2
Non maintained special school	98.1	1.6
Pupil Referral Unit	24	58.7
Independent School	3.8	14.1

Source: Department for Education (2020)

Figure 2: Reasons children with EHCP were not in school

- 43% of parents concerned about their child's health at school or someone in the household shielding
- 20% of parents had been informally advised by school that their child should not attend
- 14% of disabled children did not wish to attend
- 12% of parents reported that the provision offered was not appropriate to their child's needs
- 11% following a formal risk assessment, the school or local authority had advised that the disabled child should not attend.

Source: DCP survey 2020

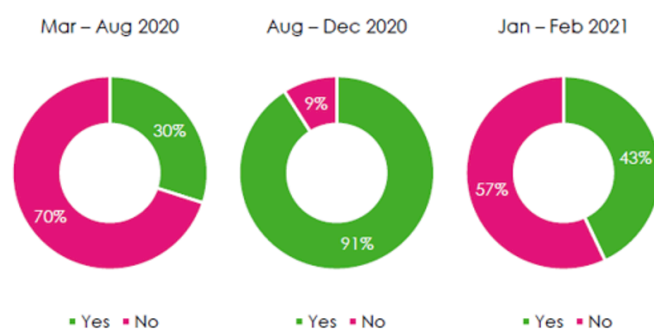
Figure 3: Attendance of children and young people by setting between March and July 2020

Setting Type	Open (%)	Pupil attendance (%)
State funded nursery	93	24
State funded primary	93	26
State secondary	87	4
Special school	86	20
Alternative provision	88	16

Source: Department for Education (2020)

Figure 4: Attendance of disabled children at a range of educational placements

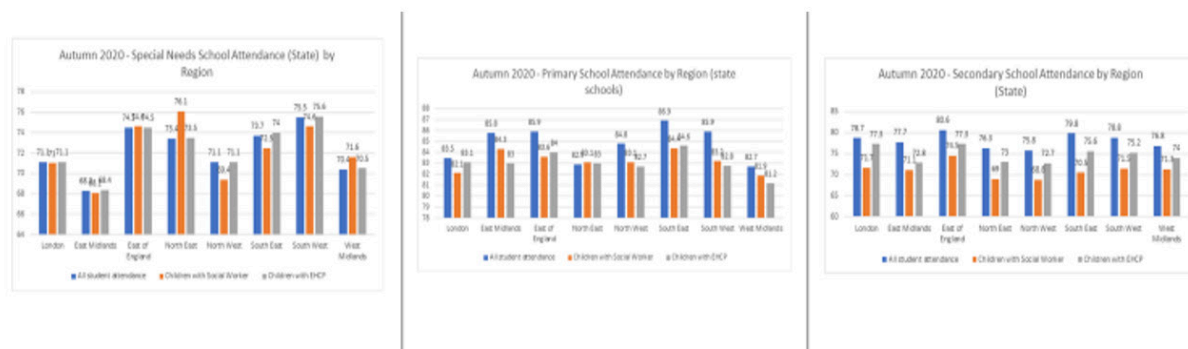
Have your disabled or seriously ill children attended their nursery, school, college or educational hub since the coronavirus outbreak?



Source: Family Fund (2021)

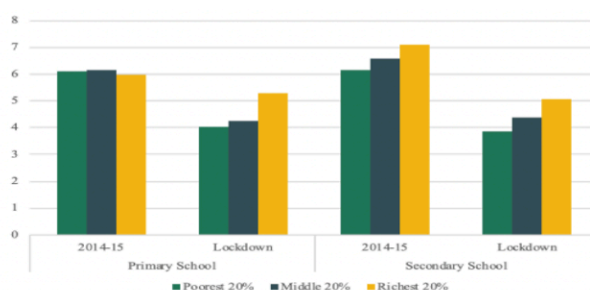
Following the closure of schools in March, pupils attending the partial school re-opening in June 2020 was dependent on the age of children

Figure 5: Attendance by provision and region, Autumn 2020.



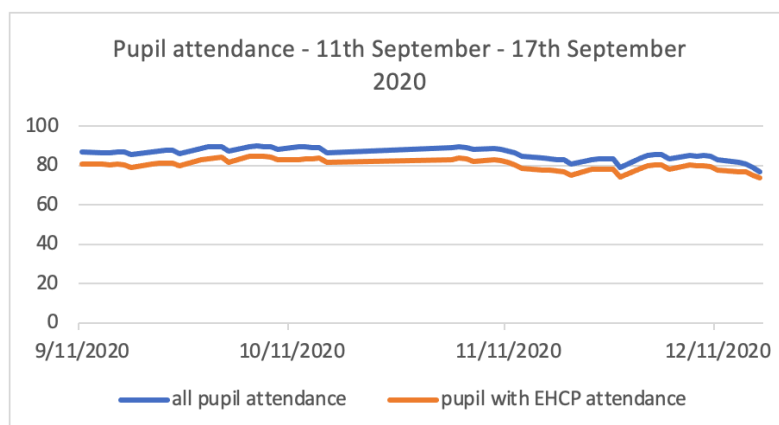
Source: Department for Education, 2020

Figure 6: Inequality in learning by age group analysed by wealth



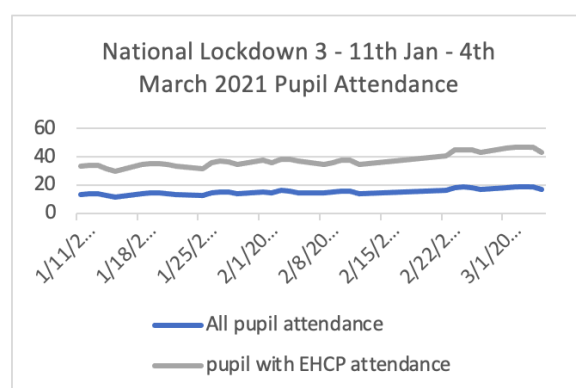
Source: Andrew, Cattán, Costa Dias et al (2020)

Figure 7: Pupil attendance Autumn Term 2020.



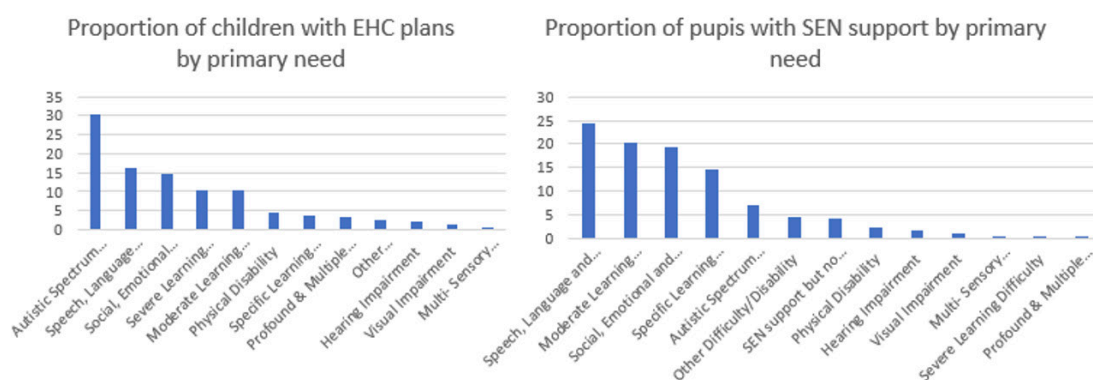
Source: Department for [Education](#)(2020)

Figure 8: Pupil attendance from January 2021



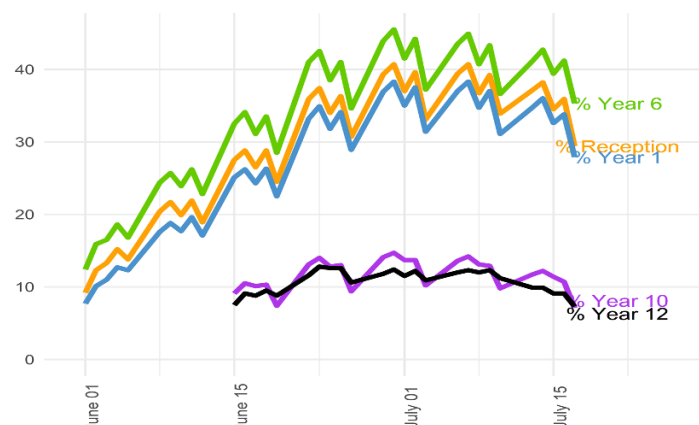
Source: Department for Education (2021)

Figure 9: Proportion of children with EHC plan and SEN support by primary diagnosis



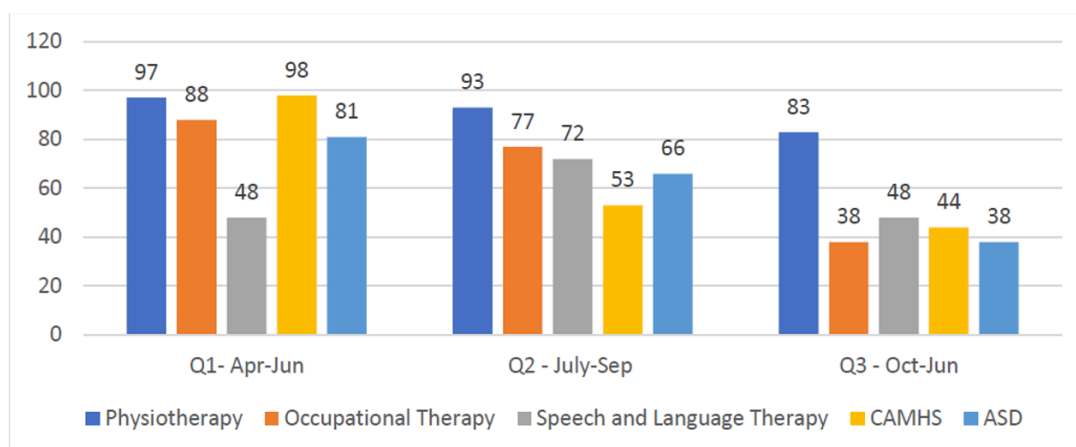
Source: Department for Education (2020).

Figure 10: Attendance of pupils in schools by year group



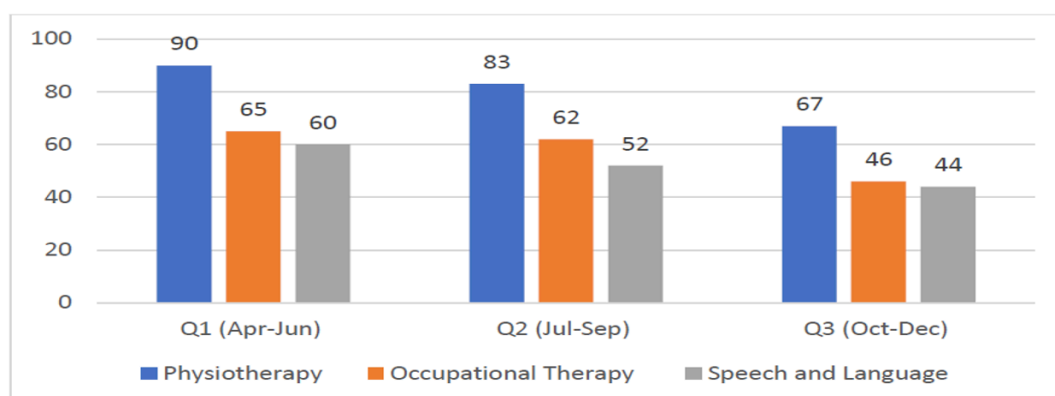
Source: Department for Education, 2020

Figure 11: NHS Trusts receiving fewer referrals for therapy services during the pandemic (2021) for the same quarter the previous year (2020).



Source: DCP FOI Requests, 2021

Figure 12: Proportion of Trusts completing fewer assessments within 13 week from referrals



Source: DCP FOI Requests, 2021

Figure 13: Shielding group by educational setting

- 52% attended Day Special Needs School or College
- 29% attended a mainstream school or college
- 9% of those shielding did not have a school provision
- 4% attended residential school or college
- 3% attended an alternative PRU provision
- 2% attended a nursery or pre-school

Source: DCP parent panel 2021

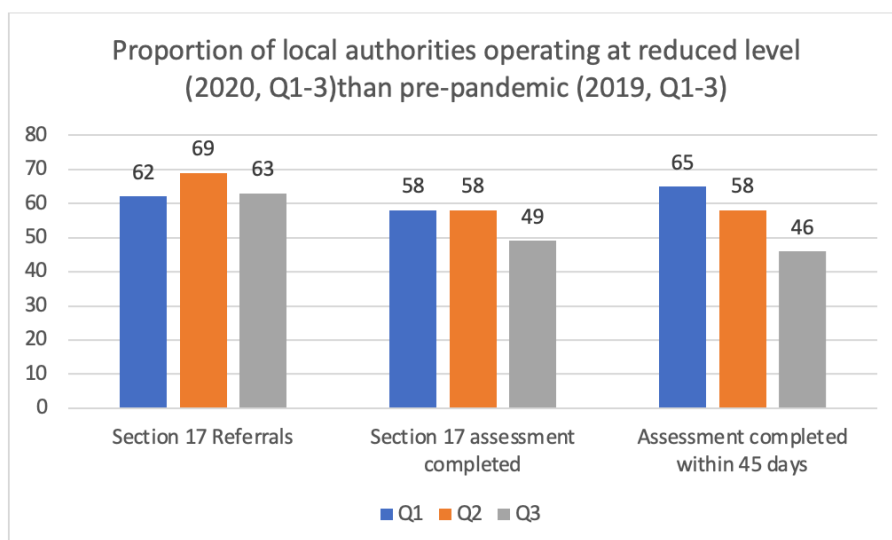
Social Care

Figure 14: Proportion of families shielding receiving care during lockdown

Formal Support	Pre pandemic % received support	January 2021 - % no longer receive
Social worker	44%	49%
Care at home	27%	68%
Domiciliary care	16%	41%
PA support	33%	54%
Short residential breaks	13%	13%
Day care away from home	28%	16%
Family Link scheme	8%	7%

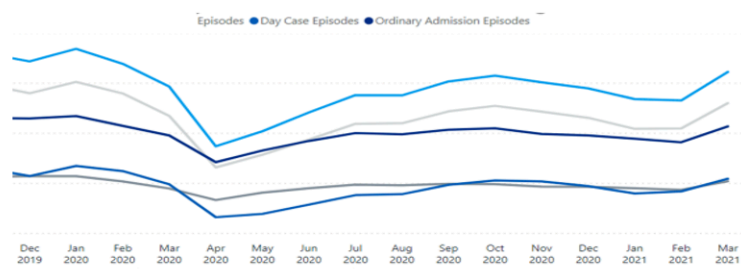
Source: DCP parent panel 2021

Figure 15: Proportion of local authorities operating at reduced level in 2020 (Q1-3) than pre-pandemic 2019 (Q1-3).



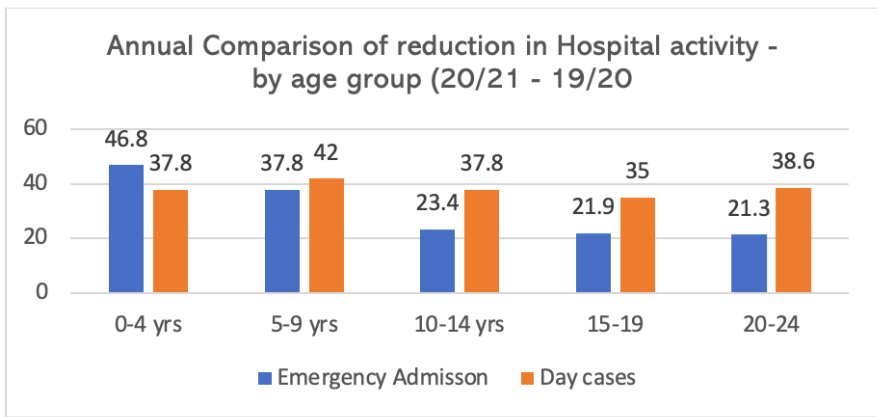
Source: DCP FOI Requests, 2021

Figure 16: Impact of COVID on emergency hospital admissions and day care episodes.



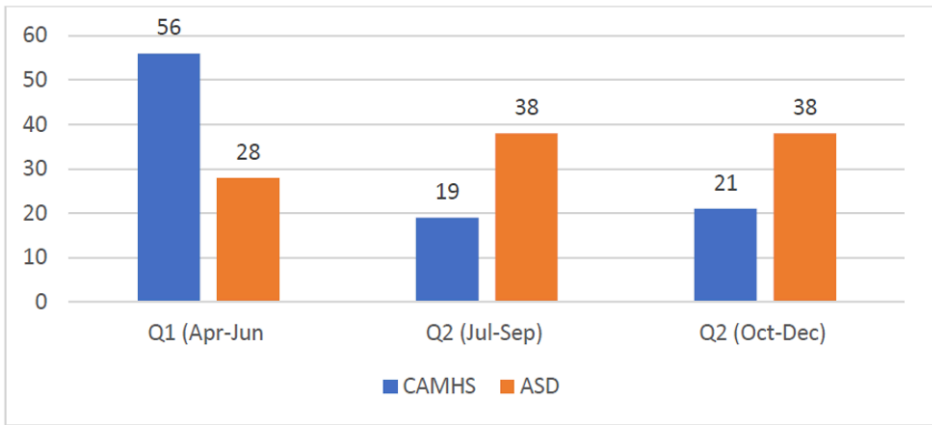
Source: NHS Digital (2021)

Figure 17: The impact of COVID on emergency hospital and day care episodes by age



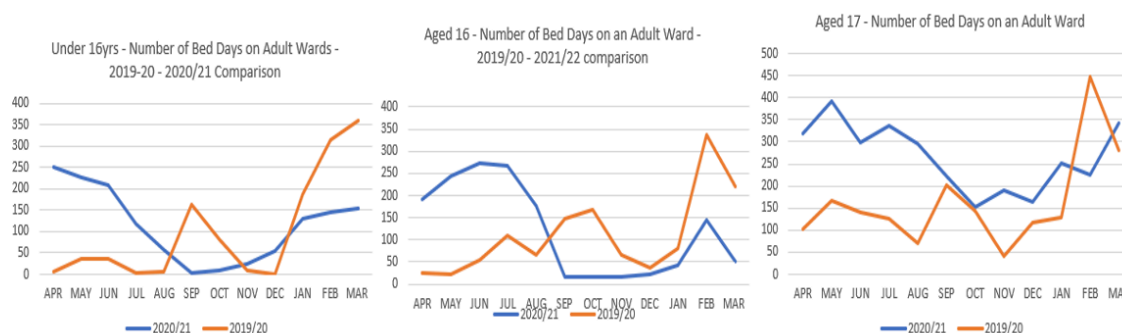
Source: DCP FOI Requests, 2021

Figure 18: Proportion of trusts providing lower number of first appointments within 6 weeks than the previous year



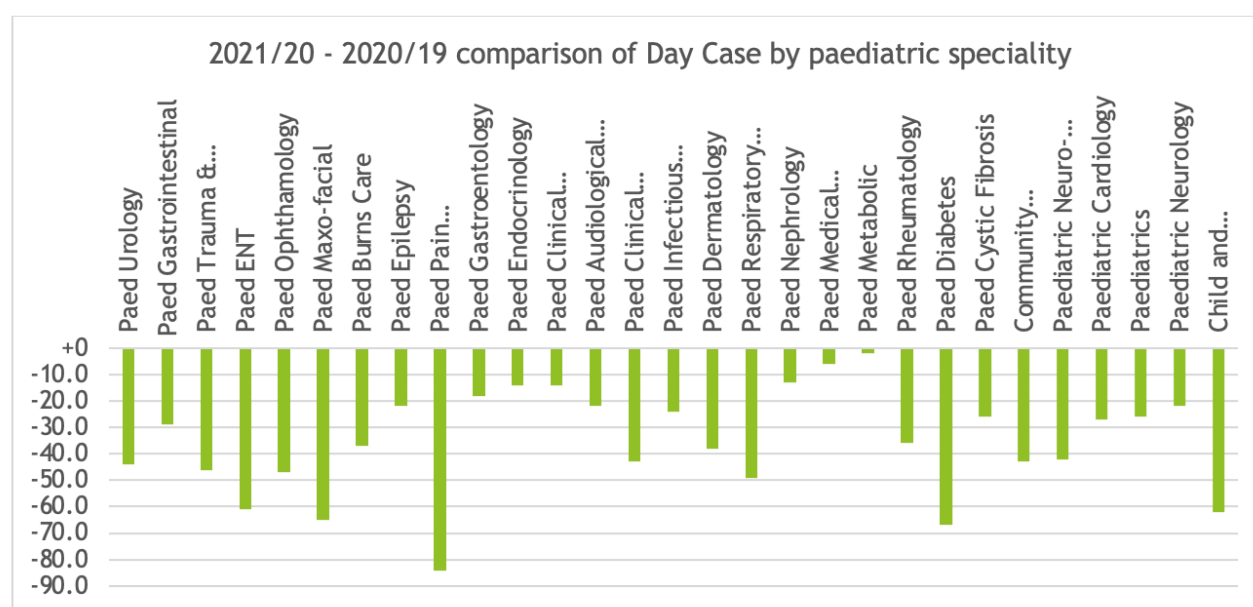
Source: DCP FOI Requests, 2021

Figure 19: Mental Health Dataset; Number of bed days for young people aged 17 and under on adult wards (annual comparison 2021/20 and 2019/20).



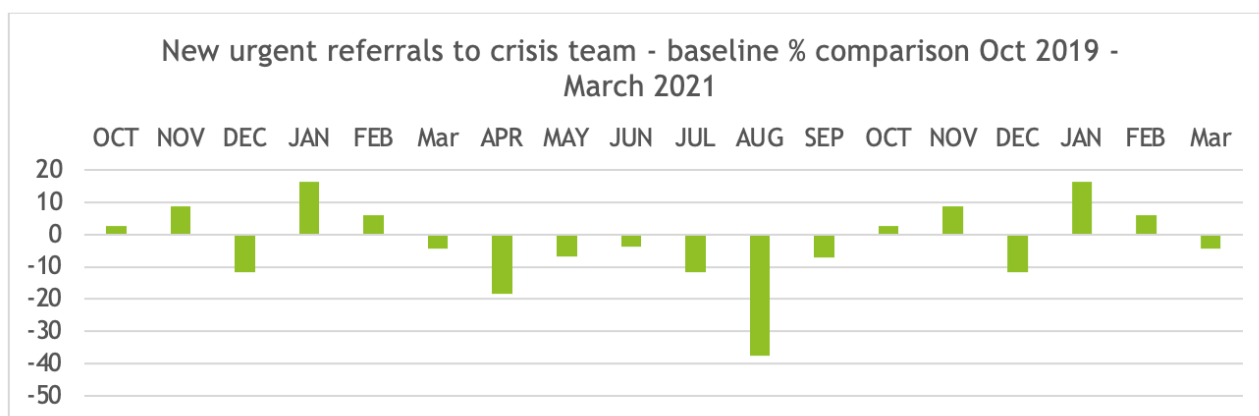
Source: NHS Digital 2021

Figure 20: Comparative data day case by speciality



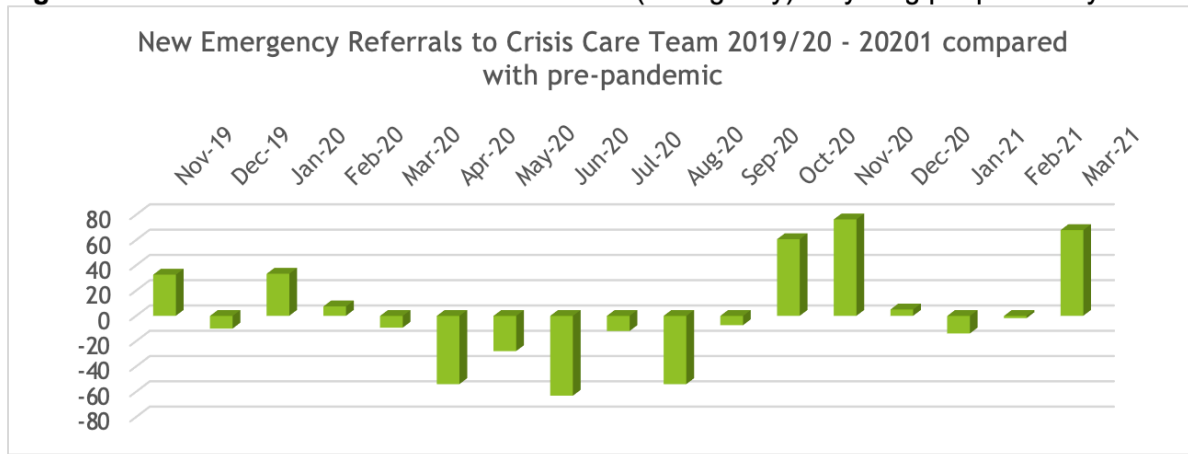
Source: NHS Digital, 2020

Figure 21: New referrals to mental health services (urgent) for young people 0-17 years



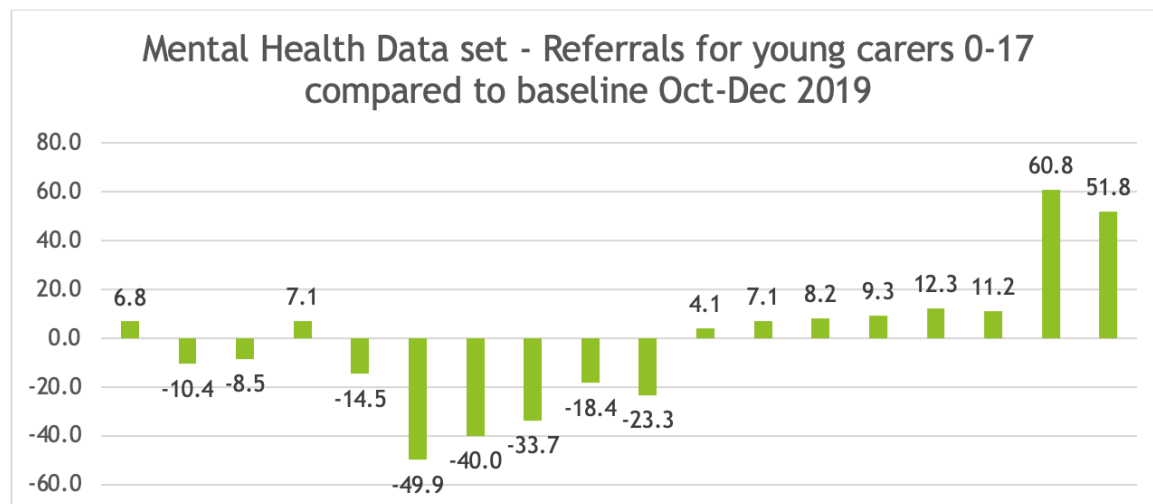
Source: NHS Digital, 2020

Figure 22 new referrals to mental health services (emergency) for young people 0-17 years.



Source: NHS Digital, 2020

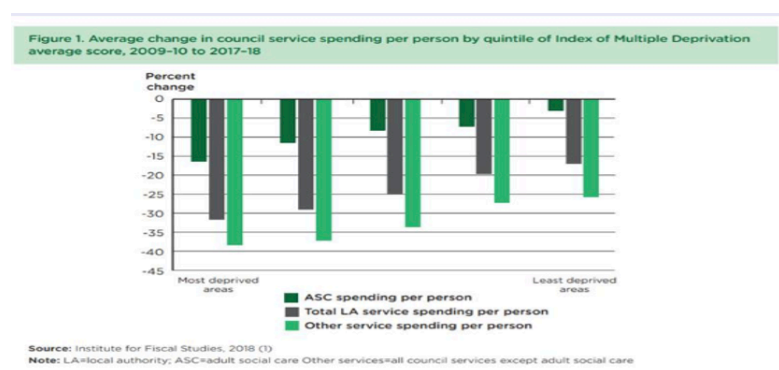
Figure 23: Mental health services for siblings / young carers



Source: NHS Digital 2020

Finance

Figure 24: Average change in council service spending per-person by quintile of Multiple Deprivation, 2009-10 to 2017-18 (Marmot, 2020B)



Source: Marmot, 2020B

Figure 25: Comparison of unpaid carer with disabilities and non-carers with disabilities by age (ONS, 2021).

Age Group	Proportion of Unpaid Carer with disabilities	Proportion of Non-carers with disabilities
16-24	32%	17%
25-34	36%	16%
45-54	32%	19%

Source ONS, 2021

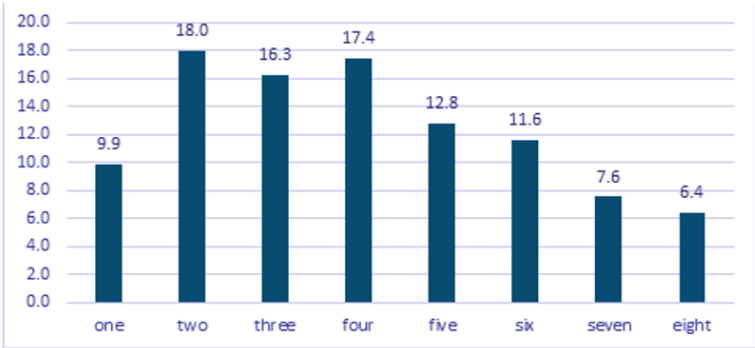
Figure 26: Proportion of parents requiring information by topic type

Education	50%
Family Support	36%
Health	33%
Rights and entitlements	29%
Social Care	27%
Finances and/or benefits	20%
Signposting	18%

Source: DCP parent panel 2021

Disabled Children and young People

Figure 27: Proportion of disabled children shielding by number of disabilities



Source: DCP parent panel 2021

Figure 28 – How delays affected shielding disabled children

56% social communication
41% mental health
35% physical health
28% medical symptoms
23% cognition

Source: DCP parent panel

Figure 29: Comparison of delays to services by age group (early years compared to all disabled children). DCP panel survey.

Delays to Appt type	0-25yrs	0-5yrs
Treatment	41%	58%
Equipment / Aid Provision	38%	58%
Equipment / Aid Maintenance	30%	42%
Operations	28%	42%

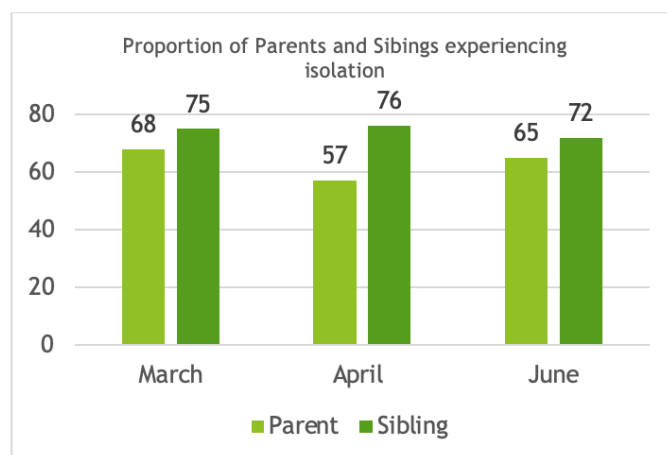
Source: DCP parent panel 2021

Figure 30: Longitudinal analysis of social isolation by age group

	Social Isolation from first timepoint to last time point		
Age	Better	Same	Worse
0-5	25	12	64
6-15	28	11	61
16-25	25	12	62

Source: DCP parent panel 2021

Figure 31: Proportion of Parents and Siblings experiencing isolation



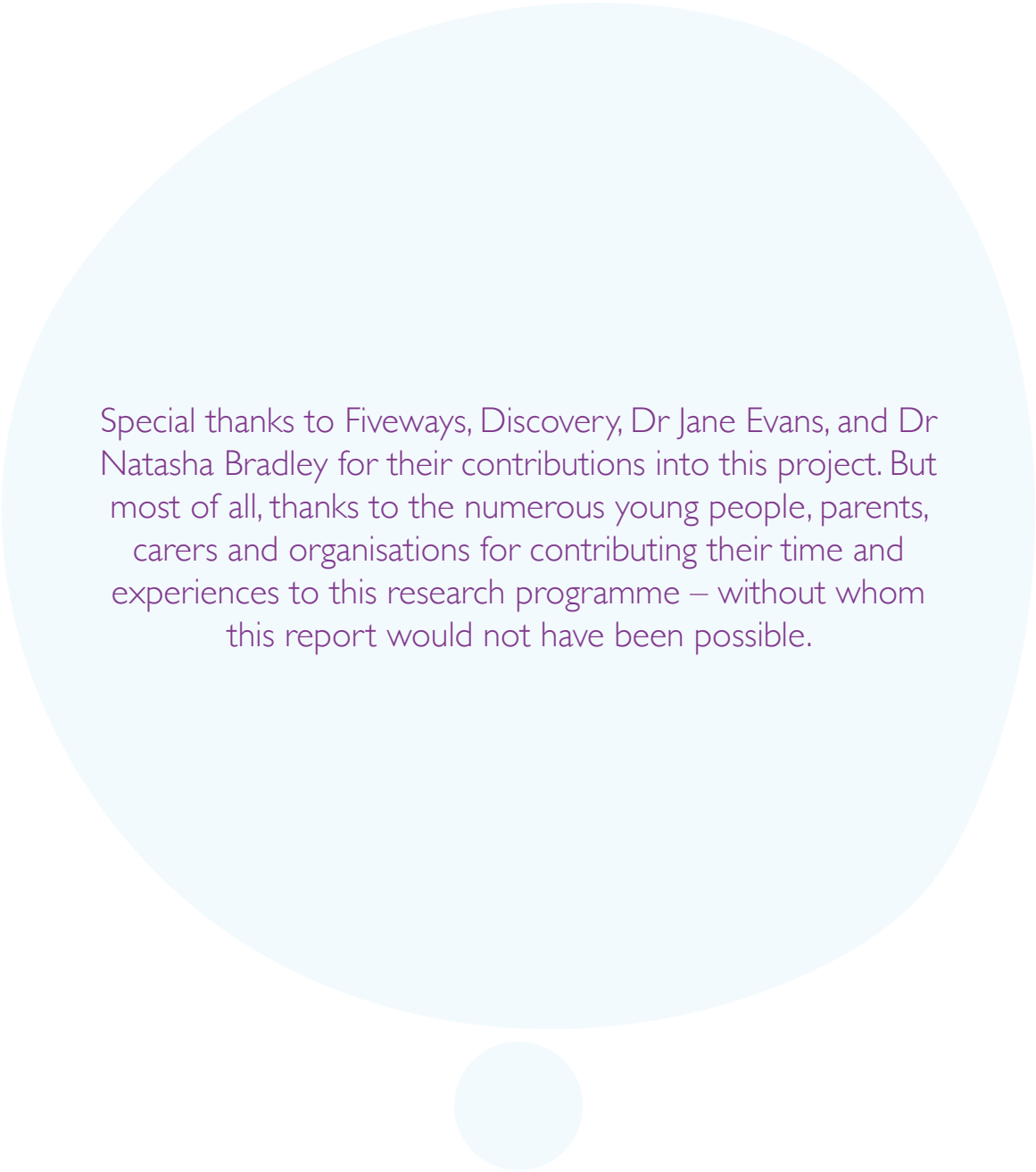
Source: DCP parent panel 2021

Appendix 3 – Future Research (Parent priorities)

During 2021 DCP undertook five surveys with 884 parents of disabled children and young people. In June 2021, they were asked what they considered to be the priorities for future research for disabled children and their families. This is a summary of responses.

Parents of Disabled Children - Research Priorities
Availability of support – respite, childcare, appropriate school transport and in schools in the context of the levelling up agenda
The needs of families within the home
Interventions to assess the whole family unit
Mainstream school exclusion
Mapping special provision nationally – look at availability for academically able children with sensory needs eg low arousal environments
Family & practitioner communication – explore paternalistic / punitive viewed care and support
Financial disadvantages of families with disabled children
Whole family mental health
How to support young people to get mental health support early
Supporting siblings with mental health needs
Accessible and inclusive public buildings – DDA 25 years on
Inclusive education and work opportunities – what does that look like?
Availability of extra-curricular care for disabled children
Impact of extra curricular activities on holiday care, wrap around care and clubs on family finance, mental health, happiness & independence
How can “play” and social opportunities be built into “adult” services for our post 18 young people who still need that approach.

Source: DCP Parent Panel 2021



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The Disabled Children's Partnership (DCP) is a growing coalition of more than 90 charities who have joined forces, working closely in partnership with parents, to campaign for improved health and social care for disabled children, young people and their families. We are administered by Royal Mencap Society (registered company in England and Wales no. 00550457; registered charity numbers are 222377 in England and Wales, and SC041079 in Scotland).