

# Experiences of Disabled Children and their Families during the COVID-19 Pandemic



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# Introduction

**The “Experiences of Disabled Children and their Families during the COVID-19 Pandemic” survey was launched by WECIL in October of 2020.**

This was in direct response to WECIL hearing informally from families about their experiences during lockdown and wanting to capture this in a more formal way. The initial questionnaire asked families to share their experiences of the COVID-19 crisis and resulted in 54 responses from parents and carers throughout Bristol, B&NES and South Gloucestershire. Following analysis of the questionnaires some emerging key themes were identified and resulted in more in depth focus groups being set up.

These groups provided a space for families to share and expand on their experiences and an opportunity to connect with key decision makers (including invited Council staff) to find out what could have worked better for them. The opportunity also provided a space to start building more of a community for parents/carers that engage with WECIL’s services.

## Summary of Findings

**The majority (60%) of responses to the questionnaires that were sent out were from Bristol parent/carers with an additional 30% coming from B&NES and 10% from South Gloucestershire.**

After analysis of the questionnaires, five key themes emerged which went on to inform the more in depth focus group discussions. These key discussion themes were around PA’s and Care Workers; Direct Payments; Special Schools and

Schooling; Professional Support and Mental Health. Focus groups were held online during February and March 2021 with facilitators providing a virtual space for 15 parents/carers and invited professionals to come together. The following report provides an overview of findings from the initial survey with a more in-depth analysis of the results of the focus groups and links to other research and evidence that is relevant to the key discussion themes.

Throughout the process participants were asked ‘what would have helped’ and this informs the areas for development

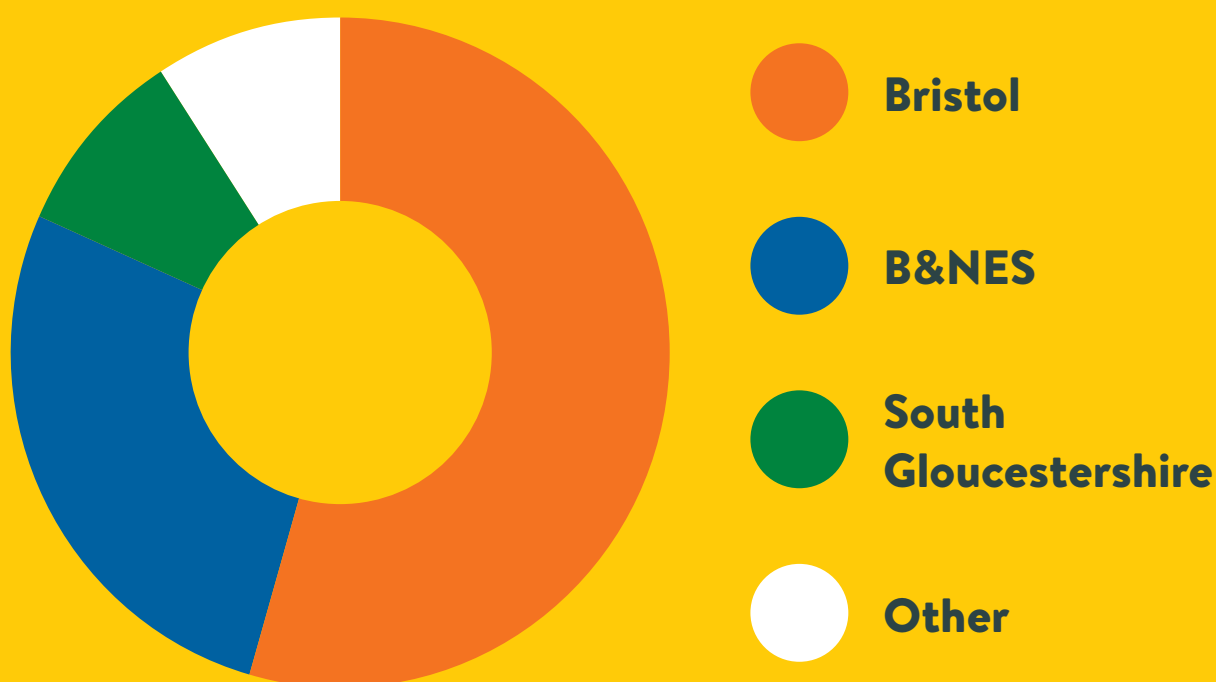
identified at the end of the document. Some of the key findings from this highlight the need for easily accessible and up to date information about services and provision; better informed and responsive professionals; trust and flexibility around the use of Direct Payments; an offer of appropriate educational support or school places for all children with an EHCP and better consideration of the emotional and social needs of disabled children and young people, including better access to safe, outside spaces.

A wider issue was also identified which highlighted a need for consistent messaging from local and national government and more joined up thinking and collaboration between agencies. Most importantly however, parents and carers felt heard and had an opportunity to express what it has been like to live through the pandemic with a disabled child.

**“This has been the first time when someone has **actually listened** to me.”**

**“I have a child who is disabled and therefore I **have a voice** and I don’t want my experience to go to waste.”**

## Responses to the questionnaires





# ★ Next Steps

It is hoped that this report can inform good practice in the event of future lockdown's or national crises, but also provide an insight for professionals who work with these families as many of the issues which arose are not just confined to a pandemic, but are experienced on a daily basis by the parents and carers and disabled children and young people we work with.

WECIL are now in the process of developing a sustainable parent/carer support network and working closely with other groups to ensure better shared understanding of the experiences of families with a disabled child and how these experiences can be improved.





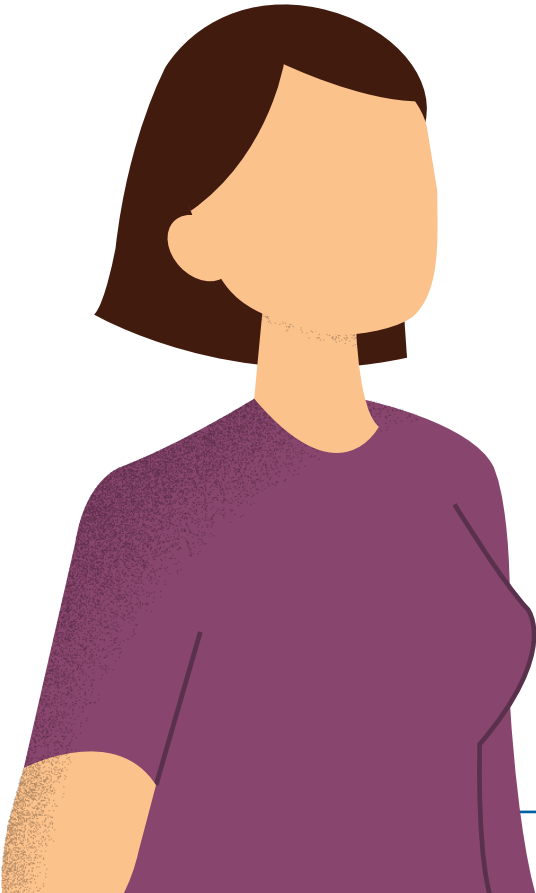
# Main Findings from Initial Questionnaire

## Personal Assistants/Care Workers

There were several issues raised in relation to Personal Assistants (PAs) and Care Workers. Firstly, families felt anxious about having PAs and Care Workers coming in to provide support, as they could potentially expose the child to the virus:

“We do not want him to stay overnight with his carer, as she is a nurse and we feel she may be exposed to COVID”

In addition, it was evident that families were not able to access the appropriate level of care for their child. This included issues such as a lack of staff experience, a lack of ability to manage considered complex behaviours and/or needs, and some were not able to provide the necessary quantity of care. Responses also suggested that if PA's and/or Care Workers were unable to provide care, families took on this responsibility without any professional support.



**“We do not want him to stay overnight with his carer, as she is a nurse and we feel she may be exposed to COVID”**

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## Direct Payments

There were several respondents that indicated they were confused about Direct Payments, specifically about how they should or should not be used and felt uninformed about what to do with their Direct Payments during the pandemic:

**“We were told we shouldn’t really be using Direct Payments at the time”**

Another parent stated their request for their Direct Payment to go towards sensory equipment was refused even though guidelines were issued early on about the need for flexibility in the use of Direct Payments during the Covid-19 outbreak. This suggests a level of confusion around Direct Payments identified by a number of respondents to the initial questionnaire.

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## Special Schools

In March 2020 the government stated that children with EHCP’s would still be able to attend school, (Education Health and Care Plans) however the survey responses indicated that this was not necessarily adhered to. One participant mentioned periods of “no school attendance” for their child and “reduced attendance” for the latter part of the year, with limited help on offer from special schools and a lack of one to ones or inappropriate work being set for their child. There were also some suggestions in the survey that special schools were not adequately supported by the Local Authority and that Local Authorities may have interpreted or applied government guidelines differently. For example, respondents in South Gloucestershire were advised against sending clinically vulnerable children to school. As one participant said “South Glos advised

schools differently”, despite the fact that “vulnerable children were allowed to go to school” nationally.

Some participants noticed inconsistencies between mainstream schooling and special schooling. This was illustrated by one respondent who stated:

**“The quality and quantity of teaching during this period was again poor, in comparison my other son is in mainstream education... there was a full timetable of lessons on teams”**

This demonstrates potentially unfair differences between special education and mainstream schooling during the pandemic and a contrasting level of support for disabled children.

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# Feeling Abandoned by Professionals

An emerging theme of feeling let down and forgotten about by professionals during the pandemic became evident in the initial survey.

The comparison between a greater level of support prior to the pandemic and a drastic decrease in support during the pandemic was highlighted in these quotes:

**“All support and respite stopped at the first lockdown, we went from a good package of help 24/7 to it being only us”**

“I felt my son was forgotten about during the pandemic with no help from professionals”

“All our appointments were cancelled straight away. They did not resume for many months even after many other services started back up. Our sons orthotics became so small they bruises his legs and caused bad blisters”

This was a consistent theme, felt by most participants who contributed to the initial survey and will inform one of the key focus areas for future consultation.

**“I felt my son was forgotten about during the pandemic with no help from professionals”**

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# Issues with Obtaining Prescriptions and Appointments

When referring to prescriptions and appointments most participants spoke of limited access, long waiting times for prescriptions to be issued and cancelled appointments. What is interesting is that from reading the responses on this theme, it could be suggested that the importance of these prescriptions and appointments for disabled children (in contrast to non-disabled children) was not fully appreciated by professionals. One respondent stated:

**“I couldn’t get prescription toothpaste... despite the high fluoride toothpaste being a long term preventative measure to protect his health and avoid any problems.”**

Another response reiterated the issue by stating how their child:

**“Needs (regular) checkups in order to monitor different health problems among physical development and learning.”**

Such examples suggest that the need for regular checkups and prescriptions for disabled children was not always understood, when in fact they are necessary to maintain the health of the child.

## Impact on Mental Health - Feelings of Isolation and Stress

High levels of anxiety among young people presented itself as one of the most recurring themes in the survey, along with feelings of depression and isolation. In addition, COVID-19 had a dramatic impact on the whole family’s mental health as well as that of the child. For example, one respondent explained:

“I became extremely anxious about my son’s health and I’m now under the doctor for anxiety and depression”.

With another stating, “...[the] change in routine, has increased my child’s anxiety to the point they won’t leave the house at all.”

This demonstrates how lockdown restrictions have impacted on the whole family’s mental health, particularly parents and carers of disabled children. Furthermore, there was a noticeable relationship between feeling let down by professionals - as discussed earlier in the



report - and families feeling isolated:

**“I really could have done with was somebody taking charge as my mental health plummeted”.**

**“It’s terrible, the lack of exercise, facilities and the fear of catching COVID is controlling everything - it’s also changed patterns that kept mental health issues in check”**

Respondents reflected a general struggle with mental health, possibly as

a consequence of feeling they have been abandoned by their usual support networks.

**“I became extremely anxious about my son’s health and I’m now under the doctor for anxiety and depression”.**

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## Impact on Other Siblings

Another issue highlighted in the initial questionnaire was the impact on the whole family unit, including the siblings of disabled children and young people. For example, lack of support for the family resulted in changes in behaviour for some disabled young people which had a wider impact on siblings and the rest of the family. In some cases, this behaviour posed a threat to family members due to its severity. Consequently, family members had to look for support elsewhere. In one case, the disabled child’s difficulties became such that one participant had to ask her younger children’s primary school to allow them to attend alongside other groups which were allowed, for their own safety and well-being. This type of situation heavily impacted the family’s ability to look

after other siblings, with one respondent saying:

**“my other children got pushed out more and more as his (son’s) care needs increased.”**

While the impact on the family as a whole and the siblings should not be understated, it is important to note that these issues often stemmed from the lack of support given to disabled children themselves. The impact on their own mental health, well-being and overall health cannot be underestimated.



## ★ What's next?

Following the outcomes from the initial survey above, five key themes were identified as needing more in-depth discussion. Online focus groups for parents/carers based in Bristol, BANES and South Gloucestershire were arranged for February and March.

The focus groups were designed to facilitate deeper conversations, to empower parents and carers and give them an opportunity to share their experiences. The groups addressed the key themes drawn from the initial survey and connected parents with decision makers to learn what could have worked better for them, their children and wider family members during the pandemic.

For those parents /carers who weren't able to join the focus groups, 1:1 online conversations were facilitated at alternative dates / times. A total of 15 participants were interviewed in the focus group stage.

**Each group were asked the same set of questions (see Appendix 1) regarding each theme.**



**Professional  
Support**



**Mental  
Health**

**5 key  
themes**



**Direct  
Payments**



**PA's and  
Care-workers**



**Education  
including Special  
Schools and  
Schooling**

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# Main findings from the Focus Groups

## Personal Assistants (PA's) and Care Workers

The focus group feedback echoed that of the original survey with participants not being able to use PA's due to fears around the risk of infection. There has also been (and continues to be) the impact on families and on care workers of having to self-isolate for periods of time which means pausing care and support while they wait for test results or during isolation periods. In the initial stages of the pandemic, with the care workforce one of the few still operating on the ground, there was little concrete information on how to continue to work safely as the Disability News Service also identifies.

**“During the pandemic they (the PAs) just didn't come in for most of the time as it was just too risky. At various points they did, but most of the time we had no support. I just assumed we just had to dig our heels in and get on with it. Both the PA's**

**have now been vaccinated and so they are coming back in.”**



**“My heart sinks when a PA says they are moving on”**

Other key challenges for families during this period have been in the recruitment and retention of PA's and Care Workers – having the time to find the right people to provide an appropriate level of care for their child, and where to go for support in this. Often parents were left with no support due to not being able to recruit suitable PA's or care staff. One parent reflected, “My heart sinks when a PA says they are moving on”

### What could help?

The availability of PA's during lockdown and beyond seems to be an issue with families reporting a big challenge in simply trying to find them. Clear guidance from the outset on how to work safely during a pandemic may have been helpful in reducing anxieties for families and PA's, along with having a central 'pool' of PAs

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which could be drawn from would be beneficial. This would need to go hand in hand with support for parents/carers in recruiting and managing any difficulties with PA's if they arise.

We will be interested in seeing the outcome of the ongoing research by Kings College London which is gathering evidence on how carers have coped with employing PA's during the pandemic. This study will help to inform social care practice now and in the future.



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## Direct Payments

Two key themes emerged from the focus group feedback around Direct Payments. The first theme was around accessing payments in the first place with several families saying they did not bother to try and access them as the process of applying and administering seemed too complicated and time consuming, or they were not able to get help with it when needed.

“I wanted a Direct Payment so he could access physical activities to benefit his physical and sensory needs. I literally got given a brick wall saying ‘we don’t know how to access Direct Payments, it’s not appropriate for your child’, and I just thought what a shame”.

**“We’ve always been asked if it is something that we want to look at and I just think ‘no’. Because of all the paperwork**

**and everything like that, you’re responsible for paying all the tax and everything else. It’s like ‘no I have enough to deal with’ ”**

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## **What could help?**

Clearer information for social workers and those administering payments on how to approve a change in Direct Payment use would be beneficial. Where good support was in place, it made a real difference and is something families would like to continue post lockdown.

“Having the name of someone to bounce things off at the council was really valuable. I’ve not had that before and it would be useful if that could continue after the pandemic. Having that phone call regularly checking in around DIRECT PAYMENT and whether there are any issues with the PA’s would be great.”

The process of applying for and administering Direct Payments for many families feels too complex and time consuming without good support in place. “I just think there are some things that are too difficult to fight for, you’ve got enough on your plate. In the end we just didn’t bother because it didn’t seem something that people wanted to help with”

## **What could help?**

Good support for families to navigate the system in the first place with training for those in direct contact with families so they are able to advise correctly on what is available. It is also not clear how

many families were aware of alternatives to Direct Payments such as Individual Service Funds as something that could be used as a middle option.

The second theme was from families who were accessing Direct Payments during lockdown reporting different approaches to administering payments and around the support they received from agencies or local authorities.

Some families reported that there had been flexibility with what they could spend the money on if they weren't using their PA's, and that they had a positive experience in dealing with agencies but for others this was not the case.

One family was given the opportunity to spend Direct Payments on educational resources while another had to return their unspent funds.

"I guess one thing that did make a difference is that because of the Direct Payments (not being used for the PA) they eventually said we could buy stuff for her (daughter) and that made a really big difference actually because I was able to use that money (Direct Payment) to buy lots of different resources to support home schooling"

"Because we weren't using our PA we had to send the money back"

There appeared to be inconsistency in knowledge about how Direct

Payments could be used in difference circumstances. Guidelines were issued early on in the pandemic around flexibility for the use of Direct Payment, however not all of those administering the payments seemed to be aware of this. This lack of consistency in how DIRECT PAYMENTS can be used despite government guidance saying otherwise is something that has been highlighted in other reports with the SCIE Future of Commissioning Social Care report finding that "Direct Payments have been flexible for some, but for others there have been limitations such as not being able to find personal assistants (PAs), or not having the right support and advice to use their Direct Payment flexibly."

**"Because we weren't using our PA we had to send the money back"**

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# Education

## (including out of hours and extra curricular activities)

Focus group feedback on education was considerable and supported many of the findings of the initial survey. Feedback has been broken down into four sub sections to cover the key discussion areas from the groups.

### Differences between Mainstream and Specialist settings

The focus groups highlighted key differences in the educational provision children were being offered during the different lockdowns depending on their educational setting. Some participants reported that at the start of the pandemic specialist settings appeared to be wary of having children in school despite government confirmation that children with EHCP's (Education, Health and Care Plan) would be provided with places.

"My other son has an EHCP but goes to mainstream school and he could have been in (school) everyday had he wanted to be, yet X, whose needs are much much greater, he was at a special school and special schools weren't open all the time and it felt unfair to me that my son whose

needs are less got more time in school than my son whose needs are much greater and this didn't feel right to me"

Some specialist schools seemed to be lacking guidance on how to support children and young people safely, "It seems that special schools have learned a lot by implementing a lot of things themselves, rather than waiting for the local authority to say what they can and can't do" whereas mainstream schools continued to provide places.

Some parents were reaching breaking point before schools would allocate places, even though the children were eligible under the government guidance, it appears that in some schools priority was being given to children of key workers while disabled children were effectively 'shut out' through fears around how to include them safely.

"So the first 5 weeks I taught them at home because our school was very very fearful, and even though we had the EHCP in place at that point they weren't prepared to have anybody really. And so it took about 5 weeks before I broke and then they had him in but they only had

him in part time and again the school was quite fearful.”

“I had check ins to see if I’m okay and if there is anything they can help with, however all I need is a break, but unfortunately the school is filled to capacity from taking on (key worker children) they cannot accept other children”

This disparity, however, seemed to level out in subsequent lockdowns.

“In the second lockdown they were both (children) at a specialist school, my daughters school were just absolutely brilliant they were home for one week and they sent home a full timetable.”

“The first lockdown, it was as if he wasn’t there. I’m not sure if his tutor knew what to do. Communication was very rare. Then this lockdown the college has been much more present and he has two video calls a day and he is given homework.”

### What could help?

Clarity and consistency in guidance from local authority and government on how to safely support vulnerable children and

**“I had check ins to see if I’m okay and if there is anything they can help with, however all I need is a break”**

young people in school settings during a pandemic.

Mainstream schools ensuring places are available for all children with EHCPs if they want them and to consider the whole family and the needs of the family when allocating school places.

### Access, differentiation and expectations

Parents and carers reported a significant number of difficulties supporting their children and young people with the work set by schools if they were learning at home. Firstly, some young people struggled to access the curriculum online. “My son can’t read very well and so he misses messages on online boards...I’m constantly having to keep an eye on him... I didn’t have enough time to give to him as I was working, preparing dinner, having another child to deal with, so I just haven’t had the time.”

The amount of work being sent home was also an issue with some families reporting that mainstream schools were overloading their children with work and others reporting that schools weren’t sending back enough.

“...I’ve got a son who is at mainstream school and his school is giving out a heap load of work that he has to do, compared to my daughter (at a special school) who is only being offered a small amount of work which can be completed in a couple of minutes, compared to my son which takes him 8 hours to complete.”

Work being sent home wasn’t differentiated and so often wasn’t appropriate for the young person to complete without the specialist support they would usually receive in school.

“The one thing that we found was that they didn’t differentiate the home learning for my daughter and she’s working approximately 2 years behind. She was having to try and learn at home (which is not her learning space) and I was trying to do home learning for 3 children,



2 of whom are in the same year group but are working at very different paces”

“The resources were great – sending lesson plans through etc - but the level of the work being set was totally over her head.”

These findings are reflected in other research with the National SENCO Workforce Survey identifying ‘the provision of appropriately differentiated work online for children and Young People with SEN was a challenge, with nearly threequarters of SENCOs highlighting this as a concern and 8 out of 10 secondary colleagues cited providing differentiated learning online for children and Young People with SEN as difficult’

## What could help?

Ensuring resources are accessible to disabled children and young people if they are learning from home and providing teachers with training around delivering online learning.

“I think all teachers have done a brilliant job but training around teaching online (would be helpful) as it is not the same as teaching face to face.”

And providing forums or online space for parents to communicate with teachers about supporting learning for example:

“What’s helped a lot this time is teachers having the ability to chat to you 1-1, using chat rooms and classroom communications. I’m able to talk to the teacher and say “my sons stuck on this or that and how do I help him?”, so this



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has proven very helpful when it comes to homeschooling.”

## Impact of changes in schooling

The challenges of home learning and change in routine of not being in school for a lot of disabled young people had an impact not just on them but the wider family. Parents reported children and young people often showing confusion around what was happening through comments such as ‘are we on holiday?’, ‘Am I unwell?’, ‘Is it the weekend?’, ‘You’re not my teacher’ and concerns about what will happen when it’s time to go back into the classroom.

“I think X was a bit like ‘but I’m at home, why am I doing work when I’m at home’ It was really difficult for him to see the difference.”

“This (being out of school) has had a huge effect on X and it’s going to be an absolute nightmare getting him back into school. The school have arranged a “Transition day” for him to go in, but he’s

shutdown”

“As well as taking a while for her to even engage with me because she doesn’t see me as her teacher she sees me as her mum, so for her this is completely out of the norm for me to be doing this with her on the daily basis and consistently, so this has thrown her a lot”

## What could help?

Parents suggested a better balance between education and social/ emotional wellbeing with schools providing a facilitated, accessible space for young people to connect with their peers where they could share what was happening and ‘normalise’ being at home. Missing out on the social aspect of school was a big issue for many.

**‘It would be good if the school could have some way of the kids chatting which is supervised by adults’**

**“This (being out of school) has had a huge effect on X and it’s going to be an absolute nightmare getting him back into school. The school have arranged a “Transition day” for him to go in, but he’s shutdown”**

These findings are backed by the OECD Policy Responses to C19 which advocates for a holistic approach that ‘addresses students’ learning, social and emotional needs’ as being crucial, especially for those who are at increased risk or from diverse backgrounds in times of crisis.

## Out of School Settings and Wraparound Childcare

Families reported inconsistencies in the provision of out of school hours support for disabled children and young people. Afterschool clubs not running due to the pandemic impacted on working parents who were left with no childcare and many clubs went online which meant parents/carers still had to supervise and therefore didn’t get a break.

“As a working parent, childcare disappeared for special needs children. The after-school club that would take X closed and they said ‘we’re not going to open’ and I was screwed because I wasn’t able to work to my full capacity and there was nobody to pick him up from school when I was at work.” Other families felt that even if provision wasn’t provided face to face, it was still helpful for young people to stay connected online.

**“He is quite sociable and the zoom calls with (groups) have been amazing. It is what he looks forward to every week. That was really important for him.”**

“I think WECIL and the group my son uses when he wasn’t in school, they were the highlight of his week because he was seeing his friends, although they were not in the room with him it was really important to him to see that everyone was feeling the same, I think that really helped him and because that made him more relaxed it helped everyone else in the family be a bit more relaxed”

## What could help?

Some feedback suggested that access to this type of provision wasn’t just an issue during the pandemic but highlighted a general gap in after school clubs and groups which can support disabled children and young people 1:1. The Unequal Impact report suggests that ‘the pandemic brought into focus an exacerbated widely acknowledged systemic issues in the wider SEND system’

**“As a working parent, childcare disappeared for special needs children”**

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# Professional Support

The feedback from the focus groups in relation to professional support was mixed and this has been broken down into different areas.

## Health

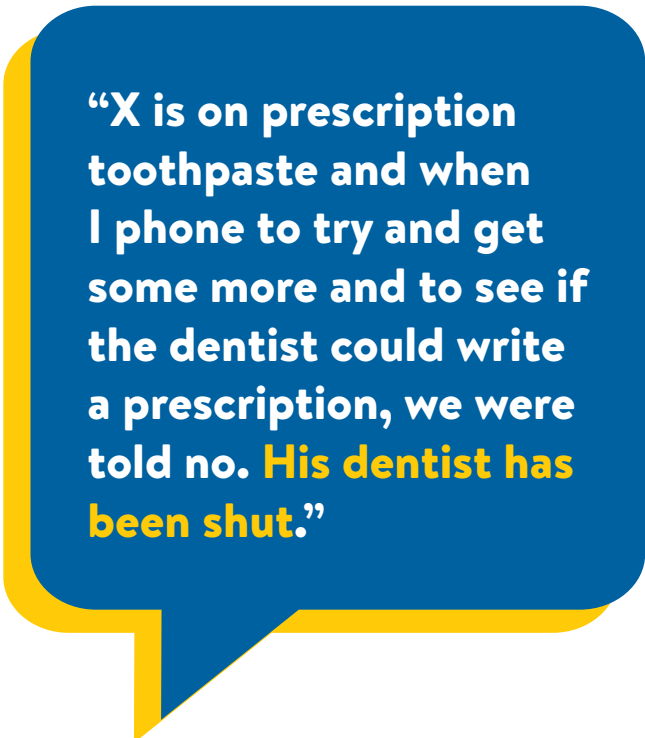
Support from, and access to GPs and other health care providers seemed to be mixed during lockdown and beyond. Telephone or online appointments were received differently by different families with some finding this helpful and others not.

“All of our appointments carried on and some moved virtually which was brilliant! Our daughter had surgery during the pandemic and there was lots of support from OT’s (Occupational Therapists) etc.”

“It’s just the access. We had several conversations on the phone with the doctor and the message just didn’t seem to get through and it needed really to be a 3 way conversation between his specialist, the doctor and ourselves and it just wasn’t possible to get that kind of coordination together.”

Access to dentists and getting hold of prescriptions was an issue for some families with one reporting ‘the dentist has disappeared!’ and another that

“X is on prescription toothpaste and when I phone to try and get some more and to see if the dentist could write a prescription, we were told no. His dentist has been shut.”  
According to figures from The Health



**“X is on prescription toothpaste and when I phone to try and get some more and to see if the dentist could write a prescription, we were told no. His dentist has been shut.”**

Foundation, disabled people were more likely to report that their access to healthcare and medical treatment had been disrupted during the pandemic when compared to non-disabled respondents.

## What could help?

Better understanding of the complex needs of disabled children and young people when accessing health services, particularly around the appropriateness of face to face or online appointments and the importance of preventative care (for example dental hygiene).

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## Local Authority Support/ Social Care Professionals

Reports from participants around support from Local Authority professionals was mixed with some having more contact than ever from key professionals and others having less or even none at all.

To put this into context, during May, June and July of 2020 the government relaxed the duty on local authorities to meet statutory requirements under Section 42 for SEND provision through the Coronavirus Act 2020 and required them only to make reasonable endeavours to meet need.

This could have potentially resulted in what our participants experienced in the differing interpretations of 'reasonable endeavours' between local authorities and the patchy delivery of services.

**"I've had more contact with the DCT (Disabled Children's Team) over the pandemic than I've ever had, and that felt really helpful, that felt like a shift change - I can't tell you how much that means. Just to know that someone had noticed and known that I had a disabled child and just to check in with me, for me that meant more than anything."**

**"The social worker just hasn't been in touch"**

**"We've had one phone call from a social worker from March 2020 to January 2021, a single phone call. They said 'let us know if there's anything we can do'... but what can I ask them to do? There were no options given to us of what they can do"**

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## Overall What Could Help?

Families reported that where things worked was when there was flexibility and choice around provision and where provision took into account the different needs of disabled young people and families – for example communication needs. Having things explained and a named point of contact for families was also valued.

“(What helps is) Professionals delivering support adapted to delivering things differently and it has carried on throughout the lockdown period and beyond. Having things online meant that I could choose when to look at stuff, for example emails coming through with reports I could decide when to open them.”



## Mental Health and Wellbeing

The mental health of both parents / carers and children and young people came up in all the discussion areas. Many reported young people's anxiety increasing

**“...he insisted that everything that came into the house was wiped down with disinfectant and everybody had to spray their shoes when we come in, and change our clothing”**

Some reported behaviours becoming more extreme or regression in their child.

“During the first lockdown there was a

major regression and he was like ‘mum can you come and sleep with me?’ at like 16 (years old). We eventually had a phased exit out of it. He's fine, he's back to sleeping in his own bed by himself with the light out now but that was a big impact for him.”

The impact of a parent/carer's mental health on the rest of the family was also a topic for discussion with parents of disabled children and young people who were already running on empty finding the added stress of lockdown too much to manage.



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**“The strain on my mental health, trying to juggle everything, was really difficult... it’s like dominoes really, because if one of us goes down we’re all screwed.”**

“At first it was a bit novel and as each lockdown progressed it just hit harder and harder and harder. And I know for one thing I think that the point before Christmas I actually got to a point where I was struggling to cope.”

One quote summed up the importance of parent / carer mental health with ‘I’m also aware that if Mummy is stressed then I have three stressed children so the best and kindest thing I can do for myself is to not be stressed.’

There were some specific areas that participants identified as being particularly impactful on their mental health during this time.

## **Loneliness and Isolation**

The impact of being locked down and not seeing friends and family face to face affected everyone. Young people didn’t

necessarily understand what was going on and why they weren’t able to see other people.

**“A lot of X’s social life is school and the WECIL group he goes to, and because that wasn’t happening in person and school wasn’t happening he got quite withdrawn and lonely and missed his friends.”**

And parents /carers lost the vital sources of support that they would usually turn to or found that their needs were being ignored.

“...they deal with my son, but no one ever asks ‘and how are you?’... I’ve never had that kind of support and it’s worse during COVID because you can’t see friends and let off steam and do all the things that usually would of helped”

“I found that I was also missing out on the conversation with other people while activities were going on. That was my therapy, and I didn’t even realise it until that wasn’t happening anymore.”

The Loneliest Lockdown Pears Foundation Survey in March of 2021 found that **49% of disabled children had not seen a friend either online or in person in the previous month** and that three in five parents were feeling socially isolated and at risk of developing serious mental health issues.

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## Lack of Access To Open Space

Families in our survey identified how important access to safe outside spaces was, particularly for children with autism. In the early stages of the pandemic, not having the opportunity to let off steam in a safe space, feeling trapped in an unsafe environment or not having exposure to the everyday sensory stimulation that they usually would, all impacted on children and young people's wellbeing.

"The longer these children stay indoors the harder it is to get them out again, I can't even get my son to the little shops ... because they are so used to being indoors now the world outside is louder and brighter"

**"...during the first lockdown disabled people were discriminated against because you couldn't access the outside space that was quiet and required for them."**

"We really struggled with being in a flat with no outdoor space, we have had drug dealers fighting with hammers - that's the kind of normal things that would happen outside - so we didn't have a safe space to go to."

Our findings suggest that the impact of the pandemic on parent/carers mental health was significant compared to parents of non-disabled children and is borne out in findings by the Oxford University survey which found higher levels of stress, depression and anxiety

reported by parents who have children with special education needs and/or neurodevelopmental differences.

## Mental Health and Wellbeing - What would help?

The importance of discussing wellbeing and having access to counselling was identified as important by a number of participants although again, there was a lack of consistency in what was being offered.

**"So I think having counselling services that are available to carers is something that's really seriously missing and no service I've found so far is able to refer you to ongoing talking therapy."**

"The carers centre has been very good and they have provided 12 sessions of counselling and the possibility of having 6 extra and that is something that was useful."

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For other parent/carers it was having access to a safe open space for them and their children to let off steam.

**“Access to safe outdoor space especially for families living in inner city areas, this would of made a massive difference to us”**

Or for someone just to show understanding, see them as individuals and check in to see how they were doing.

**“In terms of mental health support it just comes back to that phone call and an acknowledgment that this is really hard and to be able to let off steam”**



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## Next Steps and Messages to Agencies, LA's and Professionals

### Getting Back To 'Normal'

Something that participants identified as being potentially challenging was the notion of life 'getting back to normal'. Some felt that they wouldn't feel comfortable going straight back to face to face meetings or provision and that it would take time for children and young people to adjust to yet more changes.

“It would be useful to keep on having a blended approach to activities because let's say all the evening events are done physically, I'm not 100% sure we will feel confident in sending C to meet other groups of people, but at the same time I don't want him to miss out. So if there was that online option again then that would be useful.”

“It's really important to take it slow and steady, I also think there's value in the local

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authority and perhaps senco groups meeting up online to discuss how they can do this inclusion and to meet the needs of young people”

## Summarising What Helps

In summary, our respondents identified a number of areas which would help now, and in the future.

Parents and carers want easily accessible and up to date information about services and provision, and professionals who are well informed and able to give advice about what is available to families who have a disabled child.

They would like to have flexibility and be trusted to make decisions on the best ways to use Direct Payments or funding for their children and a clear and consistent approach in what Direct Payments can be used for.

In the case of another lockdown they would like to see that all children with an EHCP be offered a place at school and that work sent home to be tailored to their children’s needs. They would also like the social and emotional needs of their children to be considered.

They would welcome regular check ins from professionals who have an understanding of the whole family, and who treat everyone as individuals.

They would like consistency in messaging from government and local authorities and collaboration between agencies, joined up thinking and joined up services.

## Feedback From Participating in the Research

Finally, we asked parents and carers what it had been like taking part in this research.

“This has been the first time when someone has actually listened to me.”



**“This has been the first time when someone has actually listened to me.”**

**“I have a child who is disabled and therefore I have a voice and I don’t want my experience to go to waste.”**

“I don’t want to be somebody who sits and ‘gives out’ about the lack of services or things that are missing if I’m not prepared to stand up and have a say in it.”

**“I wanted to attend to add my views as I know a lot of parents of disabled children don’t speak out for fear of rocking the boat or that support might get taken away.”**

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“We’re the survivors, we’re the ones who are holding it together, we’re the ones who do the extra research. We’re the ones who support everything and yet we are so finely balanced.”

**“...we’re the group that cope and therefore the state has forgotten about us, because we cope.”**

We would like to thank each and every family for participating in this survey and for giving up their time and offering their feedback so honestly in such difficult circumstances.

## Next Steps

It is hoped that this survey can inform good practice in the event of future lockdown’s or national crises, but also provide an insight for professionals who work with these families as many of the issues which arose are not just confined to a pandemic, but are experienced on a daily basis by the parents and carers and disabled children and young people we work with.

WECIL are now in the process of developing a sustainable parent/carers support network and working closely with other groups to ensure better shared understanding of the experiences of families with a disabled child and how these experiences can be improved.







Address: The Vassall Centre, Gill Ave, Fishponds, Bristol, BS16 2QQ  
**Telephone:** 0117 947 9922 | **Charity Number:** 1053515

[www.wecil.co.uk](http://www.wecil.co.uk)