



An Analysis of the Survey

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

Overview of the Survey and Next Steps

The “experiences of disabled children and their families during the COVID-19 pandemic” survey was launched by WECIL in October of 2020 and asked families to share their experiences of the COVID-19 crisis. Now, receiving 54 responses, this survey and the analysis is being used to aid discussion and questions to take forward to the focus groups set up for Bristol, BANES and South Gloucestershire parents. We have invited staff from Bristol and BANES Council to attend these focus groups as an opportunity for families to speak directly to those who have the influence and power to make change.

Main Findings

Personal Assistants/Care Workers

There are several issues that were presented within the topic of Personal Assistants (PAs) and Care Workers. Firstly, families felt anxious about having PAs and Care Workers 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 also not able to access the appropriate level of care for their child. This included issues such as a lack of experience, a lack of ability to manage considered complex behaviours and/or needs, and some were not able to offer the necessary amount of care. Lastly, the responses indicated that during the time in which Personal Assistants and/or Care Workers were unable to provide care, families took on this responsibility without any professional support.

Direct Payments

There were several responses that indicated confusion about direct payments, specifically about how they should or should not be used. Those who were confused, were unaware as to whether they should have been using a Direct Payment 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. These statements

demonstrate that confusion around Direct Payments was felt by many within this survey.

Special Schools

In March 2020 the government stated that children with [EHCP's would still be able to attend school](#), however the survey responses indicated that this was not adhered to. A participant mentioned periods of “no school attendance” as well as a “reduced” attendance for the latter part of the year. Help offered by special schools was limited, e.g., lack of one to ones, or the work set was inappropriate for the child. There was a suggestion that special schools were not adequately supported by the Local Authority. Furthermore, Local Authorities may have interpreted or applied government guidelines differently. For example, in South Gloucestershire residents 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 a difference 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 [unfair differences](#) between special education and mainstream schooling and thus the contrasting level of support that children receive.

Feeling Abandoned by Professionals

There was a common theme of feeling let down and forgotten about by professionals within this survey. In addition, the responses also touched on the comparison between the great deal of support they used to receive prior to the pandemic and the drastic decrease in support they now see:

“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 and should therefore be recognised as a priority issue.

Issues with Obtaining Prescriptions and Appointments

When referring to prescriptions and appointments most participants spoke of limited access, long waiting times for the issue of prescriptions and cancelled appointments. What is intriguing about this is that from reading the responses on this theme, it could be suggested that the importance of these prescriptions and appointments was not appreciated. 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 check ups in order to monitor different health problems among physical development and learning.”

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

Impact on Mental Health - Feelings of Isolation and Stress

High levels of anxiety presented itself as the most recurring theme, along with feelings of depression and isolation. In addition, COVID-19 had a dramatic impact on the family's mental health as well as that

of the child. For example, one respondent explained how she became “extremely anxious about my son's health and I'm now under the doctor for anxiety and depression”. Another stated, “...[the] change in routine, has increased my child's anxiety to the point they won't leave the house at all.” This demonstrates the severity of how it has impacted the families. Furthermore, there was a noticeable relationship between feeling let down by professionals - as discussed earlier in the report - and families therefore 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”

This depicts that families are struggling with mental health, perhaps as a consequence of feeling they have been abandoned by professional support networks.

Impact on Other Siblings

Another common struggle for family members during the pandemic, was the impact on the family unit, including siblings. For example, the impact of the lack of support some disabled children received was such that their distress expressed itself with changes in behaviour. 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 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 stemmed from the lack of attention given to disabled children themselves. The impact on their own mental health, well-being and overall health cannot be underestimated.

What next?

We have organised Focus Groups for parents based in Bristol, BANES and South Gloucestershire. To sign up, select a date/time and click on one of the links below

Bristol Focus Groups

- [Wednesday 24th February at 1.30](#)
- [Wednesday 24th February at 18.30](#)
- [Wednesday 3rd March at 1.30](#)
- [Wednesday 3rd March at 18.30](#)

Bath and North East Somerset

- [Monday 22nd February at 18.30](#)

South Gloucestershire

- [Tuesday 23rd February at 18.30](#)

Please click on the links to sign up. For further information you can also visit our [website](#).

