

THE **IMPACT** OF

THE PANDEMIC ON

DISABLED CHILDREN'S

ACCESS TO SERVICES

Alongside the work of a national coalition of charities and organisations, our survey findings reveal an alarming reduction in disabled children's access to vital services and facilities – plus a drop in support for parents and carers.



caudwell
children

Changing Children's Lives

Introduction

At Caudwell Children we have seen first-hand the difficulties that the Covid-19 pandemic has posed for disabled children and their families.

Where possible we have continued to deliver our services, remotely in some cases, to ensure that children and families could access the support that they need and deserve.

We know that families rely on a wide range of support, however, and therefore we wanted to find out what impact the pandemic has had on the lives of disabled children and those around them.

This follows the important work set out in the Council for Disabled Children's 'Left In Lockdown' report and the Disabled Children's Partnership's 'No End In Sight' report – both of which presented a national picture of the impact of the pandemic on disabled children and their families.

The Disabled Children's Partnership (DCP) is a coalition of 80 national organisations – including Caudwell Children. Throughout the pandemic, the DCP has carried out a series of surveys with a representative panel of families from across the UK.

Following their lead, we wanted to get a sense of the picture in the Staffordshire area, where our HQ is based, and recently carried out a survey of families whose children access our services.

We'll present the findings alongside the latest national picture from the DCP, which made clear that the families of disabled children feel abandoned by government.

What we did

To get a better understanding of the impact of the pandemic, especially during recent months, we surveyed parents and carers whose children attend Caudwell Children's Short Breaks activity clubs.

The clubs provide weekly activities for children and young people – delivered in partnership with local authorities in Staffordshire, Stoke-on-Trent, Cheshire East and Nottinghamshire.

Parents and carers were asked to fill out a 10-question survey. The survey received a 100% completion rate from 44 respondents – all of whom have a disabled child in their care.

The national picture: findings and recommendations from the Disabled Children's Partnership

Key findings from the DCP report:

- Despite the easing of lockdown restrictions, a high proportion of disabled children and their families are still experiencing severe levels of social isolation
- More than half of families are unable to access therapies vital for their child's disability.
- Sixty percent are experiencing delays and challenges with accessing the health service appointments they need

- Forty-eight percent of parents reported that they are still unable to access support at their child's school or educational placement that they had received before the pandemic
- Forty-nine percent of families sought help from charities or organisations
- Sixty-five percent of parents scores reflect possible or probable depression in their child

Key recommendations from the DCP report:

- A therapies catch-up plan to address where children have regressed or plateaued in their speech, communication, physical development, or social skills.
- Short breaks for families to address high levels of family exhaustion.
- Flexibility to extend or allow repeat funding for young people in further education, especially where courses to facilitate independence and employability have been impacted.
- Additional support for children and young people at key transition points.
- Additional support for the mental health and wellbeing of children and families.
- Access to activities to overcome the social isolation that many have suffered during lockdown.

What did people say – key findings

- The vast majority (95%) of respondents think their caring responsibilities have increased in recent months.
- Most (84%) respondents say that access to services that their child relies on has decreased in recent months.
- Three-quarters (75%) of respondents say that the support provided to their child has decreased in recent months.
- Three-quarters (77%) of respondents agreed when asked if they need a break from, or extra support with, caring responsibilities.
- Almost two-thirds (59%) of respondents say they have typically had less than half an hour of free time each day during lockdown.
- More than a third (43%) of respondents believe their child's physical health is worse than before the pandemic. With only 2% reporting an improvement.
- More than half (52%) of respondents believe their child's mental health is worse than before the pandemic. With only 2% reporting an improvement.
- More than two-thirds (70%) of respondents believe that their child's access to inclusive sports clubs and facilities is worse than before the pandemic. None of our respondents believe that access has improved.
- Two-thirds (66%) of respondents believe they are in a worse financial position to afford to pay for equipment for their child since the outbreak of the pandemic.

What respondents told us

Without charities like Caudwell Children you are lucky to get the bare minimum.

The main obstacle is having to chase for hospital appointments and updates. Our child has been forgotten multiple times.

Services are overstretched so referrals are being refused.

We feel let down by all services and isolated.

It is difficult to find who to ask for support and to even know what support to look for. It's difficult to seek support for things if you don't know it's available in the first place. It would be nice to have support for parents in supporting their child as my husband has really struggled and is also experiencing poor mental health partly due to feeling helpless with my autistic son.

I begged for my autistic daughter to go to a short-stay specialist school as she was self-harming at home, but was left and she deteriorated to the point she couldn't leave the house. She was never previously that bad - schools and the local authority have failed my daughter and family.

The hardest part for me has been that our children rely on us so much for all the answers and during Covid-19 the rules change so often that I don't have the answers our daughter needs to hear. Me being a bit 'lost' in it all has made it worse for her.

They should never have shut services and schools for children with special needs during the pandemic.

I am beyond exhausted.

I need a break with my family.

These are very difficult times.

We are still waiting for Disability Living Allowance renewal to take place, after nearly a year, for both children. Being without their payments has been incredibly stressful and we have had to get the MP involved. The Department for Work & Pensions have used Covid-19 as the excuse. It's simply not good enough.

Conclusion

The findings revealed by this survey clearly convey some of the difficulties faced by families for more than a year. It has evidently been a challenging time for disabled children and those around them.

The findings suggest a direct link between disabled children's wellbeing and access to vital services and support.

We hope that this, and many other lessons from the pandemic are taken on board and help to shape a more inclusive future. One in which parents and carers do not feel that have to battle to access services for their child.

What Caudwell Children is doing to help

Here's just some of the ways that Caudwell Children is helping to fight for such a future:

- Offered Short Breaks activity clubs to more than 450 children from across Staffordshire, Cheshire and Nottinghamshire since the beginning of 2020 – providing families weekly respite and to offer children fun sessions that build their confidence and skills.
- Supporting more than 6,500 disabled children from across the U.K. annually – with an ambition to support 11,000 children this year.

- In 2019 we opened the UK's first purpose-built centre dedicated to the assessment, support and research of autism – the Caudwell International Children's Centre in Staffordshire. The award-winning centre was designed to consider sensory input at every stage of a child's journey through the building.
- Providing services worth over £85 million to more 58,000 children with 652 different medical conditions since our charity was registered in March 2000.
- Offering specialist direct family support, funding for equipment, treatment and therapy as well as digital skills training to help autistic youngsters find work and short breaks services to help disabled children build their skills and confidence.

Calling for systemic change and providing a voice for

- disabled children and their families on several UK-wide All Party Parliamentary Groups, and internationally at the United Nations.

How Caudwell Children will use these findings

As set out above, the findings in this report form a local snapshot of the broader picture already presented by the Disabled Children's Partnership.

Caudwell Children will present the findings and responses from parents in our area to MPs in Staffordshire and Stoke-on-Trent.

We'll be encouraging them to join the Disabled Children's Partnership's call for MPs and peers to become Disabled Children's Champions – pledging their voice to a campaign to ensure disabled children are no longer shut out of the public conversation during, and beyond, the Covid-19 pandemic.

Feel free to tag @CaudwellChildren on social media to let us know your lockdown stories. You can also write to your MP and encourage them to join the campaign. You can find their details here.

How you can help Caudwell Children to do more

We're working hard to provide access to the services children and families tell us that they need – but we're reliant on your support to make that happen.

- By making a **contribution** to Caudwell Children you can help us to support more children and families across the U.K - www.caudwellchildren.com/donate.
- Because we want to spend every penny supporting children and families, we don't spend money on advertising or television broadcasts. So why not **tell someone about what Caudwell Children can offer** and help us to reach more people that need our support.
- We're always on the lookout for more supporters, so we'd love it if you decided to **host a fundraiser on behalf of Caudwell Children** – get your friends and family involved and have some fun while helping us to deliver vital services.