

REPORT - HOW

ACCESSIBLE IS MOBILITY

EQUIPMENT FOR

DISABLED CHILDREN?

A survey of Caudwell Children's beneficiaries reveals the difficulties families face when trying to access mobility equipment for a disabled child.



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Introduction

At Caudwell Children we have 21 years of first-hand experience supporting disabled children and their families as they attempt to access the services, equipment, therapies and treatments they need.

Those challenges have been exacerbated by the Covid-19 pandemic, and the strains it has placed on the health and social care system.

Caudwell Children has continued to support families through this difficult period – delivering our services, remotely in some cases, to ensure that children and families could access the support that they need and deserve.

This follows our report *'The Impact of the Pandemic on Disabled Children's Access To Services in Staffordshire'* which was published earlier this year.

That report built on the work of the Disabled Children's Partnership and drilled down into how parents and carers in Staffordshire – where our HQ is based – feel about the state of social care services in the wake of the pandemic.

What we did to compile this report

To help us continue to support families as effectively as possible, we surveyed parents and carers whose child uses mobility equipment.

The survey asked a series of questions about the ease and timeframe of accessing support for disabled children – with a particular focus on mobility equipment such as wheelchairs.

Parents and carers completed a short 9-question survey. We wanted to hear from parents and carers who have been, or continue to be, supported by Caudwell Children.

A total of 59 parents and carers, all of whom have a disabled child in their care, completed the survey.

What people said - the key findings

More than two-thirds of parents and carers (69%) believe their **chances of getting vital mobility equipment for their child decreased** during the pandemic.

Two-thirds (66%) of children had wait more than 6-12 months for vital mobility equipment after their needs became apparent.

Almost **three-quarters (71%) of parents and carers do not believe that their child has all of the mobility equipment that they need.**

More than one in five (21%) of **parents and carers who applied to a healthcare trust of Government authority for support had to wait more than two years to receive mobility equipment for their child.**

Almost two-thirds of parents and carers say **it would take more than two-years to save for the mobility equipment their child needs.**

The vast majority of parents and carers report that **mobility equipment has improved their child's quality of life (85%)** and allowed their child take part in more experiences (88%).

A third (33%) of parents and carers report that **facilities like schools, public venues and public transport are not accessible** for children who use mobility equipment.

Case study - Donna and her son Dylan

In response, mum Donna got in touch to tell us about the difficulties she faces trying to access wheelchair support and services for her disabled son Dylan, pictured.

Donna wrote to us to shine a light on their story. The family live in Cheshire, so their story reflects largely on the provision of services in their area – but, we believe, is reflective of the inconsistencies in the system as a whole.



“ *Wheelchair services are a complete postcode lottery; in our area they could be considered discriminatory against autistic children.*

My son has Mosaic Neurofibromatosis type 1, Learning Difficulties, hypermobility syndrome and Autism Spectrum Condition (ASC).

He suffers pains in his legs coupled with severe fatigue that makes it hard for him to walk.

In addition, his ASC means that he's hugely anxious that his legs are going to hurt so he is often unable to even attempt to walk.

His ASC also means he is easily overwhelmed in busy, noisy or unfamiliar situations which further contributes to his difficulties.

He has had a blue badge since he was seven years old, and we now get high rate mobility.

Nevertheless, our local authority doesn't acknowledge that he needs a wheelchair. Their policy is that only children who need to use a wheelchair within their own homes should be supported.

In other words, in order to qualify for help the child must be effectively wheelchair-bound at all times.

They consider that wheelchair use outside the home is purely a social convenience, not a necessity!

However, my son is now 13 years old; well past an age at which I could carry him.

We live in a rural area. Without a wheelchair we'd be unable to walk to the park to play with friends, go to the library, or to any of the local shops.

We'd be unable to go into town to the shops, or the bank or anything that most people take for granted. That is an inadequate level of support for a disabled child.

It is hugely unfair that local authorities offer different levels of wheelchair support for disabled children. In other areas we would be eligible for help – Donna

Without his wheelchair he would be unable to enjoy a trip to the zoo, visit a castle – which he loves – or take part in any kind of educational field trip or workshop.

He would in fact be a prisoner in his own home as he is frequently unable to walk at all outside.

This year we will need to replace both his chairs. Because of where we live we have a three-wheeler and a normal wheelchair. Dylan has outgrown both.

We are currently living on one wage because I am a full-time carer to both my son and my father-in-law. So finding the money to replace two wheelchairs isn't easy, despite my son being in receipt of HRM.

Over the years we have spent thousands of pounds making sure our son has the same access to life that a child without challenges would have.

It is hugely unfair that in other local authorities we would be eligible for help from wheelchair services, whilst in our current authority his difficulties – and the difficulties of many children like him – are simply dismissed. ”

Conclusion

We know, from previous research, that parents and carers often report a direct link between disabled children's wellbeing and access to vital services and support.

It is also patently obvious that the pandemic has had a profound impact on disabled children's access to such services and support.

So it is perhaps not surprising that 69% of parents and carers say their child's chances of getting vital mobility equipment have decreased.

It is, however, shocking – and a fact that needs to be addressed urgently.


Earlier this year the Government published its long-awaited National Disability Strategy, setting out 120 commitments, including £3.82million of funding for very welcome disability awareness training in schools and colleges.

What the Government must now do, to address both the challenges that led to the strategy and the findings of this report and others like it, is urgently set out further detail.

That extra detail **must** include publishing the overdue SEND review and a commitment to long-term investment and support for health and social care services.

The structural inequalities in our society need to be urgently addressed, to ensure as a country we build back better and **fairer** for disabled people.

What Caudwell Children is already doing to help

- Providing specialised equipment for disabled children and their families – since our charity was registered in March 2000 we have provided services worth over £85 million to more 58,000 children with 652 different medical conditions.
 - 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.
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How Caudwell Children will use this report's findings

We've constantly strive to amplify the voices of disabled children and their families – and this report is no different.

Its findings will inform our engagement with Government at a local, national and international level.

Caudwell Children will continue to work with partners from across Government while also trying to lead the way by showcasing how the practical and emotional support that disabled children and families need on a daily basis can be delivered more effectively.

You can support us in that endeavour by sharing the findings of this report with your friends, family and even your local MP. 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 monthly contribution** to Caudwell Children you can help us to support more children and families across the U.K.
- 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 for disabled children.



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