



Disabled
Children's
Partnership

What childcare?

Childcare Survey of Parents of Disabled Children

Research by the Learning Hub at the Disabled Children's Partnership

Executive Summary

Good quality childcare offers children opportunities to socialise and to have fun with other children. It supports their social, emotional and physical development as they grow and develop, learning and gaining confidence as they go. Good availability of childcare supports parents who choose to work or study, fulfil other caring activities or have valuable time to themselves. Childcare provision may be formal childcare at a local school or private day nursery or may be provided by a local childminder.

The first phase of the roll out of government funded childcare commenced in April 2024, with the aim to provide 30 hours of childcare per week to all children under the age of 5 by September 2025¹. However, the National Audit Office assessed confidence in meeting the planned milestones as problematic². The context surrounding this includes a decline in the numbers of childcare providers since 2015³ resulting in a reduction in the availability of childcare for all children over recent years. This is a particular issue for disabled children, with other research reporting the availability of childcare at just 6% for this group⁴.

Childcare for the under 5 age group is just one aspect of childcare. Childcare exists for school age children as a wrap-around provision to the school day, in the form of breakfast and after school clubs. Again, this provision exists as a mix of local authority, private providers and childminders. For families with non-disabled children over time the need for childcare provision may subside as children move through the high school age groups and become independent. However, many disabled children still need childcare outside of school day to ensure they are safe and have the support they need.

The Disabled Children's Partnership is a coalition of over 120 organisations that campaign to improve health and social care for disabled children, young people and their families. Parents tell us about the difficulties they face finding suitable childcare to meet both their disabled child's needs and their needs as a family. We conducted an online survey between February and April 2024 to understand the current issues facing families of disabled children, 920 parents responded.

Our findings reveal that just 1 in 4 parents of disabled children have secured a childcare place, with just a third of those indicating that the provision meets their disabled child's needs, at a time or location needed as a family. Of those unable to secure childcare, 2 in 5 are unable to find provision that can meet their disabled child's needs, reasons for this include staffing expertise, training, accessibility of provision and equipment needed.

Almost half (45%) of families have to travel more than 3 miles to access childcare provision. In addition to travel time and direct travel costs, there are cost implications for families, with 1 in 5 paying over £100 per day for childcare. It is common for parents to report over-subscribed provision and long delays waiting for childcare places. Almost two thirds (65%) report waiting over 6 months, with 32% of those waiting for more than 12 months.

The lack of available childcare for disabled children impacts the whole family.

- **Just over half (51%) of parents are unable to work due to lack of available childcare.**
- **Just under half (45%) of parents have to work fewer hours than they would like to.**
- **1 in 4 parents say it affects the amount of time they can spend with their children.**
- **1 in 5 parents say it affects the amount of time their disabled child can spend with friends.**

Compared to parents with non-disabled children, parents of disabled children who can secure childcare are faced with a battle with local authorities to find provision; long waits to put that provision in place; increased costs at a time of unprecedented pressures on household finances and additional travel time to get to specialised provision. This leaves families with reduced quality time together and disabled children missing out on opportunities to meet friends and develop social skills to enable them to develop confidence as they grow. As the parent below illustrates, lack of available provision means that families accept places that are not as specialised as they need.

Everything related to getting childcare support ends up as a compromise. So we have something that nearly works for us. A bit too far but 45min drive is good enough. Staff skills are low but good enough to meet our child's needs. We take what dates we are offered. We have fought for years with social services and the provider, so it is nearly a working compromise.

More childcare places for disabled children are urgently needed to address the gap in local affordable specialised provision, so that disabled children and their families can thrive and have the same opportunities as other families.

Our findings reveal that just 1 in 4 parents of disabled children have secured a childcare place.

Recommendations

- Government to monitor the roll out of its childcare entitlement to ensure the needs of disabled children and their families are being met; and that funding is sufficient for providers to be able to meet children's needs.
- Government to provide funding to support childcare provision for older disabled children.
- Local authorities to ensure their childcare sufficiency assessments include accurate data on disabled children.
- Local authorities to work proactively with parents to understand their childcare needs and support settings to make suitable provision near to home.





Detailed findings

Introduction

The Disabled Children's Partnership is a coalition of more than 120 organisations that campaign for improved health and social care for disabled children and their families in England. An online survey with parents of disabled children and young people 0-25 years was conducted between February and April 2024. The aim of the survey was to better understand current experiences of the families of disabled children in accessing childcare provision. 920 parents took part in our survey. The following report outlines the results of the survey.

The survey took place in the run up to the expansion of childcare provision in England. In April 2024, the first phase of government plans to provide 30 hours of free childcare for all children under the age of five by September 2025 commenced. Our previous research into the provision of holiday clubs⁵ for disabled children found that parents were faced with poor access to provision, in the form of fragmented or oversubscribed services and providers unable or unwilling to meet their children's specific needs. This report reveals current experiences of parents with disabled children.

Demographics

74% of parents taking part in our survey had two or more children. 76% of parents had one disabled child and 24% had two or more disabled children representing just over 1000 disabled children and young people.

The majority of parents had disabled children who were of school age. 34% of disabled children aged 5-10 and 30% aged 11-15 years. 26% of disabled young people were 16-25 years and 10% were under 5 years.

Responses were received from all English regions.

Table 1 below shows the proportion of responses received by region. The highest proportion of responses were received from the parents in the South East and lowest proportion from the North East.

Table 1: Proportion of survey response by region

Region	Proportion of responses
South East	20%
London	16%
South West	12%
Yorkshire & Humber	11%
East of England	11%
North West	10%
West Midlands	8%
East Midlands	7%
North East	4%

Childcare Availability

Our findings highlight the lack of local, affordable, accessible or specialist provision that meets the needs of disabled children and young people at a time or place convenient for their family. Just 1 in 4 parents responding to our survey stated that they had a childcare place. Even more concerning is that of those, just 1 in 3 said that the place they had could both meet their disabled child's needs and was in a location and at a time that their family needed.

Many families that had a childcare place had taken that place despite the needs of their child not being met. They describe a situation where the length of time their child can attend is limited as the provision can only provide adequate support for short amounts of time.

They can only give me 6 hours a week as he needs one to one support and they can't provide that.

I'm still unable to work as we have just two sessions for three hours each session.

We are dictated dates and times that we have to use.

There's childcare provision available but demand is high and the availability seems to be for a day only so there is no consistency which is important for a child, especially those with learning disability or autism.

The pattern was similar for parents currently without a childcare place. Two in five parents reported that providers were unable to meet the needs associated with their child's disability, as examples given by parents demonstrate below.

There is no suitable childcare in my area for when school is shut. Due to my child having epilepsy, no provision is trained in issuing his rescue medication for prolonged seizures.

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There is no childcare available that meets my sons medical and physical needs

Disabled children may need help with their personal care for example with toileting, eating or changing. Parents report this not being available for disabled children as they grow.

I cannot find any suitable childcare that offers the level of support and personal care needs for my child

My child goes to a mainstream nursery and had a one-to-one. She no longer has a one-to-one...the issue is toileting as my child isn't fully potty trained.

It was common for parents to report the lack of a one-to-one staff member to be the main barrier in finding, either provided through the setting or for families sourcing their own personal assistants.

Social care is supposed to be sorting out a carer, but this has so far taken 7 months

We're awaiting a nursery place but a one-to-one needs to be found

The reasons for this were related to either the lack of staff available to provide one to one support, or that staff with the specialised training needed were not available.

I have a direct payment - but it's hard to find people to do the job

I have no idea where to go to find someone who is capable of caring for my son's medical and additional needs

Childminders do not have any training for autistic children

In addition, those without current childcare report finding a place that should meet needs but were unable to and alternatives not provided.

It went wrong as it was not specific for disabilities or accessible despite marketing advertising that it was. No alternative was given

Many families had children who attended specialist schools but despite this reported that the schools did not offer childcare provision around usual school hours.

He is in a specialist provision but they don't offer after school provision, because it's a small school. It's also hard to get a childminder or any other support.

My son is autistic and attends a resource provision attached to a mainstream. The only option for school holidays or pre and post school care would be if his resource provision offered it. Why shouldn't it be standard given need for every special school and resource provision to offer this?

Often the childcare is fragmented, with families relying on more than one childcare provider and available during term time only. This leaves families unable work the hours they want to, relying on a combination of support to continue to work.

We have a place at a special needs school and have found a childminder. All of this effort has been ours and there's no after school or summer clubs available at all.

Childcare for my son is non-existent and has been for many years. We rely on my husband working from home, elderly grandparents helping out sometimes and me taking unpaid leave from work. There is literally no other option.

A clear gap in provision for families, is for those with older disabled children. Those who secure childcare for their child when young worry as they get older due to the lack of places available for the older age group.

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There are insufficient care placements as my son gets older. As a working parent I may have to leave work due to this

It's hard to find childcare for high school age but being disabled they aren't safe to be left home alone

There is nothing suitable for disabled teenagers and young adults. There is nothing suitable for my 7 year-old

There is no childcare for teens with disability although I live in the largest urban centre in the county. You just get sent a list of childminders none of whom cater for this age group. You can access some support through social care if you meet the high threshold. If you get direct payments via social care the hourly rate is too low to find anyone

Local authority funding was attributed to reduced provision and the way that financial support was allocated to disabled children and their families. Parents referred to organisations closing and the local authority restricting the provision they could use for childcare, with parents having to top up the payment cost as allocated funds did not fully cover costs of the childcare provider.

The only suitable club has been taken away as it closed

It's part time but we both work full time so it's a massive strain. LA provision stops at 3pm when the working day ends at 5:30pm.

I can only use registered enablers that are approved by the Local Authority

Cost of Childcare

The cost for all types of childcare continues to rise in England. The cost of living crisis has meant the cost of childcare is just one aspect of pressure on the household. Rising costs of food, bills and childcare has meant that some parents have had to reduce their working hours due to the cost of childcare. One in four of disabled children have told us that they are currently paying over £100 per day for their childcare provision.

When I did have a childcare place with a private provider due to his needs I had to pay more than the other families. I was paying more in childcare than I actually earned that day.

You have to take into account that paying childcare takes a big chunk of your income on a basic salary, meaning you work to pay childcare, plus bills, transport, food, etc. leaving you with no savings at all.

The issue I have is after school care. There just isn't anything suitable I can find. In holidays I've been able to access clubs not necessarily aimed at children with SEND but who have agreed to accept my son following risk assessments. But I have had to radically reduce my hours and as a single parent the cost of living crisis is really making it difficult to make ends meet.

In addition to the cost of childcare, families with disabled children have additional travel costs due to the location of childcare, again adding pressure to the household budget.

Our childcare costs more for specialism and availability is out of borough. We have a part time place at a private specialist nursery that we currently pay for even though our daughter has an EHCP.

Distance

The statutory walking distance for the allocation of school places is 2 miles for children between 5 and 8 years and 3 miles for those over 8 and under 16 years. However, childcare does not have the same requirements as school places, meaning almost half (45%) of disabled children travel more than three miles to their childcare place.

There are no childcare options for a disabled child? No places, schools, nurseries, after school clubs that cater for disabled children in my area. It's all over 40 minutes away.

I take 4 buses per day (totalling at least 4 hours travel) x 3 days per week. Journey is 10 miles each way. We are very lucky that this provision exists, therefore I do not resent the journey, however I do recognise that it is not ideal and one of the factors that prevents me from working.

Childcare in a mainstream setting is close and the specialist setting is an hour away but is the one that meets our needs.

As illustrated by the parent quotes above, it is common for families of disabled children to travel the extra distance to access specialist provision that is not available locally. The extra travel time does reduce the time available for families to be together and disabled children to be with friends.

The role a diagnosis plays in accessing specialist provision comes into play in terms of understanding needs that should be met when accessing childcare. However, with delays in diagnosis and appointments now commonplace across health care, this will have an additional impact on families who would otherwise access childcare.

I don't feel confident using childcare when we are still waiting to find out about his diagnosis, we need to be sure before we do that.

Waiting Times

As we have discussed above, provision is in short supply for families of disabled children and many travel further in order to access childcare that can adequately meet their child's needs. This also means that many families find themselves waiting for provision that is oversubscribed with long delays.

65% of parents with disabled children state that they have waited more than six months for a childcare place, with 32% of those waiting more than a year. Families are also waiting for places at more than one provision.

We are on three waiting lists for school holiday cover and been on waiting list for over a year.

Our son has complex needs. Facilities generally are not able to provide one-to-one care for him or do not have enough first aid trained staff. Also the ones that we've approached are always full.

Waiting lists for mainstream nurseries are 2+ years for children requiring no SEN provisions, let alone one-to-one care. As such, waiting for my daughter to enter school in 2025 is our only viable option.

I have been trying for over 6 months with no joy, I'm tired of chasing up all the time on top of all the cares for my child.

I was on the waiting list for 8 months but now the funding has been cut. The local authority have paid a broker to arrange childcare and we have no support. We are given a directory to go through and we have to phone round and it is taking far too long.

My son has been on the waitlist since 2021 and if lucky will get a place in 2025. When I say place he will get 12 days a year if lucky- that's not childcare. It will cause a family breakdown as we cannot have him home and one of us will have to give up work.

As demonstrated by the last quote above, the lack of available childcare and long delays add additional pressure to family life, further described in the next section.

Impact of lack of childcare on disabled children and their families

Travelling further to access childcare means that disabled children have less chance to make friends from their local neighbourhood, leaving them more at risk of isolation than their non-disabled peer group.

My child spends less time with other peers and joining in with activities because they cannot cater for my child. It affects my child's mental health and wellbeing.

I hope that there is improvements in equality of access to additional childcare programs so that my child can access similar Wrap Around Care options, as those of his peer age group (in typical mainstream settings).

My son attends a special school & I'm lucky to work from home so I can look after him in the holidays. Though this means he is isolated as there are no holiday clubs that are appropriate for him.

For families with more than one child, there was concern reported about the impact securing childcare for their non-disabled children and not their disabled child has on their self-esteem and self-worth.

My child with SEND is not allowed to attend before and after school and holiday clubs but her neurotypical twin sister can. This is discrimination and in breach of the Equality Act.



In addition to disabled children not having opportunities to be with friends, they also miss out on time with their own family. One in four parents report spending less time with their children to the lack of childcare provision. Parents describe the extra stress lack of accessible childcare places has on their mental health and stress levels.

I had to give up work due to no childcare. I also had a child at another school, so juggling that, lack of childcare and work was near impossible

I would pay for alternative care if I could find any - but I can't. My job is consequently at risk.

Luckily me and my husband have been able to request flexible hours at work, but we only see each other for one hour a day during term time week days, and we use all our holiday separately. Not ideal!

No autism aware childcare providers when I needed them, so I worked shifts opposite my partner and had family to help

In addition to the impact on family life, lack of available childcare creates an economic impact on families with disabled children, with parents unable to work as a consequence. More than half of parents of disabled children reported that they were unable to work due to the lack of childcare provision available. Just under half (45%) of parents with disabled children had to work fewer hours, adding to financial pressures for the family.

We had to fight to have the nursery place for our son and they can do only do 3 mornings a week in term time only - when all other non-disabled children can have the full hours wanted! Means I can work less and impacting us financially.

I have never had any childcare or been able to find any and have had to leave the workforce as a result.

They will only secure school hours, having been told by social care provider to give up my job.

Parents of non-disabled children are usually able to increase their working hours as their children get older and become more independent. Parents of disabled children may continue to need childcare as their children get older and therefore the lack of childcare may impact the family economy for much longer periods.

I cannot return to work as there is no suitable childcare for an older child that still needs childcare.

"I have never had any childcare or been able to find any and have had to leave the workforce as a result."

Conclusion

In summary, the poor availability of childcare is failing disabled children and their families. Without a range of affordable accessible childcare places, parents are unable to work the days and hours they need, adding to the financial burden of families.

Due to the lack of specialist provision locally, disabled children that do spend time at childcare spend additional time travelling, time that could be spent with their families and friends. Parents without childcare are worried that their disabled children are isolated and miss out on opportunities to meet new friends. It is vital that the government roll out of childcare places ensures that disabled children their families are not left behind.





References

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The Disabled Children's Partnership (DCP) is a growing coalition of more than 120 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).

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