

The Loneliest Summer

Holiday Club Survey of Parents of Disabled Children

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

Summary

Holiday Clubs provided during the school holidays offer children the chance to meet other children, socialise, increase social and learning skills and try out new hobbies and have fun. They enable parents to continue to work and carry out other household tasks. For the families of disabled children, holiday clubs also provide the opportunity for parents to have a break from their caring responsibilities and spend time with their other children. In addition, they help disabled children to manage the transition back to the new school term. However, families with disabled children too often find there is a lack of holiday club provision that can meet their child or family's needs, leaving them without support or fun activities over the holiday period, creating further pressure for the whole family, families who often live stressful and isolated lives.

My children will have no support during these holidays, I will have no support for the holidays, because the lack of understanding surrounding their disabilities mean they are unable to participate without being put at risk.

Parent of a disabled child

To explore this issue further, Contact and the Disabled Children's Partnership conducted an online survey about 1800 parents of disabled children and young people between, 17th June to 3rd July 2023. Parents responding to the survey care for just over 2000 disabled children and just under 1900 siblings. Despite, at the time of writing, summer holidays already starting in some parts of the UK, the majority of parents of disabled children responding to our survey are without suitable holiday clubs.

Key Findings

- just 4% have a holiday club for all the days and hours the family needs.
- 1 in 10 have been able to get any holiday club provision
- 42% unable to find out information about holiday club
- Worryingly, 37% of parents reported that holiday club providers could not meet their disabled child's needs
- 28% stated that the skills, knowledge and training of staff is not suitable for their disabled child

Parents report a lack of provision; plus fragmented oversubscribed provision or non-existent provision; providers unable or unwilling to meet their children's specific needs; and lack of information

In the absence of holiday club provision, parents are left with limited options in order to arrange care during the summer period.

- 28% of parents had to use holiday leave entitlement
- 27% need help from family and friends
- 19% have to reduce the hours that they work

We haven't been offered a place, if offered I'm told it would only be one/two sessions. My son desperately needs opportunities to engage with peers, there is nothing, which is appalling for a city which counts itself as inclusive

Parent of a disabled child

The impact of which is:

- More than half of parents report that their disabled child will be isolated due to the lack of provision over the summer.
- 44% of parents said that their disabled child will struggle to transition back to school.
- 78% of parents reporting that they will feel more stressed and anxious
- 73% of parents reporting that they will feel exhausted.
- Half of parents reporting that they will get less time with their other children.

The remainder of this report provides further detail of the barriers facing disabled children, who like their non-disabled peers would like to attend activities through the long summer break.

Recommendations

Parents need to feel confident that summer holiday club can meet their needs – good communication, inclusive and welcoming attitudes, a willingness to take small steps to make the activity or experience inclusive, taking parents' views on board to make this happen.

We are calling on the government and local councils to

- ensure that at least 15% of activities funded by the Holiday And Food programme funds are specifically for disabled youngsters. Equivalent schemes in the nations to be set the same target to ensure more places for disabled children across the UK.
- carry out an audit of local offers and how they cover holiday clubs and activities

- address the workforce issues in social care and childcare sector so there are more Personal Assistants, Enablers, Support Workers and Holiday Club staff.
- increase flexibility of direct payments so they can be used to pay for activities and holiday clubs for disabled children. Allow parents to pool money to put on activities suitable for their children.
- provide training on reasonable adjustment for providers - good communication, inclusive and welcoming attitudes, a willingness to take small steps to make the activity or experience inclusive, taking parents' views on board to make this happen.

Detailed Findings

Introduction

Contact and the Disabled Children's Partnership conducted an online survey between 17th June to 3rd July 2023. The aim of the survey was to explore in more detail the issues facing the parents of disabled children and young people who may wish to use a holiday club provision during the summer period, 2023.

Contact is a charity that supports families with disabled children across the UK. Contact is also one of the lead members of the Disabled Children's Partnership, a coalition of more than 110 organisations that campaigns for improved health and social for disabled children and their families.

The following report outlines the results of the survey, providing an understanding of the experiences of parents trying to identify holiday club provision and the impact that a lack of suitable holiday club provision has on the family of disabled children.

Who took part in our survey?

A total of 1794 parents took part in the online survey. Parents responding to the survey care for just over 2000 disabled children and just under 1900 of their siblings. As described below (see demographics), almost a quarter have more than one disabled child. Seven in ten respondents had a disabled child at school ages, 5-10 and 11-15 years. The majority (77%) of parents had two or more children.

More than a third of parent carers responding, do not work due to the lack of support or due to the caring responsibilities. Therefore, a lack of holiday club provision only adds to the pressures on parents who may wish to work.

I'm about to return from Mat leave but have been put out of work due to there being no access to holiday care for my disabled

I have had to leave jobs previously due to their being no suitable childcare services for him. Limits the job I can do and income the household can receive.

Parent Carer

Demographics

Number of disabled children

- | | |
|-------------------------------|-----|
| • 1 disabled child | 74% |
| • 2 disabled children | 21% |
| • 3 disabled children | 4% |
| • 4 or more disabled children | 1% |

Age of disabled children

- | | |
|-----------------|------|
| • Under 5 years | 6.5% |
| • 5-10 years | 37% |
| • 11-15 years | 33% |
| • 16-18 years | 13% |
| • 19-25 years | 11% |

Size of family

- | | |
|--------------|-----|
| • 1 child | 24% |
| • 2 children | 46% |
| • 3 children | 21% |
| • 4 children | 6% |
| • 5 or more | 4% |

Employment Status of Parents

- | | |
|---|-----|
| • Can no longer work /
had to stop work due to caring responsibilities | 36% |
| • Part-time employment | 32% |
| • Full-time employment | 18% |
| • Not in paid employment | 6% |
| • Other | 5% |
| • Education or Training | 1% |

Holiday Club provision

Eighty-one per cent of parents responding to our survey indicated that they wanted their disabled child to attend a holiday club this coming summer. Holiday clubs provide a range of benefits to disabled children, their parent and their siblings. The benefits that holiday club place brings to each member of the family of a disabled child are listed below.

Reasons for disabled children attending holiday clubs

- 79% so that disabled child(ren) can take part in activities during the school holidays
- 77% so that disabled child(ren) can meet other children and socialise
- 65% so parents can get a break from caring for their disabled child
- 53% so that disabled child(ren) can make new friends
- 40% so parents can attend work, study or training
- 38% so parents can spend more time with other child (ren).
- 30% to help with the transition between holiday time and school time

However, despite the clear benefits of holiday clubs, only 1 in 10 parents have been able to secure a holiday club place with just 4% of parents stated that the holiday club was available for the hours and days that they need. with less than a month before the school summer holiday begins. 57% of parents indicated that they are unable to identify a suitable place for their disabled child this summer, with 17% of parents still looking to identify a suitable place.

I just want to cry. I've no idea how I will cope

At the moment I do not know what we will do and I'm losing sleep over it
Parent Carer

A third of parents (33%) said that there were no holiday clubs available for their disabled child(ren) and a further third (30%) could not find information about appropriate holiday clubs.

For those who were aware of holiday club availability locally, the responses below highlight the intermittent and sparse availability throughout the summer period, presenting a challenge for many families. As mentioned above 30% of parents feel the holiday club helps the transition back to school. Many disabled children need structure and routine to maintain sensory regulation, stimulation and reduce anxiety and challenging behaviour. When such structure or routine is absent, disabled children's needs may increase not just in the home but also upon their return to school.

It's awful trying to get her back out into the world or settle at school when she's used to just seeing me and no one else and when she's not been around other children

Due to his challenging behaviour it can be difficult to take him out, leads to isolation and a lot of time in the house, a suitable holiday club would reduce this

Parent Carer

Poor transition back to the school or training environment undoes progress made during the previous academic year and impacts learning at the start of the next. Therefore, holiday club is more than just a place to go for disabled children. It is vital to disabled children's development and provides opportunity beyond the family to practice communication and life skills, improve confidence and social skills and return for the next academic year ready to make the most of educational or training opportunities.

Availability of holiday clubs

The most common provision reported by parents was just one or two mornings or afternoons per week over the course of the summer holidays. The intermittent level of provision

reported by parents does not meet disabled children's needs. For many, one or two sessions only, are more difficult due the need for structure and routine, resulting in more unsettled and challenging behaviour at home.

- Just one or two mornings a week with limited hours 39%
- Monday – Friday with limited hours (eg mornings or afternoons or shorter days eg 10am – 3pm) 18%
- One off activity 13%
- Monday – Friday for one or two weeks over the summer 13%
- Monday – Friday, 9am-5pm throughout the summer 8%

Parents were asked to indicate the reasons that they were unable to identify suitable holiday clubs (parents could choose more than one option), with the most common reasons given, associated with information and accessibility of provision.

- 42% unable to find information about a holiday club,
- 37% holiday club providers could not meet the needs of their disabled child
- 28% indicated that the skills, knowledge and training of staff is not suitable for their disabled children.

Even where providers are able to meet disabled children's needs, they cannot meet the demand for places, with 1 in 5 parents stating that holiday clubs they identified are oversubscribed.

Parents reported clubs that disabled children could attend but only if a parent or a sibling stayed to support them. This was something not required of non-disabled children, and clearly undermined many of the reasons for wanting a place.

I used a holiday club once that claimed to be disability trained. The staff made my child change her sister's incontinence pad. These providers have no idea what disability is

The holiday club that they attended at Easter left me dumbfounded, lack of risk assessment, lack of SEN training/understanding, lack supervision, putting my children at risk.

Parent Carers

The concerns around provision that was not accessible for disabled children related to the lack of 1:1 support, inability or unwillingness to support medical needs or

personal care and refusing disabled children due to equipment or medical devices such as wheelchairs or tracheostomies.

Holiday club isn't suitable to meet medical needs and no social care package (more than a year after needs identified) to set up anything else.

More assistance and suitable equipment is needed for changing & manual handling

I can't access other summer holiday groups as my son is a wheelchair user, needs one-to-one support, uses nappies, has learning disabilities and due to manual handling it's impossible to access any other childcare, apart from one that runs for two weeks only at his school, which is so over prescribed we might only get two or three days.

The few clubs that are available to a 5 year old who is still in nappies on a drop and go basis are of short duration and are full.

Parent Carers

The lack of choice also applied to the types of activities on offer, with sports or crafts not always provided in an appropriate way for disabled children.

More options that aren't sports or crafts. Gaming clubs, music production etc, especially for teens.

Parent Carer

There was a strong response from parents about the age that holiday clubs are targeted at. It was not uncommon for Parents of the oldest and youngest age groups to be told that holiday clubs were not available for their disabled child.

Now she is older, the clubs for teenagers are inappropriate but she is too old for other clubs. The only thing available that she can attend is a private sport's club that I cannot afford.

She cannot access any under 18 activities and there is nothing post 18 in the holidays. As she is still in full time college, she cannot access adult groups in term either.

Provision for teenagers who, due to disability are not able to participate in social activities alone yet, who still need some supervision but with age-appropriate activities is needed

Parent Carers

The cost-of-living crisis has also impacted parent's choices with 1 in 5 stating that the holiday clubs available are too expensive and 14% referring to the crisis and opting

out of holiday clubs as a consequence this coming summer. In addition, almost half (47%) of parents found that holiday clubs are more expensive due to their disabled child's needs. Due to the lack of available holiday clubs, it was common for parents to talk about giving up or reducing work to care for their disabled children, impacting their family finances further.

Husband is taking unpaid leave which is not helping our finances.

I may have to consider reducing my hours but this will be a great financial stress

I have changed to a term time only job which will impact my finances

I have had to leave jobs previously due to their being no suitable childcare services for him. It limits the job I can do and income the household can receive

Parent Carers

In the absence of holiday club provision parents are left with limited options in order to arrange care during the summer period. 28% of parents had to use holiday leave entitlement, 27% need help from family and friends, 19% have to reduce the hours that they work and 17% use flexible arrangements over the summer period.

My husband and I try to work our shift patterns so we can cover the childcare between us and then have time off together as a family. We find we are often on the verge of burnout especially during the 6 weeks holidays

I work limited ours, during school times and term times because I cannot find any alternative affordable care for my child

I become a less reliable team member at work as I have to take unpaid leave, whereas other parents with non disabled children all manage to cover the holidays with clubs

Parent Carers

However, the issue is not solely related to this coming summer, with 34% of parents reporting that they do not work due to problems finding care for their disabled children, including holiday clubs. The lack of holiday club provision for disabled children, is part of a much wider pattern when it comes to the lack of support generally available.

I am a full time carer 24/7, 365 days a year, we have no carers, no family or friends to help have budget in place for 3 years for 2-1 carers but none available and not allowed to use the budget for anything else!

I will just have to do it alone for the third year and pray I don't have a mental breakdown again.

Parent Carers

The impact that the lack of holiday club provision is outlined in further detail below.

Impact of lack of holiday club on disabled children and d their families

Parents unable to find holiday clubs for their disabled children report a detrimental impact on all members of the family. It results in disabled children feeling isolated and affects their transition back to education, with their confidence, self-esteem, relationships and mental health all negatively affected, as listed below:

Disabled Children

- Feeling Isolated 55%
- Struggles to transition back to school 44%
- Negatively affects self-esteem or confidence 43%
- Negatively affects friendships and relationships with family 43%
- More downhearted, tearful and weepy 24%
- Depressed 18%

Parents reported that the lack of holiday clubs also affect their disabled children's social skills, general development, with reduced physical activity or general movement also affecting their physical health.

He is autistic and in his own world a lot, but lack of holiday club means his social skills are impacted.

He has less variety in his daily life as he is already limited in most activities he can take part in and places he can go, so he is bored and his development is impacted

If we don't have help/holiday clubs to go to we cannot get out of the house and we see a massive deterioration in my child's behaviour.

They miss out on being an active part of society and trying new things and being with different people.

Parent Carer

Life skills and newly acquired social skills are reduced if disabled children do not attend holiday club for the whole of the summer. Opportunities to use skills are limited if the family are unable to access activities.

It negatively impacts my child's development. Right now he is forming tentative relationships and attempting to take part in group activity. My concern is that he will regress / not want to interact after 6 weeks

I would love for her to attend clubs so she gets to socialise as she's an only child. But it's always a fight to have someone accept her as they say she needs one-to-one but doesn't always. It's really hard. She deserves to get to spend time with other children and have fun

Parent Carers

Parents

Parents reported high levels of physical and mental exhaustion, in addition to serious isolation.

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|---|-----|
| • More stressed and anxious | 78% |
| • Feels exhausted | 73% |
| • Feel lonely | 52% |
| • Miss out on spending time with friends and family | 41% |
| • Need to leave the job I love | 11% |

We will be stuck in the house isolated. Both my boys use wheelchairs and cannot self-propel. PA hours have been cut by the LA so cannot leave the home

It affects my mental health as I get overwhelmed at home all day trying to work and keep her entertained.

My child does not have a school placement, so I'm unable to work. I'm unable to afford holiday clubs, days out or holidays. We are a very isolated family.

Sibling

Half of siblings are impacted by the lack of holiday club provision available for their disabled children, as they get less time with their parent and cannot enjoy activities along with their peers.

- | | |
|---|-----|
| • Get less time with parent | 50% |
| • Do not get to do the activities that they want to | 49% |

- Feel isolated 28%
- More downhearted, weepy and tearful 16%
- Lose confidence 16%
- Depressed 12%

Parents report the lack of opportunities for siblings impact on the dynamic of the family and siblings experience deterioration in their mental health.

My other child often goes down the negative spiral. If little brother plays up, he says, "It's ok see to him first he is more important than me!". Self-harm has been his go to response because I am not able to see to his needs as well as little brother's which are more care specific.

In the absence of holiday clubs, siblings take on additional caring roles and are unable to mix with friends and peers their own age.

My other children end up caring for their sibling.

My other child takes on caring responsibilities and misses time with their own friends, work opportunities, and study time.

My other children can't have friends over as I will not cope with other children as well as my own whilst my disabled son is at home.

Parent Carer

Conclusion

As illustrated above, lack of holiday club provision for disabled children has a detrimental impact on all members of the family. Parents that have used holiday clubs in the past in familiar venues with staff who understand their disabled child's needs acknowledge the benefit of the provision. 46% of parents taking part in this survey, report previously having a positive experience of a holiday club.

Key problems accessing appropriate holiday clubs are associated with disabled children's needs, whether that be their physical or mental health, level of support required, personal care, medical needs, accessibility of venues or staff training and disability awareness. However, provision is scarce and inconsistent. In order to improve the accessibility and availability of holiday clubs for disabled children, 35% of parents feel better information is required, 32% feel better workforce training and 18% stated reduced costs would make the biggest difference to parents with disabled children.

We are calling on the government and local councils to ensure that at least 15% of activities funded by the Holiday And Food programme funds are specifically for disabled youngsters. Equivalent schemes in the nations to be set the same target to ensure more places for disabled children across the UK.

- carry out an audit of local offers and how they cover holiday clubs and activities
- address the workforce issues in social care and childcare sector so there are more Personal Assistants, Enablers, Support Workers and Holiday Club staff.
- increase flexibility of direct payments so they can be used to pay for activities and holiday clubs for disabled children. Allow parents to pool money to put on activities suitable for their children.
- provide training on reasonable adjustment for providers - good communication, inclusive and welcoming attitudes, a willingness to take small steps to make the activity or experience inclusive, taking parents' views on board to make this happen.