



A SURVEY OF SUMMER HOLIDAY CHILDCARE FOR DISABLED CHILDREN SUMMER 2013

INTRODUCTION

Working Families runs a network of 2000 parents of disabled children who work or wish to work. We know from our helpline callers that childcare is an issue, and that the summer holidays present a particular challenge. As the Government considers how best to address the cost and provision of childcare, we decided to carry out a survey of parents of disabled children and how they cope with summer holiday childcare. A similar survey was last run in summer 2009. Four years on has anything changed? Has the provision improved or deteriorated?

Working Families received 182 completed online questionnaires and conducted 20 follow up interviews by telephone, as well as receiving some additional online input from respondents. Despite the obligations of the Childcare Act 2006 and the Scottish Early Years Framework, there are severe gaps in holiday provision for disabled children. Only 18 – 20 per cent of local authorities claim to have sufficient places for holiday daycare for disabled children (Rutter 2013¹). The Family and Childcare Trust Holiday Childcare Survey 2013 shows that the average parent will spend one fifth of their gross wages on childcare during the weeks that they use holiday provision. How much more acute is the situation for parents of disabled children aged five – 18 years?

TO WORK OR NOT TO WORK?

Of our respondents, 66 per cent were in paid work, 34 per cent were not. Of those who were not working, 79 per cent cited problems with a childcare as a factor in not working. The non-working parents were asked to list reasons why childcare was a problem, both in and out of school holidays. It was considered to be not sufficiently specialist, logistically difficult (ie hours/transport etc.) and too expensive:

Not specialist enough	70.5%
Too expensive	52.3%
Wrong hours	29.6%
Not available every week	9.1%
Problems with travelling distance	13.6%
Clashes with care for other children	11.4%

¹ Jill Rutter Holiday Childcare Costs Survey 2013, Family and Childcare Trust . 2013

THE CHALLENGE FOR THOSE IN PAID WORK

Fifty-six per cent of those in paid work needed to make special arrangements for the summer holidays. Twenty-two per cent perceived that they might possibly need to, and for the remaining 22 per cent the bulk of the care was provided free by family members or close friends.

The difficulty of finding and arranging appropriate daycare is very evident. Only 32 per cent had solid, definite arrangements. Twenty-two per cent had yet to find care (bearing in mind that the survey was launched to coincide with the beginning of the school holidays) and 46 per cent described their provision as tentative.

The range of provision broke down as follows (NB Many families used a mixture of different types of provision over the school holiday period):

41.5%	Care provided by friend or family member in child's own home
34.2%	Care provided by friend or family member in their home
37.8%	Specialised holiday play scheme
28.1%	Paid care in the home
17.1%	Mainstream play scheme
12.2%	Childminder

In addition, 15.9 per cent of respondents also reported using other forms of care including hospice care, short breaks (respite care) and parents taking unpaid leave in order to provide care themselves.

It is clear that great reliance is placed upon close family and friends providing free care. Many of the play schemes which were available did not cover the whole holiday period, or else were inaccessible to many disabled children. What resonates from the responses is how piecemeal, precarious, expensive and stressful cobbling together the summer provision is for many parents of disabled children.

A mere 16 per cent of our survey respondents were satisfied with the arrangements they were able to access. These included circumstances where an appropriate relative was available to provide care for the duration of the holidays, and where a high earning couple could afford to employ a specialist nanny. In one situation, a charity scheme provided care for disabled children and their siblings. Such arrangements emerged as few and far between, however. Eighty-two per cent stated that 'the arrangement is a bit of a compromise'.

THE COMPROMISE IS BECAUSE.....

Compromises had to be made because

The care is expensive	43.1%
It is not available every week	40.0%

The hours are wrong	26.2%
It is not specialised enough	24.6%
Travelling distance is a problem	16.9%
It requires transport	15.4%
Clashes with care for other children	13.9%
It is not inclusive	12.3%

Other factors were cited by 29.2%. These included responses such as ‘This arrangement involves my ex-husband, so it is not ideal,’ ; ‘It puts a strain on the wider family,’ ; ‘My daughter is a young carer and has to put her life on hold,’ ; ‘I feel I am imposing on my friends and jumping through hoops at work,’; ‘My partner and I have to take separate holidays – we cannot have a family holiday together,’; ‘I am dependent on my elderly mother,’.

Clearly lots of difficult, individual compromises are being made to survive the challenging summer holiday period and at considerable expense. Sixty-four per cent saw the cost of care as an issue. Fifty-two per cent reported paying significantly more for the care of disabled children than they would for a child without a disability. In 62 per cent of these cases parents were paying at least an extra £5 an hour more for the care of their disabled child. Some care agencies charge up to £22 per hour. One single parent said she was dependent on care being provided by her 68 year old mother.

Information about the availability of childcare for disabled children is not readily available. Sixty-one per cent of respondents had sought details of provision but only 33 per cent had been able to access their local Family (Children’s) Information Service, which suggests that the majority of parents were not aware of its existence. Of those who had consulted the local information service, 67 per cent did not find it helpful.

In terms of juggling work and care, only ten per cent of families said it had had no impact on their working lives. Four per cent of respondents had actually been obliged to leave their jobs because of care difficulties, 41 per cent had had to change their hours, 31 per cent took unpaid leave and a further 28 per cent had made a ‘flexible working’ request (many parents had had to use more than one of these options).

Thirty-one per cent of respondents described other impacts on the delicate balance between work and care. Some had turned down work, whilst others reported having to bring work home to do once their children were in bed. One parent had volunteered for redundancy and another had given up her job. One family reported that, ‘We use all our annual leave to cover care, and cannot have any time off together.’ Instances were reported of ex partners having to move back in to assist with childcare and one parent reported having had a breakdown because of the stress of trying to arrange childcare over the summer.

Because specialist play schemes do not cover the whole holiday period and are over-subscribed, people are forced to juggle *ad hoc* arrangements. Further complications arise when siblings’ school holidays do not coincide. There is less provision for older children and for those with the most severe special needs.

WHAT ONE THING WOULD MAKE THINGS BETTER?

Respondents were asked about what could make the summer holiday provision better.

Thirty per cent mentioned affordability and identified money as the over-riding concern – ‘childcare prices cripple my family.’

Twenty-six per cent raised concerns about the need for specialist, appropriate and safe care – ‘So often it seems as though they aren’t that keen on having him there and the standard of care was so awful ... that I reported them to OFSTED and social services for neglect...’

Twenty-two per cent wanted longer hours and more provision – ‘The local play scheme is fantastic but limited to two weeks in the summer...’

Another 22 per cent of respondents reported concerns about the need for employers to be more flexible about leave, lack of time for self or other family members and about the location of provision. There was particular concern about the lack of provision for older children and teenagers.

Other general comments highlighted just how stressful and costly the whole experience can be – ‘No one in my area offers care to children with additional needs,’; ‘It is very stressful to find cover you can afford on a single income,’; ‘Organising it is another full-time job,’; There is no recognition that parents need this sort of care,’; ‘It is a nightmare not understood by others,’; ‘Not available in my area and it is getting increasingly difficult to work,’; ‘To get the quality is expensive, my son’s scheme is £350 per week and only runs for two weeks,’.

One comment stands out as particularly poignant – ‘Summer holidays are the worst part of the year, especially as no physio or therapies are available, so my daughter’s health takes a nose dive, and that makes caring harder as the weeks drag on.’

WHAT HAS CHANGED SINCE 2009?

Although our surveys, four years apart, are not directly comparable, the same issues arise. In 2009 10 per cent of our parents identified the cost of childcare as their biggest worry – in 2013 this has risen to 30 per cent. We found similar proportions of parents raising concerns about the need for specialist, appropriate care (26 per cent now, 29 per cent in 2009), and parents reporting that limited hours and a lack of provision meant that their needs were not met throughout the holiday period (22 per cent now, 21 per cent in 2009). It is profoundly disappointing that so little has changed for parent carers of disabled children, and that some parents are forced out of work when they can’t find the flexibility they need.

OUR RECOMMENDATIONS

As the Government consults on making childcare more affordable, the particular needs of parents of disabled children must be addressed. Our report shows that families are stressed by the difficulties of sourcing available care, and many are not satisfied with the care available. The expense of specialist holiday care, and the limited provision of appropriate care is having a profound impact on families and their ability to work.

We recommend the following changes:

- All local authorities should meet their obligation to ensure sufficient summer holiday childcare is available for all disabled children in their area. Such childcare should be available for the whole summer holiday, and made available at hours that allow parents to continue in work.
- Parents should not be required to pay extra for the cost of caring for disabled children. Some provision for disabled children may be more expensive – if specialist equipment or additional staff are needed. However, it is unjust to expect parents to pay over £5 per hour more than they would for a non-disabled child. This additional cost is not recognised in any state support with childcare costs – neither through the childcare element of tax credits, nor through childcare vouchers. The Government should address this issue as part of its current consultation on making childcare more affordable.
- Family Information Services should be equipped to provide the specialist support that parents need. Many parents are unaware of the existence of the service, and many others reported that the information provided was not helpful. FIS need to work closely with parents in their area to understand and meet parents’ needs for information.
- Employers need to show understanding of parents’ predicament. Many of those who wish to combine work and care are undertaking huge effort to remain in work during the summer holiday period, and making compromises about the care that their children are receiving. Where parents of disabled children make requests to change hours during summer holidays, or to take unpaid leave, this may not be their choice – but a choice forced upon them by the lack of appropriate, available, affordable childcare.

SCOPE OF THE SURVEY

The respondents came from all over the UK mainland. Fifty-seven per cent were from mainly urban areas, 34 per cent were from mainly rural areas and nine per cent were non-specific.

Seventy-two per cent were part of a couple, 25 per cent were lone parents and three per cent declined to say. Eighty-nine per cent indicated that they were female and seven per cent that they were male, with the balance not indicating their gender.

Eighty-two point four per cent described themselves as White British, 1.7% as Irish, 2.2% as Other White, 1.7% as Other Mixed, 0.6% as Indian, 1.1% as Pakistani, 0.6% as Bangladeshi, 1.1% as Other Asian, 2.8% as Black African. 3.9% declined to say.

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