

# On Holiday!

## Policy and provision for disabled children and their families

Report for DfES

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## 1. School holiday provision for disabled children: introduction and background

This summary describes some findings from the On Holiday! study, carried out by the Thomas Coram Research Unit between 2004 and 2006 and funded by DfES. The study investigated the experiences of disabled children and their families outside school time and especially during the school holidays. The study took an approach informed by a social model of disability, one which emphasises the social construction of disability, rather than impairment.

Recent government policy has promoted the social inclusion of disabled children and their families (DH, 2001; DH, 2004; Strategy Unit, 2005). Previous research shows how disabled children and their families are highly disadvantaged both economically and socially, and that holiday periods can be particularly vulnerable times. Findings from this study support the major conclusions reached in this previous research and add to it by examining the structures, processes and values of local government which shape the provision which supports, or fails to support, disabled children and their families.

## 2. On Holiday! study aims, objectives and methodological issues

Focusing on the school holidays, and other out-of-school times, the study aimed to contribute to the development of services for disabled children and their families. The objective was to understand how holidays and other out-of-school times might contribute to the social inclusion of families, or otherwise.

Using a case study approach, fieldwork was conducted in six contrasting local authorities. Across these six research sites, 121 staff and 90 parents were interviewed. The views and perspectives of 86 disabled children and young people were also elicited. Differences in how 'disability' was defined by providers and arranging interviews to follow as soon as possible after school holidays were particular challenges faced by the research team. Ethical measures employed included giving close consideration to informed consent, confidentiality and the variety of methods that it is necessary to employ when consulting with severely disabled children.

## 3. The six local authority research sites

Six local authorities were purposively selected for study, two London boroughs, two metropolitan areas and two

shire counties. Three of the local authorities had pathfinder children's trusts, five had developed a full service extended school and one was developing a cluster of extended schools. In order to protect confidentiality and anonymity, we named the six local authorities: London Outer, London Central, Metropolitan North-East, Metropolitan North-West, Shire County South and Shire County East.

## 4. The school holidays as experienced by disabled children and young people and their parents

The children were, on the whole, positive about the holidays although boredom was a problem for some:

*"I'd rather be on holidays but I get bored especially in the 6 weeks"*  
(11 year old boy).

About half of the children who took part in the study attended a holiday play scheme for some days which, largely, they enjoyed. Some experienced physical access problems in mainstream facilities and would have liked greater understanding of their requirements from staff and from their peers:

*"I want more teenage clubs that wheelchair people can use...there should be clubs for all teenagers so all teenagers can be together. Some people take the mickey out of them [young disabled people] but they only take the mickey out of them when they don't understand what it is. If they all mingled together then perhaps they would understand a bit more"*  
(12 year old girl, wheelchair user).

The importance of friendships was central to many young people's descriptions of the holidays; whether or not they enjoyed the holidays was largely dependent on how much they were able to see their friends. Many of the young people experienced high levels of social isolation during the holidays, especially if they attended schools outside their local area and were unable to meet up with their friends:

*"I go out with my friends near the village. I've got friends in two places – near school and near the village. But the problem is you might want to see your friends from here [the school] but it's too far away"*  
(15 year old girl with visual impairment).

Such social isolation had important implications for their independence and well being, and their capacity to lead 'ordinary' teenage lives.

Almost all of the parents interviewed described very difficult times during the holidays, many using the term 'nightmare' when referring to school holidays and 'relief' when school re-opened. The lack of routine and the unpredictability of the holidays were particularly difficult, as was the inability to carry out every day tasks, such as shopping and household chores:

*"Term time is easier because things get back to normal. There's a routine again. During the holidays, my life continues to be the same with the addition of this nightmare. Every time that happens, I have to cope with the irregularities. So when he's at school, it's much better: at least you know what comes next"*  
(Mother of 9 year old boy).

Many described not being able to do 'ordinary' activities with their disabled child, like going to the park or to the cinema, often due to the disrespectful attitudes and lack of understanding, shown by the public:

*"In the summer holiday we just can't access normal life"*  
(Mother of 13 year old boy).

Going away on holiday with a disabled child or young person was seen as too stressful for many families, who were more likely to opt for day trips and even these could be extremely challenging. The problem of juggling the needs of other children in the family and those of the disabled child was commonly described. Turning to other family members for help could be difficult. Many parents described feeling very socially isolated and unsupported during the holidays. They found it hard to trust others with their child's care and were unable to make meaningful links with informal support networks, such as other parents and members of their extended family:

*"We are so isolated; we've been totally excluded through our local community because of David's disability. This term, we have not been invited for one play or after school thing. At weekends or in the holidays...they have parties...but not with us because David's disabled. I had been hoping that parents would informally include us"*  
(Mother of 5 year old boy).

Specific challenges were experienced by families of children diagnosed as on the autistic spectrum or as having Attention Hyperactivity Deficit Disorder. Parents described children who found unfamiliar environments and situations particularly unnerving, with the result that attending holiday clubs was, for some, almost impossible:

*"He's alright when there's a routine at school but that routine is lost in the holidays"*  
(Mother of 12 year old boy).

## 5. Supporting disabled children and their families during the holidays: what is working well?

The study was able to identify a number of ways in which parents could receive the support they required. Effective social workers, the involvement of a 'bridging' professional, linking the family with mainstream and specialist out-of-school activities, access to holiday clubs and short breaks (respite care) were all highly valued:

*"I prefer to come here [the Play Centre] than being at home. It's more fun here. I get to do many different things"*  
(7 year old boy, wheelchair user).

*"[Holiday clubs] – they're brilliant, they're my absolute lifeline"*  
(Mother of 9 year old boy).

Parents reported that a safe environment, staff continuity, and children's familiarity with the setting were particularly desirable in holiday provision.

Specific examples of practice designed to support disabled children and their families during the holidays included:

- the sharing of special equipment between a primary school and a play scheme,
- close links between a school and a mainstream leisure and sports facilities,
- a flat used as a base by disabled young people during the holiday, and
- 'buddying' schemes to enable disabled young people to attend mainstream leisure activities with another (usually non-disabled) young person.

We also found some examples of local authorities demonstrating their commitment to inclusive practice by employing or funding Inclusion workers, to promote disabled children's inclusion in mainstream out-of-school services and to develop inclusive holiday provision. On the other hand, one local authority had developed some child care provision specifically for disabled children. This was aimed at working parents. A major challenge facing the parents of disabled children, particularly during the school holidays, is finding suitable child care in order to carry out paid work.

## 6. Challenges and other inadequacies

The study revealed a number of gaps in provision for disabled children and their families and challenges facing both service providers and service users:

- there was a general shortage of appropriate holiday clubs and play schemes resulting in the rationing and irregularity of services;
- provision was found to be particularly lacking for young disabled people over the age of 12;
- provision was also lacking for children and young people who presented challenging behaviour (for example, those diagnosed as on the autistic spectrum or with Attention Deficit Hyperactivity Disorder);
- there was little daycare suitable for the disabled children of working parents.

Barriers to accessing inclusive play and leisure opportunities were also identified. These included:

- a lack of accurate and up-to-date information for parents about suitable activities;
- a lack of training in practical matters (for example, on lifting and administering medication) in holiday clubs;
- poor physical access and environmental adaptations;
- negative attitudes on the part of some organisations and their staff; and
- the requirement, in some cases, for parents to accompany their child to help with his or her physical care.

Both parents and service providers also expressed some concern about therapies, delivered at school, being unavailable during the holidays. The costs of holiday clubs for parents (which varied considerably across the six local authorities studied), were sometimes seen as too high. For local authority departments and other providers, problems could arise as a result of insecure and inadequate funding for the provision of out-of-school services for disabled children.

Many parents and some service providers emphasised difficulties arising from the lack of adequate transport from home to out-of-school provision; this was a particular problem in rural communities. In one of the shire counties, parents using 'direct payments' to employ carers at home, were said to encounter difficulties in recruiting suitable carers and to experience an added pressure that arose in organising and administering the carer's employment.

## 7. Integrating children's services: children's trusts and extended schools

Effective multi-agency working is a prerequisite for integrating children's services under the newly established structures of children's trusts and extended schools (Every Child Matters and the Children Act 2004). We found reports of successful multi-agency working relationships characterised by trust, co-operation towards a common aim and a lack of competition:

*"There is a bunch of people in middle management who have a lot of trust and are able to communicate with each other and they are not in competition with one another. They seek to co-operate with each other and there are good relationships"*  
(Children's Fund Manager).

However, the study found tension in some aspects of multi-agency working. A frequently mentioned challenge was differing definitions of 'disability':

*"All the three main agencies work to different definitions. Also how we define it tends to depend on budgets as well. Also there are different statutory responsibilities which we have to take into account so it's all a bit difficult"*  
(Health services manager).

Three of the six local authority research sites had pathfinder children's trusts, one of which had prioritised working with disabled children. In one of the sites, the children's trust was seen, among other functions, as a mechanism for providing holiday provision for disabled children in a more corporate and less haphazard manner than had been the case previously.

In the children's trusts studied, the relationships between social services and education departments were reportedly stronger, with health and the voluntary sector seen as weaker, or as an 'add-on'. Particular challenges facing children's trusts were the pooling of budgets across departments and sectors, and achieving clarity of roles for different sectors within the trust.

Extended schools have the potential to provide more community-based, mainstream holiday services for disabled young people. However, in the extended schools visited, the study found little direct attention to the requirements of disabled children regarding their attendance at out-of-school activities. The schools appeared to equate 'disability' with wheelchair use, thus ignoring other disabled children. There was also a lack of monitoring as to how many disabled young people attended out-of-school activities. The accounts of local

authority extended school co-ordinators also revealed little proactive strategy to include disabled children and young people in out-of-school activities and holiday provision:

*"I haven't thought about disabled children because to be honest in the extended school policy, disabled children aren't really on the radar"*  
(Extended School Co-ordinator).

## 8. Values, ethos and political will informing policy and provision

The study highlighted the necessity of political commitment as a necessary condition for promoting social inclusion for disabled children and their families.

We found contrasting terminology referring to disabled children being used across the six local authority areas. The shire counties tended to use vague terms, when referring to disabled children, and terms which served to emphasise a medical model of disability. This use of language reflected the ethos of service provision, which, rather than empowering and including disabled children, was rarely mainstream and emphasised the importance of respite for the parents, rather than the requirements of children for social inclusion, such as could have been provided by mainstream play and leisure opportunities.

The two metropolitan local authorities, in contrast, were characterised by higher levels of community democracy and participation, evident in the use of parent-professional forums and of Youth Assemblies, on which disabled young people were represented. Some political commitment to provide inclusive services for disabled children was also more evident in these areas and in London Central.

In London Central, the study found the highest levels of inclusive opportunities for disabled children. Here, the resolve of the local council to promote social inclusion was matched with sufficient funding to make access to inclusive, as well as specialist, activities a reality for many families.

In London Outer, in contrast, while policy spoke of inclusivity there appeared to be less effective political will towards provision for disabled children, outside school time.

## 9. Ways forward: discussion and recommendations

The study set out to discover the ways in which holiday, and other out-of-school times, were implicated in the social exclusion of disabled children and their families. Overall, findings showed that the broad aims of national policy have yet to be actualised when it comes to meeting the requirements of disabled children and their families at these times.

Holidays were, on the whole, extremely stressful times for many of the families interviewed. Parents wanted and needed more holiday provision, including play schemes, help at home and leisure opportunities for their children. Many parents expressed a strong preference for using school premises as sites for clubs, for the continuation of therapies during the school holidays and for their need to access specialist equipment, such as wheelchairs, during the holidays.

Many young people enjoyed the school holidays but most said they missed their friends and wanted more opportunities, both with other disabled young people and in mainstream leisure activities.

We found, in most local authorities, that much of the holiday provision available to families was severely rationed. With regard to play schemes, parents particularly valued a safe environment for their child, alongside trained and familiar staff. Particular difficulties arose when staff were not sufficiently trained, for example in administering medicine, and when transport to and from services was not provided. Specific gaps in provision were for children and young people diagnosed as on the autistic spectrum, those said to have ADHD, for young people over the age of 12 and for working parents.

The study identified several reasons why families were inadequately supported in out-of-school time. Foremost among these was lack of local political commitment to disabled children. Some local authority personnel questioned whether it was the responsibility of their departments to provide family support during the school holidays. Also, some school-based provision depended on the 'goodwill' of members of school staff, rather than being embedded in local policy and strategies.

Effective provision for the social inclusion of disabled children and their families requires awareness, the political will to do something about exclusion, and a commitment best demonstrated by the allocation of human, institutional and financial resources. In those local authorities where families were served better, there was a wish on the part of the authority and its officers to meet

their rights and requirements. The empowerment of disabled children and their families needs a pervasive understanding, throughout the local community, that disabled children have entitlements, which the community must meet.

These understandings must also be applied to initiatives such as the establishment of children's trusts and extended schools. Children's trusts need to develop shared aims for disabled children and to co-operate in the development of strategies and the provision of funding. Extended schools need to be proactive in including disabled children, both their own students and others in the local community, in their extended activities. We did not find examples of extended schools which were already doing this, or who were monitoring the extent to which disabled young people were taking up out-of-school activities.

The social inclusion of disabled children and their families is also dependent on the wider social policy context and the tensions existing within it. The report argues that the language of choice and the market model of welfare is at some variance with inclusionary aims. Also, the continuation of special schools, under recent legislation, the Special Educational Needs and Disability Act 2001, is in some contradiction with the ethos of the Disability Discrimination Acts 1995 and 2005: many of the children interviewed were attending a special school some distance from their homes, denying them the opportunity to make local friends. Often, parents spoke of their difficulty in entering reciprocal childcare arrangements with other families. This reflects their social isolation and speaks of a lack of 'social capital', for families in terms of belonging to local networks and having access to beneficial social connections.

Our study concludes with some more specific recommendations:

- As a first step in addressing the need for more holiday services for disabled children and their families, there should be an audit by local authorities, assessing and mapping service provision for children and young people and the extent to which this provides for disabled children.

- 'Bridging' staff, as described in the report, should be appointed by the local authority so as to facilitate the inclusion process in mainstream settings, including youth, leisure, play and childcare services.

- The local authority Children's Information Service should be the location for the dissemination of accurate and up-to-date information for families of disabled

children about the range of out-of-school care, play and leisure activities available to them.

- The local authority should meet its obligations under the Childcare Act 2006 to be strategic in promoting childcare, after school and in the holidays, for working parents who have a disabled child.

- Local authorities should develop and assist the development of a range of options for the support of disabled children and their families, during the holidays, such as specialised child care, care within the family home, short-term breaks with other families (respite care), and mainstream holiday clubs, youth services and play schemes.

- Steps should be taken to ensure that young people over the age of 12 have access to a range of leisure opportunities. Access entails provision that is psychologically and physically accessible in itself and other means, such as the 'buddy' scheme described in the report, that facilitate attendance.

- Any extra costs involved in admitting disabled children and young people to out-of-school and youth services should be subsidised by the local authority, so that children may participate on an equal footing with others.

- Children should not be denied access to leisure, care, play and out-of-school activities services for lack of transport. Attention should be given to transport between school and home, so that children do not have to leave the school premises before out-of-school activities start.

- Children's trusts and extended schools need to develop a common mind and shared vocabulary towards the social inclusion and support of disabled children and their families. To this end, schools and trusts should be based in an understanding that people with impairments may be either disabled or enabled by the actions of society.

Extended schools should audit the use of services offered by the school and to monitor their use by disabled children who may attend the school already or live locally.

These recommendations need action by school staff and governors, by regional extended school advisors, and by OFSTED in its inspections.

- Staff need support and training as to the disadvantaged social position of disabled people, and their own ability, as staff, to counter this.

The local authority should identify how such training may be made available to out-of-school staff.

In partnership with others, such as the voluntary sector and the Health Authority, the local authority should also develop training as to feeding, changing and lifting disabled children, and the administration of medicine.

Specific attention is required regarding working with children who appear to present particularly challenging behaviour (such that associated with children said to be on the autistic spectrum, or with ADHD). A first step would be to identify best practice in this area, to draw on expertise developed in, for example specialist providers or schools and to develop training on this basis.

Service providers should be required to make the above training available for staff in order to make their facilities accessible for disabled children and young people.

- DCSF should undertake the development of monitoring and evaluation frameworks for inclusive leisure, play and childcare provision across the different sectors. These matters should also be given particular attention by OFSTED inspectors in registering provision, and in annual inspections.

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