



# Postcards from home

The experience of disabled children  
in the school holidays



**Barnardo's**

GIVING CHILDREN BACK THEIR FUTURE

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# INTRODUCTION

Barnardo's runs more than 50 community-based services for disabled children and their families in the UK. Through these services we are aware of the impact on families of government policies to end poverty and social exclusion.

In the summer of 2002 we published a report *Still missing out* (Sharma, 2002) which showed that families with disabled children were not benefiting from government policies to end poverty and social exclusion.

*Postcards from home* looks at the particular issues for families of disabled children during the school summer holidays. At a time when most families are enjoying a holiday away from home and days out, many families with disabled children find there is a lack of affordable, accessible and inclusive community-based leisure services. Although many local authorities and voluntary organisations provide inclusive playschemes, these are by no means universal and provision remains geographically patchy.

The challenge for everyone, especially central and local government, is to remove the barriers which prevent disabled children doing the sorts of things during the summer holidays that other children take for granted.

# WHAT NEEDS TO BE DONE

Barnardo's is calling on government to take the following steps.

## National government

- All mainstream programmes and targeted initiatives related to leisure provision should be inclusive of the needs of disabled children.
- A review should be undertaken of the actual costs of providing inclusive play and leisure for disabled children of all age ranges, particularly older children and teenagers. This should be used as a guide by all government departments to ensure that sufficient long-term funding is included in all play and leisure programmes.
- The requirements of the Disability Discrimination Act (DDA) on accessible facilities and services should be fully implemented and further strengthened by enacting the Draft Disability Discrimination Bill.
- Targets should be put in place to increase the number of trained specialised staff to work with disabled children: such staff need to be available across a wide range of provision – for example, theme parks, summer playschemes and holiday resorts.

## Local government

- Local preventive strategies should incorporate an assessment of what provision families need during the summer holidays.
- Such an assessment should take account of the needs of non-disabled siblings so that they can be included.
- Statutory and voluntary agencies should work together to ensure support services available in term time continue during the summer holidays if families need them.
- Lead partners should agree and put in place multi-agency risk management strategies to ensure that all disabled children are able to access local services and facilities.

# DISABLED CHILDREN AND LEISURE

'Disabled children have the human right to be included in their local community and do the kind of things that non-disabled children do. They have the right to support to help them to do this'. (Morris, 1998)

Play is a fundamental part of childhood, and during school holidays play and leisure are central to children's activities. This applies equally to disabled children. In practice, however, disabled children are often excluded from play and leisure opportunities that are available in school holidays. The task facing services which seek to support disabled people is to identify what is restricting their opportunities and work alongside them to remove these barriers (Ward, Elliott and Day, 2004). Removing barriers so that disabled children can participate in their communities is a challenge to society generally.

The Disability Discrimination Act 1995 established rights for disabled people to have the same access to 'goods and services' as any other member of the public. From 2004, part III of the DDA will require service providers to take steps, where reasonable, to tackle physical barriers to access for disabled people. Achieving inclusion also requires changing people's attitudes. For example, many families are excluded from leisure activities because providers manage risk in a way that excludes disabled children. Lack of training on disability awareness, health and safety and risk management often results in staff adopting a negative and unhelpful attitude.

Community-based facilities such as sporting activities, playschemes and organised groups and clubs frequently exclude disabled children. In addition, school holidays present a disruption in access to school-based services and resources – companionship and activities, facilitation of physical mobility and interpersonal communication, and day care. During the holidays, such resources must be found elsewhere or done without (Petrie and Poland, 1998).

## **Older children and teenagers**

Even in areas where inclusive holiday playschemes are available, these are mostly used by children up to the age of 12. Older children can often find themselves excluded by their age as well as by the social disadvantage of their disability (Petrie, Storey and Candappa, 2002). There is a sharp contrast between the concepts of leisure put forward by service providers and professionals, and by disabled young people themselves. Service providers think in terms of: increasing independence; creating a safe learning environment; improving social skills; developing confidence. Young disabled people describe leisure as being about friendships and fun – being with people they want to be with, and who want to be with them. They describe their interests as being the same as those of all young people – going on holiday, music, bowling, clubbing, hanging out, and going to the pub and so on.

## **Families**

Reduced opportunities for play and leisure also affect disabled children's families. Most parents can take a break from parenting responsibilities when their children are playing with friends or involved in leisure activities or summer schemes. Parents of disabled children often do not experience these breaks. Also, brothers and sisters may be required to play with their disabled sibling rather than pursuing their own friendships and interests (Ward, Elliott and Day, 2004).

## **The impact of government initiatives on leisure**

The Audit Commission's evaluation of the Quality Protects initiative found improvements in the quality and availability of services for disabled children, particularly in early years play and leisure services (Audit Commission, 2002). However, there is still a national shortage of inclusive and specialist provision, with many initiatives subject to short-term or insecure funding. Despite the improvements brought about through the Quality Protects initiative, local authorities are no longer required to ring-fence funding for disabled children's services. Similarly, cutbacks to the Children's Fund are very likely to have an impact on the delivery of inclusive play facilities, many of which take place during summer holidays. Some £200 million of National Lottery funding has been earmarked for new and improved children's play facilities. A national strategy has been drawn up by government on how the funds will be earmarked and this strategy pays particular attention to the needs of disabled children and young people.

# EXPERIENCES OF FAMILIES

For this report, we interviewed several parents of disabled children and some siblings about their experiences of the summer holidays. They all described the barriers which prevented them from going on holiday or having days out with their disabled children during the summer holidays.

## Access to summer playschemes

For the majority of families with disabled children a holiday away from home is not possible. Of the families we interviewed, only three were going away from home for a summer holiday: one to a specially adapted caravan provided by a charity and another to a cottage which the family had used previously and knew was suitable. One family was going away for a week without their disabled son because it was the only way that the family could take a break. This finding means that access to summer playschemes is particularly important for disabled children, because it is often the only chance that the children and young people have to play and to be with their friends as well as providing a break for their parents.

However, places in summer playschemes for disabled children are limited as they are costly to provide and need adequate staffing and funding. Summer playschemes require specialist qualified staff if they are to include disabled children: such staff are in short supply. Furthermore, meeting the needs of disabled children requires a higher staff ratio.

Figures from two of the New Opportunities Fund (NOF) projects exemplify the higher costs involved. At one project playworkers get £10.48 an hour: a child who needs one-to-one provision would cost £175 per day (this includes other on-costs). Another project incurs the following costs: an after school club would cost £17 for a ratio of five staff to one child and £47 for a one-to-one ratio. A holiday scheme costs £21 for a five-to-one ratio and £66 for a one-to-one ratio. Parents contribute just £6 for after school club and £11 for playschemes; the grant from the local authority does not cover the remainder of the costs, which are met through the project's own fundraising. Most projects find it difficult to fundraise and the extra costs are often passed on to parents.

### **Jake, aged 6**

Diana and David have three children, Nikki, aged 8, Charlie, aged 3, and Jake, aged 6. Jake was recently diagnosed with autistic spectrum disorder. He also has speech and language difficulties and an eating disorder. Jake will attend a summer club provided by a local voluntary organisation for a week which costs around £5 a day and he usually attends another special needs playscheme. Although the scheme lasts several weeks Jake will be allocated a shorter amount of time. Last year he received only two days.

Adequate provision at a summer playscheme is important for the family – going out with all three children is a problem for Diana because Jake needs one-to-one attention. Going out with all three children is a problem ‘even just to get a pint of milk’.

As well as staffing and related costs, service providers themselves face obstacles in delivering summer playschemes as the following case study from Barnardo’s Hamara Project in North East London which receives funding from the New Opportunities Fund shows.

### **Hamara Project – summer playscheme 2002**

This playscheme ran for three weeks during school holidays and offered play activities to disabled children aged 5-12. The children all had high care needs and the staff-to-child ratio was usually one-to-one. From observing the children it was very clear that they had a good time and enjoyed the freedom of space to play in. Their parents also benefited from having a break from the care of the children and were able to rest or spend time with their other children. Demand for the scheme outstripped the places available and each child could only be allocated one week.

The project had great difficulty obtaining suitable premises. In 2002 the project rented a church hall for a week at the beginning and end of the holiday which meant that all the equipment had to be moved in and out twice. On several occasions the hall was double booked and the garden area was not totally secure. In the third week the playscheme was held in the office, which was inappropriate. The project also had difficulty delivering enough places because of the high cost of the service.

‘We could use every place five times over if we had the funding and suitable accommodation.’

The problems identified by Hamara are typical of projects providing inclusive play. High costs, the difficulty in finding premises and staffing issues result in rationing, which directly affects disabled children and their families.

## Inaccessible or unsuitable facilities

### Lizzie, aged 11

Lizzie is 11 years old and has cerebral palsy and epilepsy. She lives with her mother, Lynne. Lizzie needs a great deal of support and help with personal care. She is a wheelchair user and due to problems with swallowing, she is fed through a tube directly into her stomach. Lizzie does not communicate verbally, and makes gestures for yes and no. With Lynne's help she can also use a computer program using pictures to communicate. This is how she was able to tell us about her summer holidays.

Lynne says that Lizzie likes to go out as an extended family, with her brother, as he can help her with Lizzie's wheelchair. Changing Lizzie can also be a big problem. Changing areas are not always accessible for Lizzie as most places only provide baby changing facilities. Lynne fears that there will be many things that she and Lizzie won't be able to do as Lizzie grows older and more difficult to manoeuvre. Swimming, for example, isn't easy to do as Lizzie gets older as she has sudden involuntary movements. She is stabilised in the wheelchair but when she is out of it she may hurt herself and Lynne is not strong enough to manage this alone.

Lizzie says that it is very difficult to go to theme parks. Lynne explains that the staff can be very conscious of health and safety regulations and often will not let Lizzie go on the rides. Lizzie likes to go to pop concerts but Lynne is careful when choosing the venue. In some venues the wheelchair spaces are at the back of the auditorium and Lizzie can't see. Other places have wheelchair spaces at the front but their carers have to sit behind. Lynne feels that this is ridiculous 'we want to have a night out together, sit together, I want to be able to ask her if she is enjoying the show'. Lynne gets frustrated that some venues are modern buildings and recently designed yet they don't consider the small things that would make such a difference to disabled people.

'I am not asking places to be perfect (in accessibility) just to try.'

In the Contact a Family survey (2002), 55 per cent said they had to travel outside their area to find accessible facilities. Wheelchair access to changing rooms and funfair rides was a popular request. In a survey of members of the National Autistic Society, less than half of respondents felt that there were appropriate play and leisure facilities in their area.

## Lack of support for parents

### Tim, aged 14

Jane and Paul have three children, Phillip, aged 24, Kate, aged 23, who has cerebral palsy and lives in an assisted living flat, and Tim, aged 14, who has cerebral palsy and autistic spectrum disorder. Barnardo's supports the family by providing a Family Link service. Tim enjoys staying with the link family for a weekend each month and the link family also have Tim to stay for two separate weeks. Jane, his mother, doesn't have a choice when these occur and they don't occur in the summer holidays when it is most needed. She feels that there is not enough flexibility in support services 'it would be nice if it was like a hotel system, where you can book him in when you needed to'.

Although there are three playschemes in the area for disabled children they allocate days independently and so some of the days allocated may overlap. This year Tim will get an allocation of just five days because the playschemes don't have enough staff. Lack of support for Tim during the summer holidays means that Jane is left alone to cope with meeting the needs of both Tim and her daughter Kate. As they are both wheelchair users, it is impossible to take them both out together. The summer holidays are exhausting for Jane.

'It is a long break and he gets fed up. You need to organise an entire day of activities, he can't just "hang out" with his friends like other 14 year olds'.

Rather than receiving the extra help they need, many parents are left to struggle on their own in the holidays as the day-to-day support available from schools and community-based services in term-time falls away. This can be particularly difficult for parents who have other children who are at home during the summer holidays.

## Parents caring for more than one disabled child

### Ben, aged 13, and Nick, aged 11

Isobel is a lone parent of two boys. Ben, aged 13, has cerebral palsy and Nick, aged 11, has autistic spectrum disorder. Ben attends a mainstream school and Nick attends a special school. Nick needs constant supervision and Isobel receives some support from social services. Nick stays at a residential short break unit for three nights a month and attends a Saturday club for three hours a fortnight. Isobel has been offered one further overnight stay and two extra days during the school holidays but not at times which are suitable for the family.

Isobel says she runs the summer holidays like a military campaign. She describes it as 44 days of being organised. Ben and Nick have very different needs. Ben needs more rest time due to his physical impairments and Nick needs to be active. This year Nick will attend a playscheme for two weeks for children and young people who have severe learning disabilities. Ben, who is more independent, will probably attend activities run by the youth service and will spend time with his friends. He will also attend activities for disabled young people and adults at an outdoor centre which include archery, sports and crafts.

Approximately 10 per cent of families with disabled children care for more than one disabled child and the intensive demands this brings are rarely recognised. Very often the children may have very different needs and access to different services is needed.

## **Impact on siblings and on family life**

### **Scott, aged 12, and Jenny, aged 10**

Kathy is a single parent with two children: Scott, aged 12, who has a learning disability and autistic spectrum disorder, and Jenny, aged 10. Kathy is very concerned about the impact on Jenny of living with a disabled brother. Kathy feels that Jenny 'has suffered a lot – even going into town, you turn your back on him and he's gone, for a long time she has had to be older for her age'. Kathy feels that there should be more support for siblings of disabled children, especially in the holidays but 'It is better for her now as she is more independent'. Jenny may attend Pop in the Park, which is a creative activity group run by Barnardo's. She has also recently accessed a young carers' group, after a long time on the waiting list. Jenny realises there are things they can't do together as a family such as go to Disneyland Paris as there is 'not enough money and support'. She feels her situation is unfair.

'Sometimes I want to do something but I can't because of Scott.'

### **Nikki, aged 8**

Nikki has two brothers, one of whom has autistic spectrum disorder. For Nikki the summer holidays bring fun as well as the realisation that they cannot do things as a family. 'We're going to have lots of fun ... I would like to go to the cinema. We can't go to the cinema because Jake would start walking around and shouting. I would like to go to American Adventure (theme park). We can't go, Jake wouldn't like the rides and when he gets stressed we have to go home.'

Many families with disabled children also have other children. Generally, siblings cannot participate in the same social activities as their disabled brother or sister. Both children and their parents find this very excluding. Parents feel very strongly that services must be inclusive to support brothers and sisters who have a disabled sibling. Young carers' groups are a good source of support, but places are in short supply. Shared activities also give families the opportunity to participate in their communities.

### **Negative public attitudes**

#### **Carl, aged 7 and Craig, aged 3**

Karen has two children: Carl, aged 7, who has autistic spectrum disorder and Craig, aged 3, who has a speech and language disorder. His behaviour can be very challenging. Karen doesn't work and John, her partner, works from home to try to help with the family but this means he has an irregular income. Karen finds the summer holidays challenging as Carl is very active and she feels that Craig misses out because Carl needs her attention. She doesn't receive any additional support during the summer holidays. Karen finds the attitudes of the public towards Carl very upsetting.

'The general public aren't aware of children with these problems... people aren't tolerant.'

Families with disabled children face negative public attitudes. In the Contact a Family Survey (2002), 68 per cent of respondents said they didn't use leisure facilities because they were made to feel uncomfortable.

Most families interviewed for this report had experienced negative public attitudes. It is often disabled siblings who feel the impact of negative public attitudes towards their brother or sister most acutely.

## WHAT HELPS?

- **Accessible holiday venues and equipment.** Many families with a disabled child cannot afford to pay for holidays with accessible facilities as these cost more; they also find it difficult to pay for additional equipment. Charities such as the Family Trust Fund give grants for recreational activities and are also working with other agencies such as the Family Holiday Association to increase choice and availability for families with disabled children.
- **Activity groups for disabled and non-disabled young people.** One young person says: 'I know that some disabled young people might be scared or nervous about socialising with people who are more able than themselves. They may ... think that they wouldn't be able to do as well as the others there, or that the other kids will be nasty or not understand them – but that hasn't happened to me' (Ward, Elliott and Day 2004).
- **Joining in ordinary mainstream activities.** One parent comments: 'When he goes to the youth club now and non-disabled lads and girls are always hanging around, they shout "alright mate" and he shouts back and sticks his thumb up to them...' (Ward, Elliott and Day 2004).
- **Accessible playgrounds.** The charity HAPA works to create playgrounds which are models of inclusive play . A parent commented: '[They] all love it too. They have disabled and non-disabled friends and have grown up accepting people's differences. It's wonderful to have somewhere that they really enjoy but are safe and taken care of' (Voce, 1997).
- **Appropriate facilities.** In the Contact a Family survey (2002), bowling alleys and swimming pools were reported to provide the best facilities – disabled parking and good access, accessible toilets and changing facilities, and helpful staff.
- **Helpful, trained staff.** In an evaluation of Belfast summer schemes which included disabled children, Thompson, Taylor and McConkey (2000) described parents' initial concerns that the staff would not be able to look after their child. However, the volunteers were trained both in play for disabled children and in the needs of the specific children they were working with, and none of these fears were realised.

- **Written local authority play policies which include support for inclusive play.** For example, Stirling Council's play service provides summer play opportunities, and brings in additional resources such as the local museum and wildlife experts (Petrie, Storey and Candappa, 2002).
- **Reliable sources of funding.** This is a problem regardless of the inclusion of disabled children, but may be a particular problem where additional support workers are needed or particular training (Petrie, Storey and Candappa, 2002).
- **Providing good information to parents about services in their area** (Petrie, Storey and Candappa, 2002).
- **The resilience of families.** Despite the difficulties and barriers to accessing holidays and activities during the summer, families with disabled children are determined to give their children a good experience as Ben, aged 13, who has autistic spectrum disorder, explains. Ben says the family go on lots of days out during the summer holidays, for example swimming and to theme parks, which he enjoys. Ben doesn't enjoy 'wet weather, when Nick [his brother] gets bored and messes up my bedroom and [having a] tired mum'.

# EXAMPLES OF GOOD PRACTICE

## The Catalyst project – St Helens

The Barnardo's Catalyst project delivers an inclusive play project funded by the New Opportunities Fund Better Play programme. Before the project was established disabled children and young people were not accessing services. Better Play is funding a full-time worker who enables children and young people aged 5-13 to access a range of services throughout the year including after-school and out-of-school activity clubs, arts and theatre groups. This community-based service is responsive to the needs of local children and young people and has been welcomed by parents. Many teenage volunteers from the local community support the work.

The project manager says that it is easier to access funding for specialist services than for inclusive services. It is therefore important for the project to raise awareness of the nature of inclusive play.

Central to the success of the work are partnerships. The project has developed excellent partnerships with St Helens social services, St Helens play section and the local sports centres, who support the work by providing workers with specific skills. The Better Play worker is currently developing other partnerships. The funding has triggered the proposal to develop an inclusive adventure playground activity centre.

## The Log Cabin

'The Log Cabin was set up over 20 years ago as there was nowhere for disabled children to play and nowhere for them to play inclusively', the Log Cabin manager explains. The service is open to disabled children, their siblings and other non-disabled children.

The project has seen many benefits of inclusive play. Disabled children grow in confidence and develop social and emotional skills. Non-disabled children learn about disabilities and both disabled children and non-disabled children learn how to interact with each other and play together. A parent of a child with autistic spectrum disorder said, 'Abigail has had a wonderful time at the Log Cabin. It has given back all of her confidence and laughter'.

The project manager identifies funding as a major barrier to providing an ongoing inclusive service. It is difficult to secure funding from existing sources and new funding initiatives exclude ongoing work. Staffing is another barrier. It is difficult to attract enough staff to manage the demand for places, particularly staff with the requisite qualifications. This can be a particular problem in the summer holidays when people wish to spend time with their own children and it becomes difficult for them to work unsociable hours and times.

## OVERVIEW

In this report we have focused on the period in the year when support from statutory and other agencies is most limited and when children are regarded as being the responsibility of their parents. For families with disabled children the loss of support services they receive during term time puts them under extreme pressure. Many families also have other children who are home during the holidays and their needs must also be met.

In spite of their resilience, families with disabled children are excluded from leisure activities during summer holidays due to a combination of insufficient parental financial resources, inaccessible and inadequate local facilities, especially inclusive facilities, and negative public attitudes.

Article 31 of the United Nations Convention on the Rights of the Child which recognises the right of the child to engage in play and recreational activities is not being complied with. Disabled children continue to be excluded from play and leisure which meets their needs, and which allows their families to do the sort of social activities that other families take for granted.

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