

'Mingling together': promoting the social inclusion of disabled children and young people during the school holidays

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ABSTRACT

The promotion of social inclusion of disabled children and their families is currently high on the UK political agenda. Research shows that disabled children and their families are highly disadvantaged, both economically and socially. This paper reports some of the findings of a qualitative study, entitled *On Holiday!*, which involved analysing the views of 297 people across six local authority research sites in England including 86 disabled children and young people. The study showed that many disabled children and their families experienced high levels of social isolation and exclusion during out-of-school periods and during the school holidays in particular. The paper recounts some of the experiences of disabled young people and their families and ways in which local authorities can promote their social inclusion. We argue that disabled young people and their families can only be truly socially included and empowered when all levels of the local authority (managers, officers and elected members) recognize the rights and entitlements of disabled children and have the political will and commitment to implement them.

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INTRODUCTION

Recent UK government policy promotes the social inclusion of disabled children and their families (Department of Health 2001, 2004; Strategy Unit 2005). The recent Every Disabled Child Matters campaign has particularly highlighted the rights of disabled children to inclusion. Research has shown, however, how they and their families are highly disadvantaged, economically and socially, and that out-of-school periods can be particularly vulnerable times.

Social inclusion has no single clear definition but a broad approach to the term emphasizes participation in the mainstream, 'normal' activities of society and making choices and decisions about everyday life (Stevens *et al.* 1999; Morris 2001; Hill *et al.* 2004). Disabled children and young people have traditionally been excluded from mainstream life, segregated in special schools, hospitals and specialist out-of-school services, for instance.

A broad approach to social exclusion and inclusion has been used in research focusing on the lives of disabled young people. For example, lack of friends has been identified by parents and disabled young people as a crucial dimension of social exclusion. Murray (2002), in her study of 100 disabled teenagers, concluded that disabled young people emphasized the need for friendships and fun during their leisure activities. Yet, as Morris (2001) commented, there is currently no policy initiative that views friendship as a dimension of social inclusion. Morris found that disabled young people lacked opportunities for contact with non-disabled peers and encountered significant barriers to going out and about in their community and using leisure facilities. Sloper (2002) presented similar findings as did Ludvigsen *et al.* (2005).

In many of these aspirations, disabled children do not differ from non-disabled children (Petrie *et al.* 2000). In one research study, Morris (2001), for example, explored what social exclusion meant to young disabled people, aged between 15 and 20, many of whom had high levels of support needs and communication and cognitive impairments. Social exclusion was defined by these young people included: not being listened to, having no friends, being left out, with no contribution to make, feeling unsafe, not having control over, or access to, money.

Poor access to sport, play and other leisure facilities is a recurring theme in much research (e.g. Petrie *et al.* 2000; Morris 2001; Shelley 2002; Sloper 2002), with insufficient support for older children to access leisure services (Morris 2001; Murray 2002; Russell 2002; Sloper 2002). Exclusion from mainstream leisure opportunities is more severe for teenagers in weekly residential schools (Abbott *et al.* 2000; Shelley 2002).

This paper reports the results of an English study, *On Holiday!*, investigating the experiences of disabled children and their families outside school time and especially during the school holidays. The study was carried out by the Thomas Coram Research Unit, 2004–2006, funded by the Department for Education and Skills. The findings of the study support the conclusions of previous research and take into account the part played by local government in shaping provisions that supports/fails to support disabled children and their families. These contextual findings are indicated as follows, but discussed in more detail in a forthcoming paper.

The paper begins by outlining the aims and objectives of the study and the research methods used. It then highlights children's and young people's perspectives on their experience of out-of-school time, focusing on friendships, social isolation and young people's access to, and experience of, holiday clubs and activities. Gaps in provision are identified, as are services that supported children and young people, particularly during holidays. We finish with a summary of what is needed to meet for the rights and requirements of disabled children.

THE STUDY

Aims and objectives

On Holiday! aimed to understand how provision for holidays and other out-of-school times may contribute to the social inclusion of families with a disabled child. The study took an approach informed by a social model of disability, emphasizing the social construction of disability and eschewing notions of disabled people as impaired.

Methods

Two advisory groups (1) a group of disabled young people; and (2) representatives of relevant national organizations, each met twice to explore, variously, ways of involving disabled young people, and to comment on research materials, emerging finding and dissemination.

Fieldwork was conducted in six contrasting English local authorities. The selection included metropolitan and rural areas, authorities deemed 'good'/'excellent' and 'weak' (Audit Commission 2003) and authorities that had already developed children's trusts and extended schools. To protect confidentiality, we named the local authorities: London Outer, London Central, Metropolitan North-East, Metropolitan North-West, Shire County South and Shire Country East.

The research team developed interview topic guides. The perspectives of 86 children and young people were elicited and 121 staff and 90 parents were interviewed. Pilot interviews were not carried out. Fully written notes were taken of all interviews, which were audio-recorded for reference and to amplify the written record, as necessary.

The *personnel* interviewed were mostly middle or senior management, from local authority social services, education and early years, special and mainstream schools, health services, play, leisure and youth services, children's trusts and voluntary organizations. We did not interview local government councillors. These interviews lasted around an hour, covering the services provided for disabled children, organizational structures, the values, ethos and political will that informed provision, funding issues, gaps in provision and multi-agency and partnership working.

Parents were recruited through voluntary organizations or schools in each local authority. Only two parents declined to be interviewed. Parents were interviewed on a one-to-one basis, and in four of the research sites, in a group setting. The interviews, which mostly lasted 30–60 minutes, were semistructured

and centred on the use of out-of-school services, problems encountered and views about gaps in provision. Nearly all parents were from white British backgrounds.

The *young people*, mostly with parents who had not been interviewed, were aged 7–19 years – 38 girls and 48 boys – 76 from a white British, five from other European and five from black or Asian backgrounds. They were reported as having moderate learning disabilities (27), severe learning disabilities (10), physical impairments (17), speech impairments (3) and behavioural difficulties associated with the autistic spectrum or attention deficit hyperactivity disorder (12). The children, whose words are cited below, are those with spoken language, but the perspectives of children with other forms of communication were taken into account in the data analysis.

Children and young people were recruited through settings such as voluntary organizations, specialist units for hearing and visually impaired young people attached to mainstream schools, special schools and mainstream schools.

The work was informed by a growing body of literature, which offers guidance and ideas about how to consult or research with disabled children and young people, including the ethical and practical issues to consider (Beresford 1997; Ward 1997; Morris 1998, 2002, 2003; Stalker 1998; Marchant *et al.* 1999; Lewis & Porter 2004; Knight *et al.* 2006). To facilitate conversations with children, we used the 'I'll go first' pack, involving pictures of activities and the use of stickers (Kirkbridge 1999), which we adapted to focus on out-of-school time. The conversations centred on activities outside school, preferences and returning to school after the holiday.

We took a flexible approach adapting to the children's age, wishes, needs and communication requirements. Several of the children and young people used non-verbal communication. In order to elicit their views and experiences, they were shown laminated pictures of activities, like shopping, going to the park, the beach, being at home. A carer or teacher, familiar with a child's non-verbal communication, explained the children's responses, if necessary.

Analysis

A qualitative approach was adopted and for each local authority a case study was constructed, based on the interviews conducted there and on any documentation obtained. The case study approach was chosen because a local authority is a unit with clear boundaries. A case study has been defined as a 'very detailed research enquiry into a single example seen as a social unit in its own right and a holistic entity' (Payne & Payne 2004, p. 31).

The analysis was carried out manually and was not computer programme-assisted. It was thematic and took account of: the experiences of parents and children; sources and types of support; the appraisal of children, parents and personnel of such support; factors underlying effective support and, if appropriate, reasons why support was inadequate; the part played by extended schools and by children's trusts in providing family support and the political ethos of local authorities as this related to policy and practice towards disabled children. The research team identified common themes, across the six case studies, as the basis for an overview.

Ethical considerations

Advance approval from the Association of Directors of Social Services Research Committee was sought and obtained. The study was informed by two advisory groups (see Methods section).

The study followed the ethical procedures of the Institute of Education, University of London, with attention to informed consent and confidentiality. Research procedures were consistent with the requirements of the *Data Protection Act 1998*.

We were very mindful of the ethical challenges of consulting disabled children directly (e.g. Beresford 1997; Ward 1997; Stalker 1998; Alderson & Morrow 2004; Lewis & Porter 2004). We told the children about the research, they were given an explanatory leaflet (where appropriate) and chose whether or not to take part. This consent was expressed through spoken language, or through sounds and gestures interpreted by someone who knew the child.

Discussions with the children or young people took place in familiar surroundings, such as a holiday club or school, usually lasting for about 15 minutes. Sometimes a familiar person, such as a carer or teacher, was present to facilitate communication. No children declined to participate in the research. The children could, if they wished, stop the conversation by verbal or non-verbal signals. Tools such as a 'traffic light' system of red and green cards were occasionally used to indicate that a child wished to stop. The children were assured that the interview was confidential unless something relating to their personal safety was revealed.

Challenges confronting the study

A problem encountered in obtaining our sample and in the course of interviews, was which children were relevant for inclusion. The Department of Children, Schools and Families' definition of disability includes a wide range of conditions relevant to disability (Department for Education and Skills 2003).

However, the school staff with whom we liaised tended to limit the term 'disabled' to physical conditions and/or to wheelchair use. They discounted children with emotional and behavioural difficulties and those with learning disabilities. This was a particular difficulty when attempting to recruit our sample through mainstream schools.

Similar problems arose with parents and young people. Striking a balance between sensitivity as to whether people defined themselves as 'disabled' and clarity about why we were including them in the research was, therefore, important. One way of doing this was to use the terms with which young people identified, such as having additional or 'extra' needs.

Where feasible, we timed interviews to follow shortly after a school holiday, because these were one important focus of the study.

This was not always possible, so for a few children, interviews took place as long as 2 months after the last school holiday. Some young people were able to recall the holidays but for others recall was more problematic.

As appropriate, therefore, we sometimes focused conversations on experience of out-of-school times more generally.

THE EXPERIENCES AND PERSPECTIVES OF DISABLED YOUNG PEOPLE OF THE SCHOOL HOLIDAYS

When the parents of the disabled children spoke of the time when their children were not in school, they often described difficult experiences. Many spoke in terms of school holidays, especially, as being a 'nightmare'. They found that little appropriate support was available for them, especially for parents of teenagers and for children who had been diagnosed as autistic or with Attention Hyperactivity Deficit Disorder (ADHD).

The children's experiences out-of-school were characterized by great variability of activities and use of services. Whatever they did, most of the study participants were positive and described activities, such as those their non-disabled peers might report. For example, a 9-year-old boy said: 'I play football. I go the park with my mum and friends. I watch TV.' Many played on the street, watched television and played computer games. A few spoke about being members of the scouts and camping and some were enthusiastic about family holidays. Although many were not able to go on holiday, some children did tell us about day trips to the beach or to theme parks, which were often highlights of the holiday.

Unfortunately, enjoyment far from represented the whole out-of-school picture. Especially in the long summer break, boredom was a common experience for disabled children, as it is for those who are not disabled (Petrie *et al.* 2000). Many of the sample welcomed returning to school. A 16-year-old young woman, typical of many, said 'The holidays are alright at the beginning, then they get boring.' Another said 'Going back to school gives you something to do.'

Compared with non-disabled children, the disabled children had additional reasons for complaint. For example, a girl said she was sick of spending much more time in her wheelchair during the holidays, than during term time. Her teacher explained that, at school, children were regularly taken out of the chair for exercise and other activities. At home, such opportunities were much more limited. Assisting children in and out of chairs can be taxing for parents, especially if only one adult is available, and for older and heavier children.

Friendships and social isolation

While those who were able to meet friends outside school time valued this greatly, a major contribution to the boredom experienced by many interviewees was social isolation. 'I'm very happy that I can come back to school and spend time with my friends.' was a response typical of many. 'Sometimes my friends are away and I get bored', a 13-year-old boy told us.

The school is an important site for friends for many children. However, some of the study participants attended special schools or units some distance from home. While they had not formed local friendships, they were unable to meet their school friends during the holidays. Consequently, they experienced high levels of social isolation. One teenager, attending a unit for sensory impaired young people in a mainstream

school, explained that she had no local friends and did not do much in the holidays: 'Sometimes I go on day trips but only with my mum and sister. I get really bored because I'd rather go out with my friends.'

Making local friends was a particular problem for young people living in rural areas and for children attending schools as weekly boarders. The physical distance between different children's homes and the lack of suitable transport were major obstacles, compounding existing exclusion. One 14-year-old said, 'I only have one friend where I live – I only see her sometimes.'

Nevertheless, some young people were able to make local friends. A 15-year-old girl told us

'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.'

Interviews with young people with sensory impairments revealed particular problems. A 15-year-old, with a visual impairment, remarked: 'For people like us, there's a limit to what we can do. We can't play football, badminton or tennis. I have to play squash with a special ball.' For her and others, making friends in the wider community was especially difficult. They wanted to mix with non-disabled young people but found the experience problematic. As the same 15-year-old said: 'I hate making new friends, because they look you straight at your eyes and say "your eyes are moving" and I think "Oh, not again".' A young woman, aged 14, indicated a different sort of dilemma:

'The trouble is you're scared of hurting the feelings of other partially sighted people and if you go around with "normal" people, you get worried about how they [partially sighted people] are going to be towards you.'

Some young people described the 'overprotectiveness' of their parents, which prevented them from going out independently and mixing with nondisabled young people. This meant that they experienced high levels of social isolation. As a 14-year-old young woman said

'I don't really do anything. My mum won't let me out because of my eyes. I'm trapped in. I can't go out with my friends. I can't go out but I have to put up with it. I'm sort of used to it now. But I wish I had the freedom to do things.'

HOLIDAY CLUBS AND OTHER LEISURE OPPORTUNITIES

A partial solution to the isolation experienced by children out-of-school lies in those holiday clubs and other leisure opportunities that aim to promote the inclusion of disabled people. About half of the children and young people in the study had attended some kind of holiday play scheme during the last summer holiday, run either by the local children's services department or by voluntary sector services.

All were very positive about their experiences, even though their attendance was generally limited, because providers limited the availability of places for disabled children (see below).

Being with other young people was one of the main reasons for young people liking holiday clubs. One excitedly described attending a holiday drama club run by a voluntary organization. Holiday clubs are non-statutory provisions and their funding basis is often precarious but this boy hoped that there would be continuing funding for the club the following summer. What he enjoyed most was that a friend also attended and that he had got to know the other participants. Friendship was also a reason why he had decided to go to the Saturday club at his special school:

'I wanted to go to the Saturday club . . . I like spending time with my friends. Once Friday's over you won't see them [friends], so I decided to go to Saturday club to be with my friends.'

Many young people preferred attending some sort of play provision, with the activities and trips on offer, to staying at home. A 7-year-old boy, a wheelchair user, said 'I prefer coming here [the Play Centre] than being at home. It's more fun here. I get to do many different things.'

Nevertheless, in describing their experiences of mainstream and specialist clubs, young people also painted a problematic picture. For children with physical and sensory impairments, while they wanted to be part of mainstream experience, they thought that providers needed a better understanding of their situation.

Two deaf children, for example, enjoyed attending local (mainstream) clubs but were also critical of them. A 14-year-old boy, for example, liked going out with his 'mates', playing football, but added

'I'm the only deaf person in the [football] club. There are no more deaf people and that can be annoying. When I'm on the ball it's hard to hear people. [None of the coaches could sign, but] it would be useful to have little signals which they could use.'

Another young man, aged 17, highlighted the importance of being able to do 'ordinary' things, but described the associated difficulties. He suggested

'All children like shopping. If they wanted to, I think there should be something to help them get young people to town with a helper, so they could buy what they wanted.'

Without such intervention, it can be very difficult for disabled children to do 'ordinary things'. A young man, for example, had regularly gone swimming with his father, but was no longer able to probably, he thought, because he was now too heavy for his father to help him in and out of the pool. However, he had been able to go swimming with a specialist holiday club in the summer, and had enjoyed this. A girl, aged 12, described her frustration at not being able to attend a local club for teenagers, because there was no access for wheelchairs and said

'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.'

Problems also arose because inadequate transport meant that disabled young people could not access a range of leisure opportunities. Accessing a Saturday club at a special school was difficult for children living outside the local authority where it was situated, because transport was provided only for those living within the authority boundaries. Even for these, the situation could be far from ideal. One young person who attended was picked up by the school bus. He described how he was the first into the bus and sat in the bus while other children were collected. On one recent occasion, he explained, he had spent two and a half hours in the bus. Being willing to tolerate such long journeys gives an indication of how much the boy appreciated the Saturday club and, perhaps, the lack of other leisure opportunities.

PROMOTING SOCIAL INCLUSION FOR DISABLED YOUNG PEOPLE

In spite of overall inadequacies, steps – to varying extents – were being taken by local authorities and the voluntary sector to promote greater social inclusion for disabled children and young people outside school time. It is to these measures that we now turn. We look at some underlying strategies, the 'bridging role', by which professionals link families with services during the holidays, and provide a few, small-scale examples of local practice aiming to facilitate social inclusion.

Strategies for inclusion

At the time of the study, Metropolitan North-East was adopting a strategic approach towards inclusion for disabled children in mainstream out-of-school services. The council had developed an inclusion group, with multi-sector representation, an inclusion charter (a quality assurance package, focusing on inclusion, used by early years provision) and an inclusive play strategy. Summer 2004 saw the introduction by the council of some inclusive provision during the summer holidays, with a decision to have an inclusive site for children and young people up to the age of 14. Special schemes were in place for children and young people up to the age of 19, who had more severe 'additional needs'.

In Metropolitan North-East, strategies towards disabled children were taken forward by dedicated staff appointments. Three inclusion officers were responsible for training mainstream out-of-school staff and ensuring that premises were appropriate for disabled children. The local authority also supported an access and inclusion officer, employed by a large voluntary organization. This officer aimed to keep inclusion on the local agenda, for example by promoting the inclusion of disabled young people in youth provision, which was even less available than out-of-school services for younger children. The access and inclusion officer consulted parents and children about any difficulties arising in mainstream services. In addition, children's social services had appointed a community resource

development officer to promote the inclusion of disabled children in mainstream out-of-school activities (the 'bridging' role described below).

In another area, Metropolitan North-West, a large voluntary organization played with a project supporting disabled young people – aged 5–18 – to access local social activities, played the main strategic role, locally. The project was developing partnerships with local leisure and play providers and community groups. The inclusion worker organized summer play schemes for disabled children and young people, and had linked to an extended school, with a view to developing inclusive after-school services.

Providing a bridge between families and services

Families with a disabled child often need someone to be a 'bridge': to provide information and to link them into the provision in a way they find appropriate. Equally, inexperienced service providers need someone who will provide an initial link with families and to point the way towards staff training and ways of making their services inclusive.

We came across two specific examples of a local authority professional, appointed to perform a 'bridging' role. These were highly valued by parents. One was the worker already mentioned in Metropolitan North-East, who was based in the social services disabled children's team. This worker co-operated closely with the team's social workers, with out-of-school services and with families in the community. The exchange of information in advance of attendance at leisure provision was identified by parents as an invaluable component of care for severely disabled children and those with additional or complex health needs. The 'bridge worker' could ensure such an exchange.

A bridge worker in London Central's play services was knowledgeable and familiar with much of the out-of-school provision in the area. She linked the disabled children's team, the family and service providers. On the basis of referrals from the social services disabled children's team, the worker visited families, made an assessment and matched the child to an after-school or holiday club. She offered service providers advice on an inclusive approach, both generally and regarding specific children. She was also able to facilitate funding for extra staff or for adapting premises.

An example of the proactive approach found in London Central was where a social worker liaised with a primary school and arranged for a child's electric wheelchair, previously used only in school, to be sent home for the holiday. This meant that the child could be taken to a mainstream play scheme by her parent, and on other outings. The school also sent a bucket chair (for sitting on the floor) and a gamma chair (for sitting at the table) directly to the play scheme, so that the child could better participate in the activities on offer.

'Buddying' schemes

Not all 'bridging' was in the hands of professionals, however. We came across several examples of smallscale 'buddying' schemes. These enabled some disabled young people to access mainstream social activities by pairing the disabled young person with a non-disabled buddy, often a volunteer, so that the

disabled young person could go to mainstream leisure activities such as youth clubs, cinemas or pubs. In Shire County South, one of the disabled young men interviewed was looking forward to being provided with a buddy with similar interests to himself. In Metropolitan North-East, a 16-year-old young woman appreciated being paired with a student who regularly escorted her to the cinema. In London Central, support staff from a special school facilitated some young people from the same school in attending a mainstream play scheme in a sports centre.

Two other examples of how disabled young people and their families could be supported were reported. The first was of disabled young people acting as volunteers in out-of-school provision that they themselves had attended. In Shire County South, for example, a 16- and a 17-year-old, both learning disabled, spent time as volunteers in a Saturday club and in a holiday club for younger people. They talked positively about this role and said it was 'good to do' and 'rewarding'. The activity coordinator commented on the importance of offering disabled young people opportunities to volunteer; it enabled them to 'try out different things' in a supportive environment. A disadvantage of such volunteering should be commented on. In some holiday schemes, young people reach the upper age limit, without other age-appropriate provision being available. When this happens, being a volunteer can be seen as a welcome solution. At the same time, it can mask the exclusion of disabled young people from the activities of their own age group and, in the case of special provision, from the activities of mainstream society.

Our final example of support was found in Shire County East. Here, a voluntary organization, supported financially by social services, provided a citycentre flat for 2 days a week during the summer school holidays. The flat catered for six disabled young people over the age of 13. It had a large living room, kitchen, bathroom and a 'sensory room', meant mainly for relaxation, with comfortable seating, low lights and a sound system. Supported by four members of staff, the young people used the flat as a base to access the facilities of the city. They went to the park, had picnics, went swimming and bowling and, where ageappropriate, to the pub. They visited the supermarket to choose their own food, which they prepared and ate together. The flat was said to be popular and oversubscribed. The voluntary organization aimed to increase the time available to young people to 3 days a week. Outside school holidays, the flat was used by adult services.

GAPS AND FAILURES IN PROVISION

In spite of the examples of good practice described above, we found notable gaps and failures in provision. The majority of young people interviewed, despite enjoying aspects of the holidays, said that they often felt bored and missed their friends. They wanted more opportunities for seeing their friends and more access to mainstream leisure environments. For the most part, such opportunities were denied or very limited. About half the young people interviewed were able to attend play schemes, but providers allocated them a few separate days or half days, or limited their attendance to 1 week out of a 6-week summer holiday. This was not the case for non-disabled children. Disabled children are discriminated against in this way because of, among other reasons, the increased staffing costs sometimes associated with their attendance (Petrie *et al.* 2000, 2003).

While most of the young people and families interviewed complained that leisure provision was inadequate, two groups of young people seem to have been particularly ill served.

Children diagnosed on the autistic spectrum

We found specific challenges experienced by families of children diagnosed as on the autistic spectrum or with behaviour difficulties associated with ADHD. Parents described children who found unfamiliar environments and situations particularly unnerving and play scheme staff whom they perceived as hostile towards their children (see also Petrie *et al.* 2000). The result was that attending holiday clubs was, for some, almost impossible (see [Note 1](#)). Nevertheless, from what parents told us, children diagnosed as on the autistic spectrum or with ADHD, need special consideration out of school. Their experience appears to have been little addressed by providers, or by local authorities and voluntary organizations.

Leisure services for teenagers

The lack of out-of-school support for young people over the age of 12 or 13 was striking. In the local authorities studied, there was little youth provision and young people's access to mainstream leisure opportunities was often dependent on their parents. Young people over the age of 12 had outgrown holiday play schemes: these were often age-inappropriate from their own perspective and from that of the provider.

Non-disabled children also 'grow out' of holiday play schemes. But they have increasing autonomy as they enter their teens and increasingly arrange their own leisure activities. This is less possible for disabled young people, unless steps are taken to support their social participation.

Across the six local authority research sites, professionals linked inadequacies in youth services directly to national policies that focused funding on juvenile offending, anti-social behaviour and preventing teenage pregnancy, rather than on disability. A manager remarked that 'The youth agenda here tends to be around crime reduction first and foremost, so disabled young people aren't really on the agenda.' And a senior manager in the youth services of a different authority said

'I feel at the moment that the "hot cake" work is if you're working with young people at risk of crime and I feel like that's our priority area and everything else goes to the wayside and I feel that's really disappointing.'

MEETING DISABLED CHILDREN'S RIGHTS AND REQUIREMENTS

The Children Act 1989 (Department of Health 1989) and the United Nations Convention on the Rights of the Child, ratified by the UK in 1991, both emphasize the rights of disabled children and young people to be included in mainstream activities. In addition, over the last 12 years, various Disability Discrimination Acts and their amendments have required that disabled people should have access to mainstream services including care and leisure (DDA 1995, 2005). The *Disability Discrimination Act 2005* extended this legislation by introducing a duty on all public bodies to promote equality of opportunity for disabled people. A similar direction is to be found in the Childcare Act 2006, which places a duty on local authorities

to ensure (not necessarily provide directly) child care for working parents, and those in training, mentioning, specifically, child care for disabled children.

While we did find examples of good practice towards disabled children and their families, we also found many inadequacies that were testified to by the children themselves, by their parents and by some of the professionals we interviewed. We asked professional staff (managers and development workers in various sectors) about whether local government appeared to understand and support disabled children and their families, outside of providing schooling. The study identified several reasons why families were inadequately served.

Foremost among the factors underlying inadequate provision for disabled children was a lack of local commitment to disabled children and their families. We heard, for example, that providing holiday and after-school activities often depended on the 'goodwill' of school staff, rather than being embedded in local policy and strategies. Some staff, in health and education, questioned whether it was the responsibility of their departments to provide family support during the school holidays, with the implication that it was a matter for social services. Others felt that holiday support was not really an issue for 'their' families.

Families appeared to be served better in local authorities where there was more evidence of a political will among councillors and officers to meet their rights and requirements and, more importantly, where this was followed through in practice. In contrast, we found local authorities where there appeared to be a culture that might be termed 'philanthropic' rather than one that recognized entitlements or rights; a tradition of providing the family as a whole with occasional 'treats' like parties and outings to the seaside. Professionals reported some reluctance among families to take up these activities, which was seen as condescending. The approach contrasts with the notions of social inclusion and solidarity, more typical of mainstream play and care provision in some of the urban areas studied.

In the urban areas, there appeared to be higher levels of community democracy and participation, evident in some parent-professional forums and youth assemblies and councils, on which disabled young people were represented. The highest levels of inclusive opportunities for disabled children were found in one of the London boroughs. Here, sufficient funding was allocated to make access to inclusive activities a reality, for example by providing free transport and some (nevertheless limited) play provision. In a different London borough, however, a manager commented that, in spite of the borough having a strong *rhetorical* position on social inclusion, their fairly extensive out-of-school provision was in reality an 'able-bodied service' not geared for disabled children.

CONCLUSIONS

This paper has put the views of young people about out-of-school times and their use of services in the foreground. It has also provided some examples of good practice among providers and local authorities and outlined local policy and practice towards disabled young people and their families. In summary, many young people themselves, despite enjoying aspects of the holidays, said that they often felt bored and missed their friends. They wanted more opportunities

for seeing their friends and more activities in mainstream leisure environments.

Disabled children and their families appeared to be best supported through a range of services, including holiday clubs and other leisure activities that took into account their specific requirements. These were often based on the strategic appointment of personnel, in both the public and voluntary sector. Unfortunately, there was usually extensive rationing of any kind of out-of-school leisure and child care for families of disabled children over the school holidays. In addition, children and young people themselves (as well as their parents) told us that services were not able to meet their needs appropriately.

Among groups who, according to parents, were particularly ill served were children diagnosed as on the autistic spectrum and those said to have ADHD. The lack of out-of-school support for young people over the age of 12 or 13 was also striking. There was little youth provision and young people's access to mainstream leisure opportunities was often dependent on their parents.

Yet, as one young woman told us

'If they (young people) all mingled together then perhaps they (non-disabled people) would understand a bit more.'

This is a point of view that should be listened to. 'Mingling together' is important across the community for disabled and non-disabled people alike. We found examples, not necessarily innovative, of provisions such as the buddying schemes that aimed to promote the social inclusion of disabled young people. We make a number of recommendations to promote the social inclusion of disabled children further. These include an audit by local authorities to assess and map service provision school holiday services for disabled children, including a review of costs and the development of monitoring and evaluation systems. Increased provision for young people over the age of 12 and for working parents, a need highlighted by the Daycare Trust (2005), is also recommended. A range of options for out-of-school support needs developing, with 'bridging' staff to help facilitate the inclusion process. Options include developing short-term breaks, home-based child care and opportunities to join mainstream play, child care and leisure, with adequate transport as part of the provision. These recommendations, in addition to appropriate national politics and legislation, have an important part to play in enabling inclusion. Provision for disabled children also depends on the actions of the local population, children's services managers, providers and staff. The empowerment of disabled children and their families needs a pervasive understanding, throughout the local authority, the private and voluntary sectors that disabled children have rights and entitlements that must be met. Such understandings, however, are still underdeveloped.

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NOTE

1) These difficulties were not recounted by the children themselves, because most of those said to be on the autistic spectrum did not use spoken language.