Opportunities for Fun and Friendship for Disabled Children and Young People

A Focused Review of the Literature

BBC Children in Need

UNIVERSITY OF
BIRMINGHAM

Opportunities for Fun and Friendship for Disabled Children and Young People: A Focused Review of the Literature

Report for BBC Children in Need

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1 Introduction

This report is the result of a literature review commissioned by BBC Children in Need to inform a proposed '*Disabled Children and Young People Friendship and Fun Programme*'. The report accompanies two complementary strands undertaken by BBC Children in Need: conversations and consultations with voluntary and community sector (VCS) organisations working with disabled children and young people; and, consultations with a selection of projects funded by BBC Children in Need that work with disabled children and young people.

2 Definitions and Methods

Estimates suggest between 5 and 7 percent of children experience disability. Definitions of disabled children vary; in this study we draw on the social model of disability, which highlights that disability should be distinguished from impairment:

> *Impairment* is the functional limitation within the individual caused by physical, mental or sensory impairment. *Disability* is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.[1]

The study involved: searches of academic literature; grey literature; websites of organisations and agencies; and, inviting contributions from e-based networks.

3 Findings

3.1 The Experiences of Disabled Children and Young People: An Overview

Disadvantage and Social Exclusion

Poverty and social exclusion are key characteristics of many disabled children, young people and their families' lives. Research demonstrates that: there is a strong relationship between low income and social exclusion

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[1] Barnes, C. (1991) Disabled People in Britain and Discrimination: a case for anti-discriminatory legislation, London: Hurst & Co

amongst families with a disabled child; families with a disabled child are disproportionately likely to live in poverty; and, disability across the life-course has a high association with poverty.

The Centrality of School

School plays a central role in the context of opportunities for fun and friendship for disabled children and young people. School is an important domain in which friendships can be established and maintained, but can limit opportunities for wider networks to develop. It can be difficult for children to sustain friendships outside of school where school is some distance from their home and community. And there may be limited opportunities within school, if children and young people spend a lot of their time there with adults.

Provision for Disabled Children and Young People

Research has highlighted that despite the problems of poverty and disadvantage, and the reliance on school as a site for leisure, local authorities have consistently failed to address the needs of disabled children and young people.

3.2 Fun and Friendship: A Review

3.2.1 Fun and Friendship

Research, consultation and programmes of participation with disabled children and young people and their families consistently provide evidence of the importance of friendship and the development of interdependent relationships as central to enjoyment and well being. Creating accessible environments where children and young people can develop friendships and meet friends emerges as a priority for disabled children and young people. Having opportunities to socialise and maintain friendships outside school emerge as particularly important.

Dependence, Independence and Interdependence

Issues of dependence, independence and interdependence are complex and assumptions about the nature of children's and young people's preferences and relationships should not be assumed. Opportunities for fun and friendship, and managing difficulties which can arise within friendship relationships, can be seen as one element of increasing independence and strengthening individual's own choice and control in their everyday lives. These are complex relationships and processes for all children and young people, and can be compounded for disabled children and young people.

High levels of dependence can lead to high levels of isolation. Reliance on others can limit opportunities for fun and friendship outside of structured activity; but supportive relationships also offer a resource on which to build. Choice for disabled children young people and families is often restricted and there is often a reliance upon a limited range of targeted and structured activities and little opportunity to engage with mainstream provision.

Social Isolation at Critical Periods

There are critical points when disabled children and young people are particularly vulnerable to social isolation. With school and school provision central to the friendship experiences of disabled children and young people, holiday periods are identified by research as particularly challenging and socially isolating for families that include a disabled child. Access to summer play schemes becomes particularly significant for families with disabled children, but there is a lack of accessible provision.

Disabled young people's transition to adulthood can be a time of vulnerability to social isolation. Whilst disabled young people often identify that making and keeping friends is the most important aspect of their lives, many have no experience of an independent social life and few opportunities to make friends. For many disabled young people their time is spent with a paid carer or family members and most have no independent access to transport. Leaving school or the move from one residential setting to another can often mean loss of friendships and disabled young people with high levels of support may be moved into residential care where they have little or no contact with people of their own age.

Involvement in Sport and Physical Activity

Participation in sport is perceived as offering opportunities for both fun and friendship, but few disabled children and young people are able to participate because of the limits of existing provision. Targeted schemes and enhanced mainstream provision can enable greater participation for disabled children and young people.

Provision for Disabled Teenagers

Our review highlights a lack of provision for disabled teenagers, particularly provision that enables inclusion in the mainstream and everyday opportunities for fun and friendship that able bodied young people take for granted. Fun and friendship has a key role for teenagers, away from the more structured provision that exists for children. Disabled teenagers can face specific and complex barriers to fun and friendship. Their desire for autonomous experiences may conflict with their support needs. Solutions identified to overcoming barriers to inclusion stress access to appropriate support including: transport, money, personal assistance, physical support, communication support, medical support and support to facilitate relationships.

3.2.2 Barriers

As we have seen, disabled children and young people face a range of barriers to accessing and developing fun and friendship opportunities. These are societal and attitudinal, practical, and can be impairment specific. There is a lack of examples of the Disability Discrimination Act 2005 (DDA) being used to promote inclusion or to question exclusion where it is identified.

Societal Barriers

Although physical accessibility issues are identified in research as important, studies overwhelmingly demonstrate that inclusion is less about the availability of special equipment and more about wider social attitudes. Despite recognising them, services rarely address exclusionary attitudes and practices in local communities. To achieve inclusion, policy and practice needs to address social exclusion and those factors, process and people who exclude and not just focus upon an individual or group as excluded.

Practical Barriers

There are a series of practical barriers to accessing mainstream provision or the ability to join in with local activities. Lack of access to suitable transport is consistently identified as a barrier to inclusion. Studies indicate that a majority of disabled teenagers are unable to access appropriate transport independently and this often means either dependence on family members for transport or staying at home. Parents and children identify a range of additional physical and environmental barriers to their inclusion in community based leisure provision. These include a lack of appropriate toilets, sinks and changing facilities, availability of specialist equipment, and provision of car parking spaces, ramps and doors that disabled children can open. A lack of information is also consistently identified as an inhibitor, including information in accessible formats and about accessible facilities.

Impairment Specific Barriers

Some groups face particular barriers associated with levels and type of impairment, and the support requirements which relate to these. These barriers may be practical or may be social responses to specific impairments. Children and young people with learning disabilities are less likely to have non-disabled friends than young people with physical or sensory impairment and have significantly less opportunity to enjoy independent access to leisure.

3.2.3 Developing Provision

We now identify the messages relating to the development of provision.

Targeted Provision or Mainstream Inclusion?

The delivery of segregated or inclusive provision is a complex area. Both segregated and inclusive provision presents positive opportunities, with children and young people expressing a diverse set of views as to their preferred option and the needs of the child, young person and their family will directly affect their preferences. In the absence of inclusive mainstream provision and opportunities for fun and friendship, children and young people (and their families) welcome opportunities that are provided. This does not negate their aspirations for more inclusive mainstream provision, nor a recognition that alongside work to make the mainstream inclusive there is a need to provide targeted provision to address the gaps that exist.

Supporting Access to Fun and Friendship Opportunities

A consistent message from research and consultation is that parents and children want to enjoy a broader variety of experience and to have the same opportunities as others to participate in mainstream activity. Friendship is an intrinsic part of quality leisure time yet for many making and maintaining friendships is challenging. This is particularly so for children and young people with communication impairments, high support needs and/or learning difficulties. Supported access is important for disabled children and young people. The type, nature and level of supported access offered needs to be flexible and responsive. Support may vary from facilitating communication, to accompanying a child to a Brownie session until she feels comfortable to attend independently, to supporting a group of teenagers on a regular basis to access a range of community based venues such as bowling or the cinema. Practical suggestions include free entry for support workers, taster sessions for children, young people and their support workers, more information on Direct Payments as a means of accessing support; provision of leisure passes; and, better training for staff so that they can routinely identify the support needs of disabled clients.

Addressing Practical Barriers

There are positive steps that can be taken, and encouraged, in order to address some of the physical barriers that prevent the inclusion of disabled children and young people. Specialist equipment can be required but also important is equipment that is accessible to all. Transport can be a complex issue as provision is different in different places, but the central role of transport should be recognised. Staff training has a key role to play in raising awareness and skills. The history of provision for disabled children, young people and their families is characterised by short-term and unstable funding, which creates uncertainty, limits the range of provision, and limits the ability to address the barriers to inclusion in order to achieve the change required.

3.3 Conclusion: Fun and Friendship for Disabled Children and Young People

For sustainable inclusion to be achieved, with both societal and practical barriers to the participation in opportunities for fun and friendship addressed, enabling support perhaps offers the most potential. Enabling support is tailored to individual needs, and is not impairment or context (for example rurality) specific. Enabling support focuses upon supporting children and young people in accessing mainstream and existing provision, as well as non-structured activities such as meeting with friends. As well as facilitating and supporting participation, enabling support addresses practical and other barriers so that when withdrawn participation can continue.

4 Consultation and Participation

It is important when involving disabled children and young people in sharing their views about provision and opportunities that (1) a range of tailored methods are used, (2) these are employed flexibly (3) that there is transparency and (4) that the adults involved have appropriate skills and knowledge . Through this approach, full participation may be recognised as not always necessary, desirable or achievable. Consultation can be appropriate if that is all that is possible, for example as a result of limited resources to support involvement, or limited choices over which the results of any involvement might have influence. Where participation cannot be achieved, openness and honesty about the limits of involvement is important.

Parent and child views may differ and the use of adults as proxies for children and young people in giving views is problematic. It is therefore important that children's and young people's views are, as much as possible, sought independently of parents or carers.

5 Policy Context

In this section we outline the policy context for the proposed programme. It is important for all stakeholders that, in building upon the messages from the evidence and literature discussed in Section 3, the programme does not duplicate existing or statutory provision, but works to supplement and complement what we know to exist.

5.1 Every Child Matters

Every Child Matters provides the overarching structure for children and young people's services in England with a common set of outcomes for all children regardless of background or circumstance. There is a particular focus upon the requirement for services and agencies to work together to address needs and issues for children and their families at their earliest stages and before they become acute. This is echoed by parallel developments Wales, Scotland and Northern Ireland. Alongside this holistic and multi-agency approach to children's welfare and wellbeing, there is a specific policy focus upon inclusive play provision in terms of facilities and play areas and the need to support a skilled workforce.

5.2 Fun and Friendship for Young People: Leisure and 'Positive' Activities

The policy focus for 'fun and friendship' opportunities for young people is focused towards leisure opportunities and access to leisure provision, organised 'positive' activities, and opportunities to meet and mix with other young people outside of adult-led structured provision. The policy agenda in this area contains less activity in practice terms than the play agenda for children outlined above, as much of the documentation in this area relates to intended and forthcoming policy and practice rather than reports on actual progress, practice and delivery.

5.3 Conclusion

Although there is a growing recognition of the need to provide for disabled young people (teenagers) there is less policy focus and commitment than that concerned with disabled children. The lack of provision outside of targeted, structured activities emerges as a clear gap in policy and practice.

6 Conclusions and Recommendations

We conclude by reflecting on the messages that have emerged from our review in light of the four aims for BBC Children in Need's overall scoping study. Rather than being prescriptive about the schemes that BBC Children in Need should prioritise within the forthcoming grants programme, we suggest a set of themes that provide the context for considering grant applications and that could inform the parameters or themes of the programme itself.

6.1 Aims and Recommendations

> ***Aim 1**: To assist BBC Children in Need in clarifying the focus and activity of the future proactive programme.*

We suggest that BBC Children in Need focus upon provision for older children and young people, aged from 12 years upwards, as there is a sustained policy focus upon younger children and play provision. Capacity should exist within the programme for locally defined proposals linked to local context. To achieve change longer-term funding should be considered so that projects are able to demonstrate effectiveness, enable learning and participation, and to enable learning to influence local policy and practice.

> ***Aim 2:** To generate a clear understanding of what activities work in building friendships and creating socialising opportunities for disabled children and young people.*

There is a lack of evidence about different models of providing opportunities for fun and friendship for disabled children and young people. According to the context of local provision, but also individual and family preferences, both targeted and inclusive provision present positive opportunities. Enabling schemes, or those that support children and young people in accessing mainstream activity, and which work to address barriers in order that inclusion can be maintained, appear to offer potential for flexible approaches to achieving inclusive experiences for disabled children and young people in their everyday lives.

> ***Aim 3:** To identify what gaps exist in current provision that could be addressed by the BBC Children in Need programme.*

Although local need will vary, a strong message emerges from the review about the lack of opportunities for teenage disabled young people to take part in both the structured and spontaneous activities that are central to the development of friendship and the socialising that their non-disabled peers take for granted. School and the school holidays present particular issues for disabled young people who can experience barriers in maintaining and developing friendships outside of school. An out-of-school focus therefore appears entirely appropriate for a BBC Children in Need programme. A key gap in provision for disabled young people is inclusive mainstream provision; BBC Children in Need should support grant applications that are explicit about the way in which they will work to address barriers in their local areas so that sustainable inclusion is achieved. Enabling provision has potential to address the gaps identified by this review.

> ***Aim 4:** To develop a programme that is informed and supported by those who will benefit and those already working to meet their needs.*

As local need will vary, it is important that assumptions about what disabled children, young people and their families need or prefer should be avoided. Grant applications should be clear about the ways in which participation or consultation has been undertaken and how it will be supported in an ongoing fashion throughout the length of grant support. The perspectives of minority groups should be included within any local mapping of need.

Finally, this review has demonstrated the difficulty in understanding the complex networks and maps of provision that exist at a local and community level, where disabled children, young people and their families live their lives. We have two suggestions for the development of an evidence base in this area in the longer term. First, for BBC Children in Need to ensure that successful grant awards include a commitment to undertake research and evaluation and to contribute to learning. And second, for an international review of practice to be supported so that learning from different contexts can be collated and the learning promoted within the UK, but also internationally.

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1 Introduction

This report is the result of a literature review commissioned by BBC Children in Need as part of a scoping study to inform a proposed '*Disabled Children and Young People Friendship and Fun Programme*'. The report accompanies two complementary strands undertaken by BBC Children in Need: conversations and consultations with voluntary and community sector (VCS) organisations working with disabled children and young people; and, consultations with a selection of projects funded by BBC Children in Need that work with disabled children and young people.

The purpose of the literature review was to contribute to the overall aims of the scoping study, which are:

1. To assist BBC Children in Need in clarifying the focus and activity of the future programme.
2. To generate a clear understanding of what activities work in building friendships and creating socialising opportunities for disabled children and young people.
3. To identify what gaps exist in current provision that could be addressed by the BBC Children in Need programme.
4. To develop a programme that is informed and supported by those who will benefit and those already working to meet their needs.

Within the scoping study and the literature review, 'fun and friendship' has been broadly defined to include any activities, opportunities and processes that support fun and friendship rather than a narrow definition focusing upon a particular or range of particular provision. The review recognised the centrality of fun and friendship to the everyday lives of *all* children and young people. Our focus was on evidence or messages from children and young people themselves about their experiences of and availability of opportunities for fun and friendship, the activities or processes that support fun and friendship, and the areas where more support is required.

In the following sections of the report we: give an overview of disabled children and young people's lived experiences, and outline the definitions used within the review and the methods that were employed; explore the messages that emerge from the literature review, through three sub-themes we have been able to identify of *fun and friendship, barriers,* and *developing provision*; highlight learning about consultation and participation and the involvement of disabled children and young people; outline the policy context within which any programme operated by BBC Children in Need will operate within and alongside; and, provide our conclusions and related recommendations.

2 Definitions and methods

2.1 Identifying Disabled Children

Definitions of 'disabled children' as a group vary (in surveys, in local arrangements, between services and in terms of 'eligibility'), and so do estimates of the prevalence of the experiences of impairment and disability in childhood. Further, the causes of exclusion for young people are understood and defined in different ways, with some (more clinical) approaches focusing on impairment (or 'function') as the source of difficulty, and more social approaches instead focusing on disabling environments and interactions. It is important to note here that this review of evidence concerning fun and friendship opportunities for disabled children and young people is not seeking to be impairment specific, but is concerned to identify both barriers and examples of opportunities to ensure inclusion in enjoyable activities and relationships for children and young people.

Although our focus is on disability rather than impairment (see 'definitions' below) it is helpful to briefly identify some of the disability statistics, which indicate the wide relevance of this review. Disability data may be disputed and discussed, but it provides a useful part of the map of the 'ground', and can arguably be used to 'galvanize awareness of the relationship between society and disablement' (Fujiura and Rutkowski-Kmitta, 2001:93).

There is indicative data about the prevalence of impairment in childhood from official national surveys, with most estimates suggesting between 5 and 7 percent of children experience disability: the General Household Survey (ONS, 2004) suggests that about 1 in 14 children are disabled, whilst the Family Resources Survey (FRS, 2002-3) indicates that approximately 1 in 20 children aged under 16 are disabled (both figures cited by Prime Minister's Strategy Unit (PMSU), 2005). It is important too to note the changing demographics that population studies highlight. The number of children identified as having complex needs appears to have increased in recent years. This can be understood to be the result of a range of factors including: (i) improved life expectancy for some severely ill or impaired children, and (ii) increased formal diagnosis of and / or prevalence of childhood mental distress, and of Autistic Spectrum Disorders.

2.2 Definitions

Children and Young People

The focus of this review was commissioned to be children and young people aged 8-18 years. It should be noted that in the review 'children' refers to those aged between 5 and 12 years old inclusive and 'young people' refers to those aged between 13 and 18 years old inclusive.

Disability (and Disabled)

In this review we draw on a social model of disability, which highlights that disability should be distinguished from impairment.

Drawing on the 1995 report from the Prime Ministers Strategy Unit (PMSU, 1995) we define disability as: *disadvantage experienced by an individual resulting from barriers to opportunities that impact upon people with impairments.*

Here, the PMSU has taken on board the distinction made by the Disabled People's movement in the UK between disability and impairment:

> *Impairment* is the functional limitation within the individual caused by physical, mental or sensory impairment. *Disability* is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers.
>
> (Barnes, 1991:2)

We do not move beyond this inclusive definition to define specific impairments.

Barriers

Barriers are:

- attitudinal, for example amongst service providers; result from policy, that fails to take disabled people into account; and
- physical, for example through the accessibility of venues and facilities; and, relate to empowerment, for example where the views of disabled people are not taken into account

(adapted from PMSU, 1995).

Play

The 'Getting Serious About Play' review (DCMS, 2004), which informs the Big Lottery Fund play programme, defines play as: what children and young people do when they follow their own ideas and interests, in their own way and for their own reasons. Play provision is defined as being at its most successful when: it offers children and young people as much choice, control and freedom as possible within reasonable boundaries.

Leisure

Whilst our definition of play includes young people, a definition of leisure is used within this review that reflects more the priorities of young people: to take part in activities, sports, clubs and groups but also opportunities to be spontaneous in developing and maintaining friendships.

2.3 Methods

This review was commissioned by BBC Children in Need and was a 'focused', rather than 'systematic' review. 'Systematic' reviews have a particular methodology and are designed to achieve a comprehensive and transparent assessment of all available research. Within more limited resources, our strategy drew on the expert knowledge and networks of members of the study team to guide our review of published literature. This knowledge informed our search terms and search strategy, but also highlighted particular pieces or research that contained insights for our overall themes.

In summary, the following approach was adopted:

- We undertook searches of academic databases of published, peer-reviewed, literature.
- We searched published, non-reviewed material that often captured practice and policy developments ('grey literature').
- As well as using search tools to search the web in general, we searched the websites of a range of government departments and VCS organisations (and listed in Appendix I).
- We also accessed disability-related e-based networks (discussion groups and forums) with which members of the research team are connected. An open message was sent to each relevant discussion group/ forum inviting participants (practitioners, service users and families) to comment on their experiences and perceptions concerning opportunities for 'fun and friendship' for disabled children and young people out of school hours (listed in Appendix II).

Meetings of the research team were held regularly. This enabled us to discuss themes emerging from the review, identify gaps and agree strategies to address them, and to work collectively to make informed professional judgements about the relevance and appropriateness of sources identified to the focus of the review, and thus for decisions about which material was included. Meetings and discussions with BBC Children in Need provided further opportunity for insight and guidance.

3 Findings

3.1 The Experiences of Disabled Children and Young People: An Overview

Before we discuss the findings to emerge from our review of literature and evidence about their opportunities for fun and friendship, we can provide an overview of disabled children and young people's lives more broadly as the context within which any targeted provision may be experienced.

We saw in the previous section that it is difficult to identify overall numbers of disabled children and young people in the UK; research has also identified that at a local authority level there is often a lack of available information and therefore a lack of local understanding of need (MENCAP, 2006). Nonetheless, there are estimations and some available data, despite these difficulties.

Disadvantage and Social Exclusion

- It is important to recognise that poverty and social exclusion are key characteristics of many disabled children, young people and their families' lives.

Working with children and young people from disadvantaged backgrounds is central to BBC Children in Need and the evidence about the links between poverty and (both child and parent experiences of) disability which emerge from research are stark. In 1999 the then Prime Minister Tony Blair announced the 'historic aim' to 'eradicate child poverty within a generation', subsequently defined as 20 years. Research by Barnardo's (Sharma, 2002) suggests that whilst overall numbers of children in poverty can be expected to fall 2004/5-2010, the number of disabled children in poverty will increase by 30,000. A paper prepared by 'Every Disabled Child Matters' (EDCM, 2007) a coalition of organisations campaigning for disabled children and their families) draws on a range of (high quality and creditable) research to highlight how:

- There is a strong relationship between low income and social exclusion amongst families with a disabled child;
- Families with a disabled child are disproportionately likely to live in poverty;
- Disability across the life-course has a high association with poverty.

Children and young people in deprived communities have very limited access to leisure opportunities (Power, 2008); but disability compounds the difficulties faced by disadvantaged families. The high incidence of poverty amongst families with a disabled child is linked to the additional and ongoing expenses – 'the cost of care' – and the barriers for parents in entering employment – 'the income penalty' (EDCM, 2007). The government's drive to end child poverty has however focused on parental employment, which raises questions for the extent to which this can deliver for families with disabled children: the Children's Plan (DCFS, 2007) and Aiming High (DfES, 2007) contain commitments to help parents into work, but the childcare provided within this agenda is not intended to provide the opportunities for fun and friendship that are central to the focus of this review (and that we return to the policy context in Section 3).

The multi-faceted nature of the social exclusion experienced by disabled children, young people and their families was highlighted by research from the National Evaluation of the Children's Fund (Barnes et al, 2006). The Children's Fund was an England-wide programme (2001-2008) to develop preventative services for 5-13 year olds, and one strand of the evaluation (2003-2006) focused upon services targeting disabled children. Barnes et al (2006) highlight the need to recognise the following dimensions of social exclusion as experienced by disabled children and young people:

- *Material:* including both poverty and poor and inappropriate housing;
- *Access to public and private resources:* with barriers existing for disabled children and their families;
- *Spatial:* lack of transport and limited mobility placing restrictions on where people live and the resources they can access;
- *Health and Well Being:* with physical attributes often a prerequisite for participation in play and leisure;
- *Cultural:* with disabled identities marginalised, unrecognised and under-valued;
- *Self-determination:* assumptions about cognitive and physical capacities leading to a lack of opportunities; and
- *Decision-making:* a lack of participation in decisions that affect everyday life.

The same report drew attention to tensions over the place of school as a site for social inclusion; for some children schools could provide access to services and thus inclusion, but for others difficulties in accessing school out of hours compounded their exclusion (Barnes et al, 2006).

The Centrality of School

- Material identified for this review alerts us to recognising the importance of school in understanding the context of opportunities for fun and friendship.
- School provides sites for fun and friendship, but can also limit opportunities for wider networks to develop.

School is an important domain in which friendships can be established and maintained. Thus Lewis et al (2007) highlight the value placed by disabled children and young people on friendships with peers within school in offering support and solidarity when difficulties are experienced. In a Scottish study of 26 disabled children the majority of these were able to identify at least one child as an important friend (Connors and Stalker, 2000). One consequence of this appears to be that if friendships are to an extent school dependant then isolation is often experienced outside of the school context; disabled children and young people may have to travel some distance from their home and community to attend their school and maintaining and developing friendships outside of school is difficult without resources, including transport, which disabled children and young people can lack access to (Barnes et al, 2006). Lewis et al (2007) report that few of their case study children talked extensively of peer support outside school and a number of studies highlight the difficulties faced by DCYP in developing and maintaining friendships outside of school settings. This is particularly so for those who are perceived as having complex needs and/or are educated at schools distanced from their home neighbourhoods (Barnes et al, 2000; Action for Leisure and Contact a Family, 2003; John and Wheway, 2004; Lewis et al, 2007; Murray, 2002; Sloper et al, 2007). One of the results of this is an increase in social time spent with family members. Connors and Stalker (2007) note that friendships 'happen' for teenagers at leisure and community venues and spaces as well as at their peers houses, all of which are likely to be inaccessible to disabled teenagers.

Even within the school environment opportunities for disabled children and young people to interact with peers may be limited (Woolley et al, 2006). A qualitative study of the views and perspectives of disabled children aged 11-16 (Barnes et al, 2000) found that within both mainstream and special schools, disabled children spend the majority of their time with adults rather than other children, which can mean them being denied opportunities for autonomous action or engagement in age appropriate behaviour. The authors of this study argue that the very systems and structures designed to support disabled children within school can have unintended consequences for their social lives and play a role in isolating and separating disabled children from their non-disabled peers. They give examples of children 'thrown together' whilst travelling to school or encouraged to share break times on the basis of shared impairment rather than other commonalities. This finding is echoed by Woolley et al (2006) whose study of disabled children's play in six primary schools found that whilst children were able to play in a variety of ways this was sometimes restricted both by special routines that shortened play time and by increased time spent with adults rather than peers. Lewis et al (2007) report that opportunities to engage in less structured activities during school time appear particularly problematic for some disabled children and young people. They suggest that this may be due to the dependency of these activities on friendship groups that are vulnerable to the attitudes and behaviours of other children. Problems in engaging with peer groups may also be compounded by a lack of opportunity to develop social skills in environments away from school.

There is some evidence to suggest that disabled children and young people may be more vulnerable to bullying than their non-disabled peers, and that this contributes to isolation (Connors and Stalker, 2000; Lewis et al, 2007; Stalker, 2000). An ESRC (Barnes et al, 2000) study found that disabled children and young people identify bullying as a central theme in their lives and that it is often cited as a reason for moving from inclusive to special schooling. However the researchers also observed bullying in segregated settings and note that some disabled children were bullies as well as bullied. Lewis et al (2007) report that the children in their studies had experienced both positive and negative attitudes from other people but that many report experiencing negative attitudes from other children in the form of bullying. Other research suggests that whilst high levels of both physical and verbal bullying are reported by disabled children and young people these are comparable to rates reported by their non-disabled peers (Lindsay et al 2008). Studies also indicate that disabled children and young people employ a range of strategies to overcome being excluded from friendship groups, and that some report integrated social relationships with their peers although this is often through a process of minimising impairment (Barnes et al, 2000; Woolley et al, 2006).

Whilst school provides important opportunities for friendship, it is important to recognise that attending school, whether it is an inclusive or integrated mainstream school or a special school or unit, does not in itself lead to friendship. Research from the US exploring the dimensions of friendship amongst a sample of 27 16 and 17 year olds with 'developmental disabilities' highlighted how friendships that were dependent upon school were less intimate, less stable, of a lower self-reported quality and were less mature than the friendships of non-disabled teenagers who maintain and develop friendship outside of school. Nonetheless the researchers note that school remains the key site for friendship opportunities for disabled young people and raise concerns about the implications for this once compulsory education comes to an end (Matheson et al, 2007). US research has also drawn attention to the role of adult mediation in the development of friendships in schools. Integrated schools were found to lack inclusive education where teachers did not 'facilitate' contact between disabled children and their non-disabled peers and indeed some teachers 'blocked' interactions by creating separate activities or space, or 'missed' opportunities by making assumptions about the nature of peer interactions. Some friendships between disabled and non-disabled children were negatively affected when the non-disabled child was seen by staff as a natural 'helper' for the disabled child (Meyer, 2001). As with the UK research outlined above, US research also highlights the vulnerability of friendships outside of the school context without ongoing resources aiming to develop and maintain them (Evans and Meyer, 2001; Matheson et al, 2007, Meyer, 2001).

Provision for Disabled Children and Young People

- There is a lack of provision, including to provide opportunities for fun and friendship, for disabled children and young people.

Research has highlighted that despite the problems of poverty and disadvantage, and the reliance on school as a site for leisure, local authorities have consistently failed to address the needs of disabled children and young people. A study by MENCAP (2006), commissioned by 'Every Disabled Child Matters', reviewed a sample of 20 English local authority children and young people's plans to explore the extent to which they address the needs of disabled children and young people and whether they had involved disabled children and young people and their families in developing the plans. The findings of the study alert us the differences between top level policy aspirations and front-line practice. The review found that whilst the plans identified disabled children and young people, there were rarely plans to address their needs outside of 'vague' commitments to 'responsive and integrated services' (MENCAP, 2006:1). They found that where issues were identified and addressed they related in the main to education and school. There was an absence of planning for children and young people with a learning disability and just 5 of the 20 plans referred to youth provision. We return to the policy context in more detail in Section 5.

3.2 Fun and Friendship: A Review

Our review led us to identify a range of studies and these can be grouped within three themes:

1. the ways in which disabled children and young people experience *fun and friendship*
2. the structural, material and interpersonal *barriers* which they and their families experience,
3. issues and implications for *developing provision*.

With a few notable exceptions, systematic accounts in the public domain about 'fun and friendship' for disabled children are extremely sparse. This raises serious issues about the nature and quality of evidence concerning 'fun and friendship' for disabled children.

The systematic review of academic databases threw up a small number of highly relevant peer reviewed studies that have been drawn on fairly extensively in this report. These included qualitative studies of disabled children and young people exploring a number of aspects of their lived experience including their views and experiences of friendship, leisure time and school (Barnes et al, 2000; Connors and Stalker, 2000; Lewis et al, 2007; Turner, 2003). A small number of academically rigorous studies that explore specific research questions such as barriers to access have also been included (Aitchison, 2003; Beart et al, 2001; Buttimer and Tierney, 2005; Kristen et al, 2003). Many of the other sources identified by systematic searching were limited in their usefulness because they focused too narrowly on specific – often therapeutic/educational interventions aimed at identified professional groups working with particular impairments. The 'grey' literature and website searches turned up a number of highly relevant reports specifically focused on the experiences of disabled children, young people and their families in relation to fun, friendship and leisure. Many of those included have been commissioned by children's charities working with disabled children such as Contact a Family, Barnardos, NCB (National Children's Bureau) or by organisations working directly in the field of leisure such as National Playing Fields Association (Action for Leisure and Contact a Family, 2003; John and Wheway, 2004; Rabiee and Beresford, 2007; Shelley, 2002; Sharma and Dowling, 2004; Ward et al 2004). A number of reports produced by JRF (previously known as the Joseph Rowntree Foundation) also had high degree of relevance to the review (Morris, 2002; Murray, 2002).

3.2.1 Fun and Friendship

- Disabled children and young people can rely on structured and adult led provision, and lack opportunities to engage in the spontaneous activity that is central to the development of friendships and the way in which non-disabled children and young people have fun.
- Social isolation can be a significant feature of disabled children and young people's lives when opportunities to socialise and make friends are limited.

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Research, consultation and programmes of participation with disabled children and young people and their families consistently provide evidence of the importance of friendship and the development of interdependent relationships as central to enjoyment and well being. Although leisure includes time spent in solitary activity, disabled children and young people perceive friendship as a fundamental part of leisure time; with social relationships identified as key to making leisure time fun. Creating accessible environments where children and young people can develop friendships and meet friends emerges as a priority for disabled children and young people (Action for Leisure and Contact a Family, 2003; John and Wheway, 2004; Meyer, 2001; Murray, 2002; Sloper et al 2007).

What children and young people do in leisure time varies and includes activity such as watching television, playing or ‘doing stuff’ and ‘hanging out’ with friends through to more structured activity or activity that involves access to particular environments or facilities (Murray, 2002; Ward et al, 2004). Whilst individual preferences vary, consultation and research shows that disabled children and young people identify broadly the same interests as non-disabled children and that leisure means ‘doing what everybody else does’ (Action for Leisure and Contact a Family, 2003) and ideally includes the opportunity for independence and the chance to go ‘out and about’ (Shelley, 2002, Murray, 2002). John and Wheway (2004) define play as activity that is ‘freely chosen, personally directed and intrinsically motivated’ (p.13). ‘Freely chosen’ means that children chose when and which play activity to take part in and that this play is not part of a set programme, or a curriculum, with prescribed activities. Their research indicated that disabled children are more likely to be offered controlled activities in segregated environments as an alternative to ‘free’ play than non-disabled children. They identify a tension between offering disabled children and young people a range of safe experiences, yet ensuring that they are not over protected or disempowered. Ward et al (2004) identify risk and safety as major concerns for parents whose children are attending inclusive provision.

Professionals working in children, young people and family services may have understandings of the importance of ‘leisure’ that differ from the perspectives of disabled children and young people themselves, limiting their opportunities and outcomes. Buttimer and Tierney (2005) warn that for adolescents with a learning/intellectual disability professional attention may be focused on a ‘skill deficit model’ that stresses what individuals are not able to do rather than are able to do. Barnes et al (2006) similarly found that disabled children and young people valued opportunities that stressed what they were able to do as the tendency amongst professionals (and families) was to stress what could not be done. Both Prost (1992) and Russell (1995) describe how for people with learning disability professional and service assumptions of normalisation have focused upon their participation in statistically normative activities, rather than in activities they would chose to participate in. Murray (2002), reviewing the stated aims and objectives of a range of leisure projects, points out that service providers often view leisure opportunities for young people with disabilities (and in particular those perceived as having learning disabilities) as opportunities to ‘learn’ and ‘develop skills’. This she argues sits at odds with young people’s own agendas about leisure as principally focused on ‘having a good time’.

Play and leisure can be understood to be central to children's self-development in terms of practical, social and emotional skills, knowledge and understanding. Even without focusing on tightly defined outcomes, leisure and play for their own sake are important ways for children to express themselves and experience self determination. It is important to remember that the role of friendship and leisure opportunities in improving the quality of life generally is stressed by children, young people and parents as something that is important for all regardless of any impairment (Action for Leisure and Contact a Family, 2003; Aitchison, 2003; Connors and Stalker, 2000; Lewis et al, 2007; Murray, 2002).

Our review included an overview of current policy, reported in Section 4. This review highlights a strong focus upon *play* for children, and clear gaps in provision for young people alongside a broader lack of evidence of mainstream inclusion. Our literature and evidence review is structured to reflect these gaps.

In the context of the centrality of school outlined earlier, having opportunities to socialise and maintain friendships outside school emerge as particularly important, as well as challenging, for many disabled children and young people. With barriers existing to inclusion in mainstream play and leisure, disabled children and young people can experience high levels of social isolation (Action for Leisure and Contact a Family, 2003; Barnes et al, 2000; John and Wheway, 2004; Lewis et al, 2007; Murray, 2002; Sloper et al, 2007).

Dependence, Independence and Interdependence

- Issues of dependence, independence and interdependence are complex and assumptions about the nature of children's and young people's preferences and relationships should not be assumed.
- High levels of dependence can lead to high levels of isolation. Reliance on others can limit opportunities for fun and friendship outside of structured activity; but supportive relationships also offer a resource on which to build.
- Choice for disabled children young people and families is often restricted and there is often a reliance upon a limited range of targeted and structured activities.

Issues of dependence, independence and interdependence are complex and we begin to explore them here. Relationships are interdependent, and levels of dependency usually decrease on the journey to adulthood. Opportunities for fun and friendship, and managing difficulties which can arise within friendship relationships, can be seen as one element of increasing independence and strengthening individual's own choice and control in their everyday lives. These are complex relationships and processes for all children and young people, and can be compounded for disabled children and young people. And disabled children and young people can find themselves dependent upon structured, organised and adult-led activities (Barnes et al, 2006).

Lewis et al (2007) identify the dependency of some disabled children and young people with complex and/or high support needs on adult support and on leisure spent in more structured environments. This limits opportunities for spontaneous interaction and independence. Their studies reveal that barriers to accessing community based informal activities restrict opportunities for disabled children and young people to interact with peers or other children and young people. Barriers cited in the report include the need to transport children to discrete and 'purpose-driven groups' and activities that decrease the opportunity for developing inclusion in the immediate community. This suggests that because disabled children are involved in 'special' activities they are less likely to engage in informal ones. Their report also says that extra-curricular activities for children with high support needs are limited and that any participation has to be planned well in advance. This, the authors suggest, denies disabled children and young people the opportunity of engaging with informal community networks and decreases the potential for applying social skills across different domains - thereby compounding social isolation.

Barnes et al (2006) found that where separate provision was developed for disabled children and young people, rather than integrated or inclusive mainstream provision, there was a lack of long-term and sustained outcomes for service users. Without working to develop networks outside of school sites or between disabled children and young people and the communities where they lived, targeted provision could only make an impact for those who accessed the opportunities and only for the time it was funded. In their research, provision that supported disabled children and young people to access mainstream and existing provision was much more highly valued by users and the authors suggest that this approach was more likely to achieve a sense of inclusion. Without this approach, disabled children and young people remained dependent upon a narrow range of targeted provision, often based on the assumptions of others. This point is echoed by Murray (2002) who argues that the experience of segregated provision means that not only do disabled children and young people lack the opportunity to engage with non-disabled peers but also that non-disabled children and young people have little opportunity to learn how to be with and support (and be supported by) their disabled peers, i.e. in interdependent relationships.

Lewis et al (2007) report that for some young people with complex health and personal support needs, high dependence on other people is seen as a matter of fact. Murray (2002) argues that it is important to re-think the concept of 'independence' in engaging with disabled young people's experience of inclusive leisure. She argues that the idea of 'independence' traditionally understood as doing things alone excludes many disabled young people and suggests this be redefined as 'interdependence' recognising that some young people will both need and welcome support to access new experiences and friendship. However the issues around providing appropriate support to facilitate relationships and access more generally are complex. This is particularly the case for disabled teenagers for as Murray points out, just the presence of an adult support worker impedes the process of 'hanging out'.

Messages across a range of research suggest that those with high support needs may never experience the opportunity to engage spontaneously with peers; barriers to developing and maintaining friendships therefore can be seen to depend in part on the type of impairment (i.e. specific support requirements), and responses to impairment. Children and young people perceived as having learning disabilities are less likely to have non-disabled friends than other disabled children and young people. This research suggests that young people with learning disabilities are more likely to attend segregated schooling, least likely to have friends outside school and most likely to identify family members as best friends (Beart et al 2001; Buttimer and Tierney, 2005; Lewis et al, 2007;Murray, 2002).

Research on the leisure activities of young people with learning disabilities indicates that these are often solitary, conducted with members of the family or with others who have learning disabilities (Beart et al, 2001). Where activities are community-based these are predominantly organised through day centres (Buttimer and Tierney, 2005). Studies show that whilst the key barriers to accessing community based leisure identified by both parents and young people include transport and money, the most significant is perceived as 'not having a friend' or lack of carer/one-to-one support (Beart et al 2001; Buttimer and Tierney, 2005; Murray 2002). Young people who rely on 'facilitated communication', use sign language or express themselves through behaviour/body movements are unlikely to have access to communication support outside school and hence rely on friends and family to interpret for them. This clearly impedes opportunities for spontaneous engagement with others or access to ordinary leisure activity (Murray 2002).

Evidence shows that individual support to access leisure and friendship is limited and that dependence on family is high. Whilst this dependence puts considerable strain on families and may account in part for the lack of formal support mechanisms it also stresses the importance of understanding disabled children and young people's access to friendship and leisure in the context of family life. Whilst professionals sometimes perceive families as problematic and over-protective of disabled children evidence shows that many young people understand why this may be so and are keen to find ways to negotiate with parents to resolve tensions between protection and independence (Lewis et al 2007). Morris (2002) argues that disabled young people identify families and their role within families as very important but that this is not often recognised by services. Murray (2002) stresses the point that families can be a source of strength and key to enabling disabled young people to deal with difficulties. She argues that the inclusion of families in service responses is important and that positive family relationships should be made more visible.

The complexity of family relationships and dependence and interdependence is provided by this perspective of parents, as reported by a service provider contributing to an e-forum discussion:

> *We had an after school club for parents and kids with learning difficulties to work together. From experience, even at 7 [years old] they knew that learning was harder for them. The club started out by looking at how to get the most out of your brain or how to "work smarter- not harder." I asked the parents what helped most and they said "seeing that you had survived having 4 children with learning difficulties", but mostly it was in learning & understanding why their children did what they did. This helped reduce stress and gave them a chance to like their children as they were, rather than how they wished they were i.e. like everyone else's. The children liked having tasks designed to make them succeed, rather than setting them up to fail - learning that they could learn. For all children to succeed or have good life chances they need 'resiliency' to cope with things; changes, being different, life being tough or unfair and this is something that can be built into school life/after school as well as homelife.It just has to be done more so for some children than other because of circumstances. The kids liked finding others with similar problems to theirs and the mothers got a lot from*

> *swapping stories and realising that they were good parents even if initially just guilt ridden and exhausted ones.*

Central to independence is choice and a strong message to emerge from research is the lack of choice afforded to disabled children and young people, relating to the reliance on a limited range of targeted and structured activities. The Action for Leisure and Contact a Family survey (2003) identifies the extension of choice as of paramount importance to parents. In this study choice is identified as important in a number of ways: choice around times of available provision to fit around school, work and family; choice of whether siblings are involved or not; choice of available activities from organised play schemes to free play in playgrounds, arts and crafts, weekend camps etc. The key message from parents in this survey was the importance of recognising diversity and letting children choose –children are not all the same and what is needed is a range of experiences to meet individual preference and ability. Parents wanted their children to be offered activities appropriate to age, interests and strengths. Whilst some parents want children to be stimulated and challenged, others stressed relaxation and security.

Both Ward et al (2004) and Action for Leisure and Contact a Family (2003) describe the importance of meeting individual needs through tailored support. They suggest it is essential to find out what individual children like and want to do through discussion and/ or meetings. In reviewing elements of good practice from case study examples both studies recommended parental involvement in the planning and organisation of activities/placements, and pre-placement planning meetings between staff and parents to identify the best ways programmes can support individual children. The complexity of independence and dependence should be explored with families so that appropriate options can be explored and choices made.

Social Isolation at Critical Periods

- There are critical points when disabled children and young people are particularly vulnerable to social isolation, including school holidays and transitions between care and support.
- Holiday times are particularly challenging for families where children or young people have a disability: the lack of routine and assistance with care can cause real hardship; there is a lack of accessible provision; and, friendship networks often rely on school and therefore do not function during holiday periods.
- Transitions to adulthood – involving a move away from school provision, child-centred services and the friendships dependent upon them – are a vulnerable time for disabled young people.

Whilst high levels of social isolation are reported across research with disabled children and young people, this isolation can be exacerbated at critical times, and ironically at those times that are available for leisure. As so many disabled children and young people are dependent on school as the domain in which friendships are made and sustained, certain periods such as school holidays, out of school hours, transition to adulthood/leaving school emerge as times of particular isolation from friends.

In a study of staff, parents and disabled children and young people across six contrasting Local Authorities, Petrie et al (2007) identify the importance of friendships as central to many young people's descriptions of school holidays. Whether children enjoyed the holidays or not was largely dependent on how much they were able to see their friends. However many young people experienced high levels of social isolation during the holidays, especially if they attended schools outside their local area and reported being unable to meet up with their friends outside school. This isolation was found to have important implications for their independence, well-being and capacity to lead ‘ordinary’ teenage lives.

With school and school provision central to the friendship experiences of disabled children and young people, holiday periods are identified by research as particularly challenging and socially isolating for families that include a disabled child. In a study involving 90 parents and 86 disabled children and young people Petrie et al (2007) report that parents described difficult times during the school holidays, many using the term "nightmare" when referring to school holidays and "relief" when term started again. The lack of routine and the unpredictability of the holidays were identified as very challenging, as was the inability to carry out practical, day-to-day tasks, such as shopping.

For the majority of families going away on holiday with a disabled child is either not an option or experienced as extremely stressful (Sharma and Dowling, 2004; Petrie et al 2007). As a result parents are more likely to opt for day trips, although these are also described as challenging. Petrie et al’s (2007) study found that many parents talked about not being able to do "ordinary" activities with their disabled child like going to the park or to the cinema. In addition they often experienced unhelpful attitudes and a lack of understanding from members of the public.

Given these difficulties, access to summer play schemes becomes particularly significant for families with disabled children. Structured holiday provision often offers the only chance for disabled children to play with others and for parents to have a break (Connors and Stalker, 2000; Petrie et al, 2007; Sharma and Dowling, 2004). However parents describe experiences of patchy provision and some children report experiencing problems in physically accessing mainstream facilities (Petrie et al 2007). Sharma and Dowling (2004) report that places on accessible summer play schemes are limited because of the high cost incurred through the need for higher staff to child ratios and specialist staff. Many projects find it hard to fund raise and hence costs are passed to parents. Suitable premises are also difficult to find. As a result parents find facilities inaccessible and often have to travel out of their local area to access the provision they need.

Studies report a general lack of day-to-day support for parents during school holidays and parents struggle as other term time support is not available. This can be particularly difficult for parents with other children and especially so for parents caring for more than one disabled child. Families want flexible, reliable well-planned and coordinated short breaks that give their children stimulation in a child-centred setting (Connors and Stalker, 2000; Petrie et al, 2007). Sharma and Dowling (2004) report that parents often describe the difficulty of juggling the needs of their disabled child with those of other children and that both parents and children find it particularly excluding if siblings cannot be involved in organised activities. It may be that the consistently reported need for respite is indicative of the lack of (inclusive) support for everyday life. As discussed above many parents want non-disabled siblings to be included in holiday activities. Holiday provision therefore needs to be flexible and designed in a way that suits whole families. But we know that there is a lack of effective family-focused practice across service provision for all groups despite recent policy interest in these approaches to 'high risk' families (Morris et al, 2008).

Morris (2002), in a review of research looking at disabled young people's transition to adulthood for JRF, identifies vulnerability to social isolation as particularly acute at this time. Whilst disabled young people often identify that making and keeping friends is the most important aspect of their lives, many have no experience of an independent social life and few opportunities to make friends. For many disabled young people time is spent with a paid carer or family members and most have no independent access to transport. Some rely on personal assistance over which they have little or no control. In addition, she found that leaving school or the move from one residential setting to another can often mean loss of friendships and disabled young people with high levels of support may be moved into residential care where they have little or no contact with people of their own age.

Isolation at critical periods such as on leaving school may, when compounded with disability, be particularly problematic; as one of the parent contributors to an e-forum noted:

> *The biggest issue for me is that the groups available in my area (xx area) do not cater for high functioning autistic/ASD. All children/young people are 'lumped together' and in particular for my son, being high functioning autistic, in a language resource, mainstream school, he has just outgrown what is on offer. The downside is that he now doesn't go out and has no friends (the older he has got, the harder it is). Personally, what I would like to see is him going out with 2 or 3 other similarly able youths, with a guy of around 18/19 (so that the group doesn't stand out). Swimming, go karting, shopping, using public transport, buying lunch etc. etc. are all very worthwhile social skills/activities/being part of a friendship group/having to communicate to make arrangements etc.. He is going to college in Sept. 2009 and I am dreading it (especially as he will probably be doing a male dominated course). I have spoken to the charity groups locally, over many years, but the message isn't getting through. I have also approached the [charity] to try and find a 'befriender' - as yet to no avail. This will be the first summer holiday he hasn't gone to a 'group' - the last time he went was last summer - and with the likelihood of being away, even for a week, looking extremely remote financially, I am looking forward to it with loathing.*

Involvement in Sport and Physical Activity

- Participation in sport is perceived as offering opportunities for both fun and friendship, but few disabled children and young people are able to participate because of the limits of existing provision;

- Targeted schemes and enhanced mainstream provision can enable greater participation for disabled children and young people.

Sport and physical activity are particular types of leisure and organised activity. Kristen et al (2003) identify three descriptive categories of parental perceptions of the benefits of the participation of their physically disabled children in a sports programme: 'achieving good health' 'being part of a social group' and 'learning a sporting activity'. They identify a further nine conceptions fitting under three broader categories: feeling well, training one's motor abilities, being out in the countryside – (good health); having a good time, experiencing togetherness, making new friends – (social group); discovering a sporting activity, gaining self confidence and gaining knowledge and skills - (sporting activity). Participating in sport is thus perceived to contribute to the promotion of physical, mental, social and emotional well-being and the authors conclude that that sporting activity is an important arena in which social integration can be facilitated and well-being generated across a number of dimensions.

Despite the potential benefits of inclusion in sport for disabled children and young people the evidence suggests that they are largely excluded from participation. In a survey commissioned by Sport England (Finch 2001) findings show that whilst many disabled young people desire to be engaged in sport, opportunities to do so are scarce. Thus 45% of young disabled people were found to receive less than one hour's physical education per week at school compared to 18% of their non-disabled peers.

Case study reports of localised schemes however suggest that rates of participation can be hugely increased if appropriate provision is made available. Andrews (2007) reports on three such schemes including 'In the Zone' a Birmingham based scheme in Wilson Stuart School and Sports College. This college has given 85% of its pupils (who are physically disabled) opportunities to take part in out of school sporting activities. Their aim is to create opportunities at community based clubs through outreach and partnership working. A second scheme 'Active Nottingham' now has a total of 66 sports clubs that promote activities for disabled people. This has been achieved through a Local Authority run Awareness, Participation, Opportunity and Coaching scheme (Apoc) offering a three week coaching course following which participants can then offer to work at local community based clubs. Clubs are encouraged to fit in with day centre and school timetables so that transport is not a barrier. Although the coaching scheme has been LA led, funding has often been found from outside mainstream budgets.

One e-forum respondent outlined the service he provides linked to local football clubs:

> *There are several sessions every week in Manchester that I am personally involved in - as a qualified coach and signer/communicator [for deaf children]. I am paid by Manchester City FC, Manchester United FC and the FA to support these sessions - either as a coach, or recruiting the children we teach - or as an advisor on deaf issues. I also volunteer my time for an exciting new club - Manchester Deaf FC - which is being supported by the above bodies to become an independent club who we hope to enter into a mainstream football league. I am also a tutor for the very new NDCS "Deaf Friendly Football" national project... We have an exciting "Ability Counts" league in Manchester that provides a regular competitive outlet for young deaf players - who can progress to the regional FA Centre of Excellence - with a "player pathway" now emerging to feed into the national sides (I have yet to see one of my players break into the England team - but that's the*

goal!). We just had a great result this week - with a successful application for a travel grant to fund taxis for a 14 year old deaf boy - who was previously getting up to four buses to attend a deaf-friendly football session.

Provision for Disabled Teenagers

- Fun and friendship has a key role for teenagers, away from the more structured provision that exists for children. Disabled teenagers face particular problems in accessing activities and opportunities that encourage spontaneous fun and friendship.
- Disabled teenagers can face specific and complex barriers to fun and friendship – their desire for autonomous experiences may conflict with their support needs.

Our review highlights a lack of provision for disabled teenagers, particularly provision that enables inclusion in the mainstream and everyday opportunities for fun and friendship that able bodied young people take for granted. In the Contact a Family survey (2002) many parents reported increased difficulties once children reached age 12 years and above as teenagers expressed more of a desire for independence compared to younger children. 72% (n=250) of parents of children of this age group prioritised more activities for teenagers as the most helpful development. Based on a sample of 349 young people aged 12-19 the study found that 70% could not access clubs during out of school hours or holiday times. Parents also reported that young people who were away at residential schools during the week were excluded from local activities at the weekends and during holidays. Petrie et al (2007) found holiday provision to be especially lacking for young disabled people over the age of 12. This was identified as a particular problem for working parents, who needed childcare during working hours.

As discussed above issues relating to the possibilities for independent engagement in friendship and leisure are critical for disabled teenagers. In a study of leisure participation amongst adolescents with learning disabilities Buttimer et al (2005) report that the majority were dependant on parents to participate in and organise activities for them. Whilst independent access to transport and 'not having a friend' were identified as the most significant barriers to going out, some young people also identified 'not being allowed to' by parents as important. Discrepancies between parents and teenagers perceptions over choice and reported activity were also found, suggesting that programmes should be careful not to base their provision solely on parental perspectives.

In a qualitative study involving 100 disabled young people aged 12-19 Murray (2002) reports that discussions about leisure reveal that this is experienced not as a separate activity but integral to daily experience. The young people she spoke to perceived leisure activity as principally concerned with 'hanging out' and 'doing things' with people they enjoyed being with or in other words defined as being about mutually enjoyable relationships. Discussions of leisure led to discussions of growing up, leaving home, exams, school, money, aspirations, and sexual relationships, issues of concern to all teenagers. Making choices was identified as important and tensions between dependence/ independence and child/adult status were recognised. Murray's study identifies a range of barriers to making friends and participating independently in leisure activity. As discussed above the need for one-to-one support was identified as impeding the process of making friends and maintaining friendships whilst the presence of adults mitigated the possibilities for 'hanging out'. Murray argues for the need to recognise the importance of interdependence. Her study found that for young people who require support to access new experiences this is often recognised by them and appropriate support welcomed. The solutions identified to overcoming barriers to inclusion stress access to appropriate support including: transport, money, personal assistance, physical support, communication support, medical support and support to facilitate relationships.

3.2.2 Barriers

As we have seen throughout our discussion, disabled children and young people face a range of barriers to accessing and developing fun and friendship opportunities. These are societal and attitudinal, practical, and can be impairment specific. Barnes et al (2006) found that none of the services across two local authority Children's Fund partnerships, nor the strategic partnerships themselves, used the Disability Discrimination Act 2005 (DDA) to promote inclusion or question exclusion where it was identified. Similarly, no examples have been identified during the course of our review.

Societal Barriers

- Whilst research and policy may emphasise inclusivity for disabled children and young people, there are societal barriers including the attitudes of others but also in the structures of service provision.

The desire to feel included as part of the wider community and to be able to access community-based activities is stressed by a broad range of research studies and consultations (Action for Leisure and Contact a Family, 2003; Beart et al 2001; Buttimer and Tierney, 2005; Connors and Stalker, 2000; Murray 2002; Shelley, 2002; Ward et al, 2004) Yet evidence also clearly shows that many disabled children and young people and their families experience the world as hostile and excluding. Studies show that whilst disabled children and young people don't perceive themselves as different to their peers, they are clear that what does make them different is the way that others, and society, treats them (Evans and Plumridge, 2007). They are able to identify the different barriers that they face to their inclusion in the mainstream and that these barriers are perceived as both attitudinal and environmental (Connors and Stalker, 2007). Our understandings should be considered in light of the dimensions of social exclusion we saw above, which provide recognition of the structural barriers to inclusion.

In a survey of parents of disabled children and their experiences of accessing mainstream leisure provision conducted by Contact a Family, Shelley (2002) reports that parents experienced a range of apprehensions and difficulties when just getting out and about locally. These included issues such as: queuing (73% didn't go on outings that involved queues this applied particularly to parents of children with communication difficulties and ASD); feeling uncomfortable and being stared at (68%); lack of suitable local facilities (55% had to travel out of area); restricted budgets (46%) and lack of transport (25%). 80% of parents said their children could not use local clubs most commonly because they could not meet their special needs. In these circumstances the inability to provide more specialised support was identified as more significant than cost, transport or distance. Additional barriers identified by parents include: children excluded because of severe physical difficulties but no learning difficulties; children excluded because their chronological age is too high but still need the protective atmosphere accorded younger age groups; children placed at school out of borough and lacking local contacts.

Whilst physical accessibility issues are identified as important, studies overwhelmingly demonstrate that inclusion is less about the availability of special equipment and more about wider social attitudes. The majority of problems faced by disabled children and young people are social barriers to participation rather than a function of impairment (Barnes et al, 2000; Connors and Stalker, 2000; Murray, 2002). Qualitative studies and surveys of larger numbers of parents, children and young people identify issues such as fear of rejection, isolation, hostility, and being stared at as key barriers to mainstream inclusion (Action for Leisure and Contact a Family, 2003; John and Wheway, 2004; Petrie et al 2007; Murray, 2002; Sharma and Dowling, 2004; Shelley, 2002). Attitudes of staff within mainstream provision are highlighted by a number of studies, and a need for staff training that includes challenging stereotypical assumptions is identified and recommended by a number of reports (Action for Leisure and Contact a Family, 2003; Barnes et al, 2006; John and Wheway, 2004; Shelley, 2002; Murray, 2002; Ward et al, 2004).

The research by Barnes et al (2006) as part of the National Evaluation of the Children's Fund found that services developed failed to address exclusionary attitudes and practices in local communities, despite recognition amongst service providers, as well as users, of the need to address such barriers for inclusion to be achieved. An understanding social exclusion as multi-faceted and as a process rather than static state, allows us to consider how to address those factors, process and people who exclude and not just to focus upon the individual or group excluded.

Our discussion above about experiences of fun and friendship and of opportunities for these to be fostered and developed identifies a number of barriers we can briefly summarise here:

- A reliance on school and lack of out of school opportunities;
- A reliance on structured and targeted activity and lack of provision for spontaneous fun and friendship;
- Adult assumptions structuring activity without the involvement of children and young people;
- A reliance upon family members for support, coupled with a lack of family-focused provision to build upon the positive features of these relationships;
- A focus upon short term provision rather than mainstream inclusion itself as barrier to the development and maintenance of opportunities for fun and friendship.

Practical Barriers

- There are a series of practical barriers to accessing mainstream provision or joining in with local activities. These include transport, facilities arrangements and lack of information.

The evidence identified within our review also identifies a set of key practical barriers that disabled children, young people (and their families) face in accessing opportunities for fun and friendship.

Lack of access to suitable transport is consistently identified as a barrier to inclusion. Studies indicate that a majority of disabled teenagers are unable to access appropriate transport independently and this often means either dependence on family members for transport or staying at home (Beart et al, 2001; Buttimer and Tierney, 2005; Connors and Stalker, 2000; Lewis et al, 2007; Morris, 2000). For young people perceived as having learning difficulties transport issues are tied up with supported access and linked to parental and young people's fears of getting lost or running into danger if alone (Buttimer and Tierney, 2005). Being unable to access transport independently often means that disabled teenagers are effectively unable to access out of school, community based informal leisure provision which in turn can make it difficult for them to maintain friendships with non-disabled peers (Barnes et al, 2000). The absence of independent means of travel is particularly significant for those living in rural communities, resulting in more extreme exclusion from community based leisure opportunities (Buttimer and Tierney ,2005).

Transport was also noted by our e-forum respondents; for example this service provider describes how:

> *Transport has been a bit of an issue as the students live outside the Winchester area – some taxis have been kind or parents have car shared.*

Parental car-sharing clearly has repercussion for young people's independence, increasing the reliance on adults that we have discussed earlier in this report.

Parents and children identify a range of additional physical and environmental barriers to their inclusion in community based leisure provision. These include a lack of appropriate toilets, sinks and changing facilities, availability of specialist equipment, and provision of car parking spaces, ramps and doors that disabled children can open. Thus Shelley (2002) reports for example, that a lack of adequate disability parking (most often referred to in connection with theatres, museums and playgrounds), or accessible toilets (particularly at football matches, playgrounds and parks) often restricts family outings. However the major barrier highlighted by this study was a lack of changing facilities for older children wearing incontinence pads. Even those amenities that scored highly on other factors scored badly in this aspect of their facilities.

A lack of information is also consistently identified as an inhibitor – this includes information in accessible format (for example in Braille or in pictures/symbols), information on accessible facilities, and publicity information that portrays images of disabled children. Consultations show that parents would welcome better information in the form of: directories of mainstream and special needs sports/leisure provision which include and welcome disabled children and young people; guides to accessible days out for families with a disabled child or young person; website information on accessible clubs and facilities.

This teacher, contributing to our e-forum discussion, describes how the broad range of barriers inter-relate:

> *In my experience (teacher in SLD school) this provision / experience ['fun and friendship' out of school hours] is lacking for children with a disability- there are many reasons for this - -children live outside 'normal' catchment areas and come to school on transport so they miss out on after school activities; parents' school gates friendships are restricted due to the above; funding - high percentage of staff required to support these activities; [lack of] premises with appropriate disabled facilities*

Impairment Specific Barriers

- Some groups face particular barriers associated with levels and type of impairment, and the support requirements which relate to these. These barriers may be practical or may be social responses to specific impairments. Children and young people with learning disabilities and communication difficulties are within these groups.

Whilst common themes and experiences emerge from the literature we need to recognise that barriers to inclusion can vary according to the nature of impairment. Murray (2002) argues that such differences need to be acknowledged if services are to provide appropriate support, and if services fail to engage with these differences the barriers may be rendered invisible resulting in problems being located within the context of individual impairment.. A Swedish study (Skar, 2002) worked with a small sample (8) of children aged 6-11 years 'with motor disability' to explore their attitudes towards and experiences of their technical aids. The research found that when young the children saw the aids as an extension of themselves, but as they got older they found themselves more inhibited by them as they encountered less accessible environments. Adopting the social model of disability does not deny the experiences of different impairments In applying the social model to children and young people, Connor and Stalker (2007) argue that if you fail to recognise difference and treat everyone the same you risk failing to recognise and meet the needs of the minority.

As already described, children and young people with learning disabilities are less likely to have non-disabled friends than young people with physical or sensory impairment and have significantly less opportunity to enjoy independent access to leisure. In common with those who need facilitated communication and those with complex health needs, young people with learning disabilities are less likely to have relationships with peers independently from adults. Young people with visual impairments also experience particular difficulties in going out independently and can be dependent on individual responses of the public (Murray 2002). Murray reports that for young people with complex impairments and high support needs the issues are *'not so much about the details of what happens to them in the 'outside world' but rather about their right to be present in that world'* (Murray, 2002:38).

Some barriers to inclusion in mainstream leisure identified by the Contact a Family study (Shelley 2002) were directly related to impairment. For example the distress experienced by children with Autism and Asperger Syndrome if required to queue or be in large crowds. Queue -'jumping' schemes, offered at some leisure parks, were valued: however, even when needs arising from impairment are recognised in this way, one parent reported an attitudinal barrier: *Even on queue jumping schemes one has to undergo abuse and hurtful comments from the public which spoil the day for all.*

In a study of the experiences of disabled children and young people and their families during the school holidays Petrie et al (2007) found that parents of children who had received a diagnosis of autistic spectrum or an attention deficit hyperactivity disorder faced particular challenges in accessing play schemes and mainstream leisure and play facilities. The study also revealed a shortage of appropriate holiday clubs and play schemes, which resulted in the rationing and irregularity of service uptake.

Epilepsy may, through anxieties and ignorance of others about the nature of the condition, arouse particular concerns about 'fun and friendship' activities (Lewis and Parsons 2007, in press). A parent on an e forum told us about her 17 year old son who has epilepsy:

> '*He is still 'fitting.' We went out to a restaurant last week and he took a dive! People were very helpful ... the restaurant wanted to ring an ambulance! Luckily for him he has a girl friend whom he met at school and she is his companion and accompanies him everywhere and is very understanding. He can't drive or ride his bike although he occasionally does, he got a free bus pass which pleased him. However the bus service is very poor in the evening and all the buses run on a spoke system all going into the centre but if you wish to go across town it is impossible... He has been swimming with his girlfriend at the new pool in [town] but every time he has had a fit afterwards! I fear his social life would be very limited if it wasn't for his girl friend.'*

Such quotes illustrate the considerable barriers and complexities faced by the families of such disabled young people which they are left to sort out for themselves. Such difficulties are exacerbated if the family is not proficient in spoken English.

Some disability-specific charities run 'fun and friendship' events which take particular note of disability-relevant barriers. For example, from an e-forum:

> *The RNIB's music advisory service (see www.rnib.org.uk/music) runs events for children and young people up to 18 years old. Recent events have included a day of Monsters, myths and music at the Royal Opera House, a day of using Soundbeam technology at RNIB, and a musical menagerie singing day at Wigmore Hall. The main focus and aim is making music but one of the common benefits which children cite on the evaluation score is the chance to meet new people, make new friends and work as part of a group. This is something which not all of them have had a chance to do, music often being something done in isolation.*

3.2.3 Developing Provision

We now identify the messages that emerge from our review that are relating to the development of provision for disabled children and young people that provides opportunities for fun and friendship.

Targeted Provision or Mainstream Inclusion?

- The delivery of segregated or inclusive provision is a complex area. Both segregated and inclusive provision presents positive opportunities, with children and young people expressing a diverse set of views as to their preferred option and the needs of the child, young person and their family will directly affect their preferences.
- Segregated provision can address important gaps in existing services.
- Mainstream provision is not inclusive and sustained activity to address this is required.

The issue of the role of targeted, or segregated, provision in relation to inclusive, mainstream provision is a complex and contested area. The evidence identified for our review enables us to outline key issues and debates, and to identify key messages for BBC Children in Need.

Research and consultation provide mixed evidence on whether, how or when special provision for disabled children and young people is able to support their development and contribute to inclusion. In the absence of inclusive mainstream provision and opportunities for fun and friendship, children and young people (and their families) welcome opportunities that are provided, with impacts for them relating to their otherwise isolated experiences and the simple opportunity to do things that are otherwise unavailable to them. This does not negate their aspirations for more inclusive mainstream provision, nor a recognition that alongside work to make the mainstream inclusive there is a need to provide targeted provision to address the gaps that exist (Barnes et al, 2006). Opinion about the role of targeted provision across children, young people, parents, is not homogenous nor does it neatly cluster around particular impairments. For example, many parents and young people value the opportunity to mix with their disabled, as well as with their non-disabled, peers.

Children's experience of either mainstream or special education and the ways in which this might be networked to other opportunities for leisure are important. John and Wheway (2004), exploring the experience of children attending special schools, identified travel time to school, lack of opportunity to see friends outside of school, lack of contact with children living more locally, and parent's lack of contact and experience of 'neighbourliness' with other local parents and families as barriers to inclusion. One solution they suggest is for all disabled children to be offered the opportunity of regularly visiting, and taking part in activities at, their local mainstream school. Lewis et al (2007) found no systematic differences between special and mainstream school pupils in terms of participation in activities outside school. The main special-mainstream difference found was in relation to level of additional support needs. Thus out-of-school options were restricted for pupils for whom greater support was required. This was because support or available places were limited or participation had to be well planned in advance, so was less spontaneous. These situations created real or perceived, barriers to participation.

In their research concerning access to leisure, Action for Leisure and Contact a Family (2003) identify 'special' versus 'mainstream' provision as a tension amongst parents, for whom 'inclusion' is a central and emotive issue. Whilst the majority of parents and children in their study felt that inclusive provision was important, a significant minority indicate a preference for specialist provision. Other consultations with parents reflect this and indicate a number of different reasons for it. In some cases parents feel their child cannot cope with the pressures of inclusion in the mainstream - for example parents of children with degenerative conditions. For others previous negative experience has meant they do not feel confident that their child will ever be safe or accepted in mainstream (Action for Leisure and Contact a Family, 2003; Shelley, 2002). For families with children with severe/complex needs specialist settings are often preferred for the individual support and expertise available. Action for Leisure and Contact a Family (2003) identify inclusion as being about an 'attitude of mind', and this can be understood when we try to identify exclusionary practices.

Issues around segregation or specialist provision take on different forms depending on whether they refer to clubs (where special provision is sometimes valued) or access to public spaces and commercial facilities such as cinemas, bowling allies, or football matches. In discussing disabled children's' access to playgrounds John and Wheway (2004) argue that segregated spaces are exclusionary and in the past have been developed to keep disabled children invisible. In the Contact a Family survey of access to leisure provision, Shelley (2002) reports that whilst the majority of families want to access the full range of facilities that the rest of the population take for granted, parents were overwhelmed by a host of physical and attitudinal barriers. Connors and Stalker (2000) also report that disabled children want to access the same leisure venues as their non-disabled peers and point out that this has implications beyond statutory service provision and in particular for the commercial world.

Evidence suggests that whilst mainstream provision is often experienced as exclusionary disabled children and young people's experience of access to special facilities and events is different. In Murray's (2002) study of disabled teenagers' access to leisure some of the young people involved identified positive experiences of segregated provision. These included the opportunity to share personal experiences of oppression and exclusion to facilitate an understanding that problems of disability do not reside in individuals but within a disabling society. Murray stresses the value of extending the opportunity to young people to develop friendships with others with similar impairment as it is through these relationships that experience of disability can be shared and understood. However she also reports little evidence of empowerment being integral to segregated schemes for young people with learning disabilities. Turner's (2003) consultation work with young disabled people (aged five to 25) also provides evidence of positive experience of segregated provision. Turner states that 'the majority of disabled children and young people feel most comfortable attending leisure services exclusively for disabled children' (p50). Unity-Sale (2006) in reporting on a special disco for young people with learning difficulties suggests that the popularity of 'Funky Feet' makes an argument for specialist provision in some instances.

Our review has identified little research that considers the experiences of disabled children and young people from black and minority ethnic (BME) communities. A study with disabled adults undertaken for JRF (Singh, 2005) highlighted the value of approaches that recognised from the outset the complexity of participants identities, of their support needs and their experiences of multiple exclusion. It is not clear why there is such a paucity of research focusing upon disabled children and young people from BME communities. Evidence from the National Evaluation of the Children's Fund (NECF) suggested that how services are targeted and need identified is a complex issue (Hughes and Fielding, 2006) and we saw at the outset of this report the lack of information about the number of disabled children in any single area. In research for NECF Morris et al (2006) explored services for black and minority ethnic groups, and one of these was a holiday project for South Asian families with disabled children. As with all the provision within the targeted programmes reported on, children, young people and their families valued specialist provision as it was addressing an important gap in mainstream provision. Nonetheless, it was also recognised that provision to address such gaps could only exist in the short term and the barriers to inclusion in mainstream services should be addressed so that inclusive, culturally sensitive and appropriate provision was available to all. This echoes messages from NECF research focused upon services for disabled children and young people:

> *Services, which have a broad view of inclusion, aim to support children's social networks and tackle disabling barriers holistically at the levels of the individual child, family, school and wider community, are likely to have a more lasting impact on promoting the social inclusion of disabled children and their families* (Evans and Plumridge, 2007:239).

Discussion of segregated versus inclusive provision for disabled children and young people also involves issues of independence and consideration of sibling involvement. Access to well-resourced inclusive clubs and facilities are discussed by Shelley (2002), who identifies the difficulties faced by parents wanting their children to be able to access a range of mainstream clubs, but facing an 'option' of one 'special' club. Young people attending 'inclusive' leisure provision often stated that parents or siblings would be involved in actively supporting their involvement which could sometimes mean that disabled children did not receive opportunities for leisure away from their families. Conversely, Sharma and Dowling (2004) found that there was a negative impact on families where siblings were segregated in their activities because of disability:

> *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* (Sharma and Dowling 2004, p12).

Some e-forum respondents described segregated 'fun and friendship' activities more positively, for example a service provider highlights a range of reported and perceived benefits:

> *'The teachers of the deaf in Salford have run, on a voluntary basis, for the past 11 years, a youth club for all hearing impaired children and young people in the Salford area. We meet once every half term, in the evening, to do games, crafts etc and to provide a social network for the children and their families. Most of*

> *these children are in mainstream schools so the youth club provides valuable links to other children facing the same hurdles as themselves. Parents also appreciate opportunity to speak with other parents who have hearing impaired children. We always have fun - organising summer picnics, parties, theme nights, and for the past 4 years have hired a coach to take families to the NDCS Fun Day.'*

For this parent segregated provision is also important, providing opportunities for her son to mix with disabled peers:

> *I have a profoundly deaf son(9) and foster a little girl(7) who is also deaf and [cochlear] implanted. They both go to a holiday play scheme run by Hampshire Deaf Association. This usually happens 2x a week for 3 weeks over the summer and for 2 days over the Easter vacation and half term holidays. It is supported by charitable donations and a small grant from Southampton City Council, so it is never guaranteed to continue, but is offered on a 'holiday by holiday' basis. My son is a singleton in a mainstream school and this is the only opportunity he has to mix with a deaf peer group as an individual. The little girl does attend an HI Resourced provision so has a small deaf peer group at school. We do also attend fun events run by the South Hants Deaf Children's Society - as a family.*

Supporting Access to Fun and Friendship Opportunities

- Disabled children, young people and their families want to access a broader range of fun and friendship provision. Supporting access promotes sustainable inclusion.
- Supported access is important for disabled children and young people. The type, nature and level of supported access offered needs to be flexible and responsive, whilst many disabled children and young people value this support, some limits are identified.

A consistent message from research and consultation is that parents and children want to enjoy a broader variety of experience and to have the same opportunities as others to participate in mainstream activity (Action for Leisure and Contact a Family, 2003; Sloper, Rabiee and Beresford, 2007; Shelley, 2002; Murray, 2002). For many disabled children and young people their worlds are experienced as highly restricted often limited to home and school (Beart 2005). One of the key points made by disabled children and young people as part of the *Ask Us!* Consultation (JRF, 2001) is that they want more things to do in groups and after school, the chance to go 'out and about' and have more independence. In a recent survey of disabled children and their parents The Children's Society (Children's Society/Every Disabled Child Matters *Undated*) found that disabled children identify 'more fun things to do' as one of their top three priorities for change. Parents stress the importance of inclusion within their communities and identify this, and not having to fight for support, as two of their three priorities.

Friendship is an intrinsic part of quality leisure time yet for many making and maintaining friendships is challenging. This is particularly so for children and young people with communication impairments, high support needs and/or learning difficulties. Murray (2002) suggests that a failure to recognise the importance of friendship for young people with communication impairments, learning difficulties and/or high support needs means that there is little acknowledgement that they may require support to facilitate friendships. She argues that support is often focused on engagement in activities rather than on enabling friendships to be developed.

There is clearly a need to develop appropriate support provision but issues surrounding this are not straightforward. One important factor is the need for flexibility and recognition that each young person is different. The type of support needed or wanted is different for each individual and may range from workers linked to specific children and young people to placing additional staff within an activity. Support may vary from facilitating communication, to accompanying a child to a Brownie session until she feels comfortable to attend independently, to supporting a group of teenagers on a regular basis to access a range of community based venues such as bowling or the cinema.

In relation to one-to-one support Murray (2002) identifies a number of features of positive relationships between support worker and young person as follows: support workers who enjoy being with the young person; support workers being comfortable and confident in understanding young person's communication methods; young person feeling comfortable with and liking their support worker; opportunity for two support workers to work with the young person lessening the intensity of the relationship.

In a discussion of access to sport and leisure provision Devas (2003) argues that if leisure providers were to fully adopt direct access they could deliver services without the need for support worker involvement. She suggests that one of the disadvantages of relying on support workers is that they obscure the lack of accessibility and act as a buffer between the disabled person and the world. However, recognising that access workers can only work with a person once they have managed to access the service she suggests they work in partnership with support workers to facilitate inclusion.

Provision of appropriate support emerges as essential for some young people and reports give practical suggestions on how this can be facilitated. Ideas include free entry for support workers, taster sessions for children, young people and their support workers, more information on Direct Payments as a means of accessing support; provision of leisure passes; better training for staff so that they can routinely identify the support needs of disabled clients (Action for Leisure and Contact a Family, 2003; Murray, 2002; Shelley, 2002). Some studies highlight the success of self-help initiatives involving bottom-up action by parents in approaching local authorities and developing partnerships to promote inclusion (Shelley 2002).

One e-forum respondent working in a special school gave an example of how flexible access had enabled young people with learning disabilities to join in musical programmes:

> *The orchestra club is held at the local high school and involves students from local primary schools too. This has been a great opportunity for our students to be part of a bigger event and sit alongside other children. There has been a certain amount of negotiation needed with the conductor and high school staff and students in order to ensure that the communication and structure of the session supported our students needs. Hence symbols are used to signal what is happening, and students use their personal schedules to understand the sequence of the session. Transport is a requirement for our students to attend this off site club. The overall*

> *aim of the after school clubs is to offer more opportunities for students to experience high quality creative experiences. The atmosphere in these sessions is different from lessons, and students who attend may well work alongside other students and adults whom they do not normally meet during their school day.*

Overall, a strong message from the e-forum respondents is that people were imaginative and positive in seeking ways to make 'fun and friendship' activities more inclusive and, as in these quotes, that these were explicitly contrasting school-based activities.

> *Our pupils have severe learning difficulties, aged 4-11. Recently we have started 3 Extended schools activities which are new to our school. (1) An after school cookery club, attended by pupils and parents together, led by an outside provider. One parent said "I never imagined that I could ever cook with my son. Now we'll cook at home together." (2) A gardening club for SLD pupils at a mainstream primary school. A win win situation, as our pupils get a rare opportunity to work alongside mainstream pupils and they have a greater opportunity to increase their disability awareness and (3) a Yoga club. Firstly for a group of profoundly disabled youngsters and then following this successful pilot, for a group with autism. all 3 activities have provided great enrichment activities which our school alone could not have provided. Undoubtedly all 3 have been fun and allowed friendships of different kinds to become established.*

Others wrote of shared (disabled and non-disabled) craft days, telephone training, sports events, interview skills, film making, learning to sign, puppet-making, drumming, skiing, horse riding, adventure activity centre programmes, and picnics.

Barnes et al (2006) highlight a particular model of provision as offering the potential to achieve inclusion within mainstream provision for disabled children and young people: enabling schemes. In their research for the National Evaluation of the Children's Fund a reoccurring theme is the structural nature of social exclusion and the need to address these barriers if inclusion is to be achieved. The enabling schemes that feature in their research involve providing specialist support to disabled children and young people to enable them to attend mainstream and existing provision, rather than establishing segregated or targeted provision for them. The enabling services adapted they way that they worked to individual children and they worked with services to ensure that appropriate adaptations were made or steps taken. One problem with the services was that due to their resources they were only able to provide the enabling support for a fixed period (6-12 weeks depending on assessment). Nonetheless the services worked to ensure that once enabling support was withdrawn, access could continue. This was not always successful, but where it was impacts were described in terms of the importance of accessing mainstream provision as a feature of everyday life. One father highlighted how the service meant that *'[my daughter] can do what other eight year olds do, which she can do now without assistance which is brilliant'* (Barnes et al, 2006: 23).

Addressing Practical Barriers

- There are positive steps that can be taken, and encouraged, in order to address some of the physical barriers that prevent the inclusion of disabled children and young people.

- Specialist equipment but also accessible space and equipment, increased staff skills and training, and long term funding for capacity development are all positive measures.

In addition to messages about supporting access, there are also messages that emerge from the literature about measures that can be taken in order to address some of the physical barriers that exist for disabled children and young people in accessing opportunities for fun and friendship.

Ward et al (2004) point out a number of practical issues may need addressing before services are able to offer more inclusive provision. These include issues related to transport, lifting, and handling that may require small grants to buy in specialist equipment. Flexibility in funding requirements or expectations is an important factor as there is likely to be great variety in what is provided in different local authority areas and the localities within them, often depending on the history of provision. Transport is a complex issue in this context with different configurations in different places; nonetheless transport and the central role of transport in access is important to recognise.

John and Wheway (2004) in discussing access to outdoor play say that a focus is often put on new playground provision but that it is just as, if not more, important to make existing provision more accessible. They recommend that all play equipment should be designed as more accessible rather than concentrating on 'special' equipment. They also point out a strategy of making playgrounds accessible cannot be done in isolation to the environment in which they are placed. They lay emphasis on developing more low-key and low-budget improvements to accessibility, for example even pathways, wide entrances, dropped curbs for parking, internal pathways, bright colours, removal of obvious barriers, provision of benches, arguing that these are reasonable and achievable by all.

The importance of continuous staff training is emphasised. This includes work around attitudes and fears, awareness raising and the development of staff confidence in counteracting exclusionary processes. A consistent message is that although many services are willing or even enthusiastic about developing inclusive provision they often lack confidence or are fearful of getting things wrong (Action for Leisure and Contact a Family, 2003; John and Wheway, 2004; Petrie et al, 2007; Ward et al 2004). Training may also be needed for specialised tasks for example feeding, changing, lifting and the administration of medicine. Whilst there may be a need to provide additional training for support workers and volunteers linked to individual children. Ward et al (2004) report that the development of inclusive provision requires additional staff time both spent behind the scenes in preparation and in supporting individual children and young people. This may give rise to the need for additional staff and/or volunteers, whose recruitment may take time. Planning for inclusion needs to build in this additional time factor.

Consultations with parents and service providers consistently identify the need for long term funding to build reliable, coordinated and trusted provision. Service provision is currently experienced as patchy and uncoordinated. The need for parents and children to develop trusting relationships with staff over time is essential for children and families to feel accepted and genuinely included, and for this to happen personnel need to be consistent (Barnes et al, 2006; Contact a Family 2003; Edwards et al, 2006; Sharma and Dowling

2004; Ward et al 2004).. The National Evaluation of the Children's Fund (Edwards et al, 2006) highlighted how quite apart from the type of provision, key to the positive service experiences of children and young people, regardless of age or other characteristics, was continuity in project and key workers.

Long-term funding is also important as the time-scale for change is long-term. Building inclusive services takes time and careful preparation and therefore requires committed levels of funding. Accessing leisure opportunities requires money and cost is major consideration for families, particularly given the additional financial cost of caring for a disabled child. The history of provision is too often characterised by short-term and unstable funding, which creates uncertainty, limits the range of provision, and limits the ability to address the barriers to inclusion in order to achieve the change required. Short-term and limited funding also has implications for staff skills and resources, with little capacity for staff development, training and for activity beyond front-line provision.

Several e-forum respondents were grateful for funding from the BBC Children in Need but the short terms aspect of such funding was problematic:

> *We've had BBC Children in Need funding to support our after school and holiday club. Much needed, appreciated by parents, but very costly! £25,000 from 1 bid. Would like to see funding for this sort of thing as a regular thing as every year I have to go through the scrounging process to keep us open another year!*

3.3 Conclusion: Fun and Friendship for Disabled Children and Young People

In this Section we have reviewed the broad range of messages to emerge from our review, focusing upon opportunities for fun and friendship for disabled children and young people. We have seen how disadvantage is a characteristic of many disabled children and young people's lives, with an understanding of social exclusion as multi-faceted enabling us to recognise the structural and process barriers that limit the inclusion, and inclusive experiences, of disabled children and young people. School can be a central site for friendships to develop, but a reliance on school has associated difficulties: friendships at school cannot be assumed to be mature or complex friendships and can be restricted by the school environment; the maintenance and development of friendships outside school takes ongoing commitment and resources and opportunities are limited. There is a lack of provision for disabled children and young people that enables or facilitates the spontaneous fun and friendships that are recognised as essential for the development and inclusion of all.

Both targeted and inclusive provision is valued by children and young people. Often targeted provision is welcomed as it offers opportunities to mix with others and it addresses gaps in mainstream provision by providing activities and opportunities otherwise denied to disabled children and young people. Nonetheless it appears that for sustainable inclusion to be achieved, with both societal and practical barriers to the participation in opportunities for fun and friendship addressed, enabling support of the kind identified by Barnes et al (2006) perhaps offers the most potential. Enabling support is tailored to individual needs, and is not impairment or context (for example rurality) specific. Enabling support focuses upon supporting children and young people in accessing mainstream and existing provision, as well as non-structured activities such as meeting with friends. As well as facilitating and supporting participation, enabling support addresses practical and other barriers so that when withdrawn participation can continue.

To illustrate the potential of an enabling approach, which should not be prescriptive but responsive to local and community context as well as individual needs, we include below three case studies all taken from Ward et al's (2004) review of best practice in developing inclusive play and leisure for disabled children and young people.

Case Study One – Wider Horizons Halton

Wider Horizons is a service providing support for disabled children aged 5-13 to access mainstream leisure opportunities.

Sophie and Sarah are 8 year-old twins who have moderate learning difficulties and hearing impairments. Previous bad experiences when their behaviour was viewed as challenging meant they did not access mainstream leisure. Their Mum approached Wider Horizons when she felt the girls would like to try Brownies both to have fun and benefit from interacting with other children in an inclusive setting. Wider Horizons contacted a small local Brownie pack whose leaders were keen to include the girls with the projects support.

A Wider Horizons worker did some preparatory work with the leaders explaining their needs and giving advice on hearing impairments. The worker also played games with the girls before attending Brownies to encourage appropriate behaviour. The worker then accompanied the girls for the first two sessions explaining the girls' disabilities to the other Brownies and giving practical advice on communication.

After the first two sessions both the girls Mum and the Brownie leaders felt confident about proceeding without the support worker who stayed in touch with them to check progress and offer additional help with days out etc. The Brownie experience gave the family the confidence to try other activities and the twins now attend a dancing class.

Case Study Two – Salford Families

Salford Families provides support for families with disabled children including holiday play schemes, support groups and activity groups.

Rebecca is 10 years old and has mild learning difficulties and some coordination difficulties. Rebecca had been attending the same inclusive play scheme for four years supported on a daily basis by a volunteer from Salford Families. She is quite nervous and lacks confidence and both her and her mum had been anxious about her attending the play scheme alone.

This year the volunteer again accompanied Rebecca but after the first few days noticed that she was arriving each morning with friends rather than her Mum. The staff at the scheme felt there was no longer any need for the volunteer to stay as they now knew her so well and were confident that they could care for her. The family support worker met with Rebecca's Mum who was happy for the volunteer to withdraw from the play scheme and for Rebecca to go with her friends.

Salford Families kept in contact with the play scheme throughout the summer to check that every thing was going well and Rebecca was continuing to enjoy the scheme. Rebecca had a great time and is planning to return next year without additional support.

Case Study Three – Liverpool Families

Liverpool Families provides support for families with disabled children and young people including holiday play schemes, support groups and activity groups.

Every Saturday Joe a support worker from Liverpool Families accompanies four (male) teenagers with severe learning difficulties to an activity of their choice. The activities vary each week and include things such as bowling, shopping going to the cinema and playing pool. The group meet in a designated place such as a shopping centre or train station with members either being dropped by their parents or catching the bus. Each member of the group takes responsibility for different tasks such as paying for tickets or buying drinks and snacks. Their particular favourite activity is playing pool and they have never experienced discriminatory or negative behaviour from other pool players.

The support workers role is to ensure the lads are OK and having a good time. Aside from that the group members are in control of what they do electing a group leader each week and deciding what activity to do what to eat etc. Joe reports that the lads have gained in confidence and awareness of themselves and their abilities through their activities. Special occasions such as birthdays are also celebrated by the group with a trip to a restaurant of their choice.

4 Consultation and Participation

In this section we review messages about consultation and participation practice with disabled children and young people.

- A diverse range of disabled children or special needs are increasingly being invited to share their views (a precursor to fuller participation) about their experiences and provision across a wide range of contexts (including leisure);
- There needs to be transparency about methods and sampling so that full participation is recognised as not always necessary, desirable or achievable.
- Methods need to be sensitive to the contexts as well as to individuals' capabilities and preferences;
- Time, commitment and appropriate skills by the adults involved are essential to effective participation.

Disabled children have been consulted about their provision in various contexts (including education, social services, leisure, health, law and family rights). This has been done in a range of ways, often individualised to reflect particular capabilities. This reflects the impact of the 1989 United Nations Convention on the Rights of the Child, as well as, internationally, general policy and practice shifts towards recognising children's rights to express views about their provision. This is reflected in the UK in the 'Working Together' guidance issued as part of the Children's Plan (DCSF, 2007).

It is important when involving disabled children and young people in sharing their views about provision and opportunities that (1) a range of tailored methods are used, (2) these are employed flexibly (3) that there is transparency and (4) that the adults involved have appropriate skills and knowledge . Through this approach, full participation may be recognised as not always necessary, desirable or achievable. Consultation can be appropriate if that is all that is possible, for example as a result of limited resources to support involvement, or limited choices over which the results of any involvement might have influence. Where participation cannot be achieved, openness and honesty about the limits of involvement is important (Edwards et al, 2006).

This formal seeking of children's views raises particular ethical issues (well rehearsed in the literature e.g. Alderson and Morrow 2004, Willow 2002, Lindsay 2000) and these may be sharpened when the children involved have disabilities or special needs (Cameron and Murphy 2006, Clegg 2004, Lewis and Porter 2004, 2007, Ware 2004). These ethical issues span:

- confidentiality and the ethics of openness,
- power relationships and the emotional context,
- unintended repercussions of protocols,
- anonymity,

- consent/assent,
- gatekeepers and
- potential intrusion.

These apply also in the context of seeking views through disabled children's membership of research or evaluation reference or advisory groups. In that context, there are additional ethical issues relating to expectations. For example, young people with learning disabilities (and others) may assume that involvement will necessarily lead to the changes wanted. There are also wider 'citizenship' issues concerning whether, why and how children and young people represent not just their own views but also those of under-represented groups (e.g. disadvantaged children or sub-groups of disabled children).

Parent and child views may differ and the use of adults as proxies for children and young people in giving views is problematic. It is therefore important that children's and young people's views are, as much as possible, sought independently of parents or carers.

The involvement of disabled children in reference or advisory groups spans a continuum of types of involvement from merely advisory to roles as research leaders. Increasingly in recent years, the involvement of disabled people as co-researchers has been regarded as 'good practice' (Lewis et al 2008; Oliver, 1997). This has been informed by growing participatory and emancipatory research paradigms (Walmsley, 2001) as well as user-focused policy imperatives (Kirby et al, 2003). Matters for clarification within any project include the place of formal contracts, the possible use of established groups, stage and nature of planning for reference group involvement, style of group working including the ground rules for interaction, personal gains for individual disabled group members, and post project involvement (Booth, 1998; Clough and Barton, 1998; Lewis et al, 2008). Badham (2004) highlights an example from Solihull in which disabled children and young people managed to secure £30,000 funding from the Children's Fund to buy play equipment. Key messages from this example are: the importance of sustained contact and taking time; the importance of time to build trust; and, the need to highlight the mutual benefits in building participation and partnership between service providers and children and young people.

When disabled children's views are sought, whether in their own right or when acting in a more representative way in reference groups then further issues arise relating to (1) sampling and (2) methods. Addressing both these sets of issues has implications for the set of views obtained. Accessing views is more complex for some disabled children than for others through cognitive, emotional or situational characteristics. So the danger of including disabled children's views through only or primarily articulate young people with physical disabilities needs to be acknowledged. Avoiding this prompts questions about methods (Aitken and Millar, 2004; Beresford et al, 2004; Lewis et al, 2007). These will need to take into account:

- particular capabilities (including the possible need for facilitators or signers),
- parallel versions of e.g. survey forms (e.g. in large print, colour sensitive or low reading levels), and

- preferences for auditory, visual, kinaesthetic and/or motor modes of input/ response.

Individual or small group /focus interviews may require particular forms of stimuli (e.g. puppets/ role play/ drawing/ video/ photographs/ objects) which may need to be individualised to take into account particular patterns of (possibly co-occurring) disabilities. In addition, interpretation of stimuli or questions may be non-conventional or idiosyncratic as the experiences of disabled children may differ from the 'norm' (e.g. children with autism may have a recurrent response to a particular stimulus; children with sensory impairments may never have experienced certain 'normal' events e.g. colour television for a child with visual impairment; a child with high support needs may have missed routine experiences such as spontaneous 'playing out' with friends).

These messages highlight that, as with non-disabled children and young people, the participation of disabled children and young people can be achieved with adequate resources, including time, and care taken to ensure that any involvement is appropriate. Involvement should be tailored to the purpose and context; honesty is vital so that if consultation is recognised as important and appropriate where full participation cannot be achieved, for example as choices over outcomes are restricted.

5 Policy Context

In this section we outline the policy context for the proposed BBC Children in Need grant programme targeting 'fun and friendship' for disabled children and young people will operate. It is important for all stakeholders that this programme, in building upon the messages from the evidence and literature discussed in Section 3, does not duplicate existing or statutory provision, but works to supplement and complement what we know to exist. In this section we outline the overall policy context for children and young people, for disabled children and young people and for opportunities for 'fun and friendship'. We also briefly explore differences between England, Scotland, Wales and Northern Ireland as we discuss the policy developments.

- The overarching policy context is moving towards a holistic and multi-agency approach to children's welfare and well being, with the intention that universal outcomes benefit all children including those who are disabled;

- The available evidence suggests there is a greater gap in provision for disabled young people than disabled children, due to the commitment to, and high profile of, inclusive play across the regions. Nonetheless local variations in the extent and timing of provision suggest that play could still be a focus for grant funding

5.1 Every Child Matters

In England the Children Act (2004) provides the legislative framework for 'Every Child Matters' (DfES, 2003) (ECM), the government's overarching structure for children and young people's services. ECM provides a common set of outcomes for all children, regardless of background or circumstance, with a particular focus upon the requirement for services and agencies to work together to address needs and issues for children and their families at their earliest stages and before they become acute. Childrens services must produce a 'Children and Young People's Plan', which establishes the local framework for multi-agency working that will deliver the ECM outcomes which are commonly known as 'Be Healthy'; 'Stay Safe'; 'Enjoy and Achieve'; 'Make a Positive Contribution'; and, 'Achieve Economic Well Being'. More recently in England, 'The Children's Plan' (DCSF, 2007) sets out what the newly constituted 'Department for Children, Schools and Families' intends to achieve by 2020. This broad framework builds upon ECM to include fuller and more focused strategies for education, health, and crime and workforce development.

The Children Act (2004) only applies in part to Wales, where the Assembly selected to have certain provisions; in particular there is a similar duty upon services to co-operate for the well being of children. The Welsh Assembly agreed a set of seven core objectives for children and young people, that predated the work in England, in 2002 and an accompanying 'Framework for Partnership and Extending Entitlement'. Disabled children were not identified as a particular group for focus, rather the objectives relate to 'all' children and young people: have the best start in life; access comprehensive education; enjoy physical and mental health; have access to play, leisure, sporting and cultural activities; are listened to and treated with respect; have a safe home and community; are not disadvantaged by poverty (Welsh Assembly, 2002).

In Scotland, the framework for children is ‘Getting it Right for Every Child’ (Scottish Executive, 2006) and is similarly a programme for change focusing upon joint and multi-agency working for early intervention and which applies to all children, regardless of their background. The Scottish framework is not as developed as ECM, but the Every Disabled Child Matters campaign includes a focus upon Scotland due to similar concerns about a lack of detailed and focused guidance and responsibility for disabled children.

In Northern Ireland, the ‘Our Children and Young People – Our Pledge’ ten year strategy was published in 2006 (OFMDFM, 2006). There are 6 overarching outcomes, again for all children regardless of individual circumstance, so that children and young people are: healthy; enjoy, learn and achieve; experience economic well being; make a positive contribution; and, live in a society that reflects their rights. Disabled children and young people are identified as presenting particular needs and the strategy contains a commitment to produce an associated strategy ‘aimed at improving the health and well-being of those with a physical or sensory disability’ (p.42).

Across the UK, ‘Extended Schools’ (‘Community Schools’ in Scotland) are part of the government’s agenda to widen access to a range of services both by increasing their availability and by ensuring accessibility. This agenda includes a focus upon extended schools as sites for leisure, play and recreation provision and thus in the sections that follow when we discuss provision for children and for young people, it is important to note that these are often presented within the context of extended schools being part of the network or patchwork of provision that will exist locally.

The Children’s Plan (2007) contains a number of commitments that relate to disabled children and young people’s wellbeing. These include a commitment to develop a national play strategy for inclusive play (see below)but also funding for short breaks for families with a disabled child and other supports for families, such as individual budget pilots and childcare so that parents can enter work. The plan recognises that disabled children face additional barriers to accessing provision of all types and the tenor of the plan is that future provision will need to be explicitly inclusive.

In Spring 2008, following a commitment contained within the Children’s Plan, the ‘Fair Play’ play strategy for England was published by DCSF (2008a), for consultation. This commits £235m to play for 8-13 year olds, although it is not clear how this related to previously existing Big Lottery Fund funding. Nonetheless, it continues the policy momentum towards supporting and developing *inclusive* play provision. The stated aim is that there is play in every area, and that:

> *Play places are attractive, welcoming, engaging and accessible for all local children and young people* ***including disabled children*** (DCSF, 2008b:7, emphasis added).

We can see here how disabled children begin to be more clearly identified within the broad commitments to inclusion. Under the Children’s Plan, Local Area Agreements are required to include priorities for children’s play, and indicators will be used which include children and young people’s perspectives on local facilities. Importantly, both the Children’s Plan and Play Strategy contain commitments to developing a play workforce that has the skills necessary to facilitate, support and provide inclusive play. BLF funding is also used to support 'Sport England', which in turn works with the 'English Federation of Disability Sport' to promote inclusive and non-discriminatory sports provision.

In Wales, whilst the Welsh Assembly led the UK with their 2002 play policy, there is far less information available about the detail of this agenda, or its impacts thus far. We do know that there are a range of initiatives in place in Wales to support play. In Scotland, 'Play Scotland' is funded by the Scottish Executive to promote the importance of play and to increase play opportunities across the country, including workforce development (Play Scotland, 2006a). A 2006 research study on the state of play provision in Scotland (Play Scotland, 2006b) highlighted a lack of a statutory duty of play. BLF funded a 'Scottish Play Commission' which reported in June 2008 and recommended to the Scottish Government that they: develop a national play strategy; create a national play indicator; promote play across the local authorities; and, support play workforce development. These themes echo English and Welsh developments, but suggest that they are less developed than in these countries. There is not an explicit commitment to disabled children.

In Northern Ireland, 'PlayBoard' is funded by the Assembly to promote play and increase play opportunities. There is a commitment in the (2006) 10 year strategy outlined above and the subsequent 'Action Plan 2007-2008' (OFMDFM, 2007) to develop a play strategy but this is not available at the time of writing.

Across these policy documents there is a recognition that for children and young people in rural areas, issues around access, transport and opportunities for leisure (and fun and friendship) can be more limited than for their urban peers. It is not clear how this recognition is being addressed at a local level. In considering the policy and practice context, it may be important to recognise that greater rurality and pose particular issues in Scotland, Northern Ireland and Wales as well as the rural regions of England.

5.2 Fun and Friendship for Young People: Leisure and 'Positive' Activities

The policy focus for 'fun and friendship' opportunities for young people is more focused towards leisure opportunities and access to leisure provision, organised 'positive' activities, and opportunities to meet and mix with other young people outside of adult-led structured provision. The policy agenda in this area contains less activity in practice terms than the play agenda for children outlined above, as much of the documentation in this area relates to intended and forthcoming policy and practice rather than reports on actual progress, practice and delivery.

In England, the 'Youth Matters' green paper outlines the government's commitment to developing provision for young people, but as a green paper is at the consultation stage rather than firm commitments (DfES, 2006). Within a broad commitment to universal, inclusive and responsive services, disabled young people are highlighted as a group who face 'additional barriers' in accessing both structured and informal provision and space. It is also stated that:

> *'the forthcoming duty on all public authorities to promote equality of opportunity between disabled and others arising from the Disability Discrimination Act makes very clear that those providing services must ensure that they are suitable for disabled young people'* (DfES, 2006:7)

'Next Steps' describes how 'Youth Matters' will be delivered and there are more encouraging signs for disabled young people in light of this explicit commitment (DCSF, 2006). £115m has been made available for the 'Youth Opportunity Fund' to be spent by young people on local provision and the 'Youth Capital Fund' to improve facilities (approximately £500,000 for each local authority area). The picture is less clear in the regional governments of the UK. The Welsh Assembly policy documents for young people relate to education commitments or to the development of the Welsh Youth Service with the strategy 'Young people, youth work, Youth Service' (Welsh Assembly, 2007). This strategy places provision within a much stronger vision of a universal youth service than the rather fragmented approach of Youth Matters, so that the youth service supports young people alongside the provision of 'accessible' recreational and social opportunities. The strategy is in consultation stage, and whilst stressing inclusivity and access for all, there is not an explicit focus upon disabled young people.

In Scotland, provision for young people is also placed within a broader national youth work strategy 'Moving Forward', following an earlier consultation document (Scottish Executive, 2007). In Northern Ireland, the 2006 10 year strategy appears to have subsumed a 2005-2008 youth work strategy that contained, alongside a broad commitment to inclusive provision, an explicit commitment to 'Increase the accessibility of youth work facilities for disabled young people in relation to their physical and sensory needs' (NI Executive, 2005:7).

5.3 Conclusion

This brief overview of the policy context has drawn our attention to the inclusive *intention* of emerging policy for children and young people but also questions about the extent to which this exists in local policy and *practice*. It is likely to take several years before more recent policy provisions take effect and some local authorities will be more advanced than others, whichever region of the UK they are within.

Despite these questions over the way in which policy is influencing local provision, there are some clear themes that emerge for our consideration of opportunities for fun and friendship. Firstly, there is a large and sustained policy focus upon play provision for children, with investment in inclusive play across all local authorities and associated requirements to produce inclusive play strategies. Secondly, although there is a growing recognition of the need to provide for disabled young people (teenagers) there is less policy focus and commitment. The lack of provision outside of targeted, structured activities emerges as a clear gap in policy and practice.

6 Conclusions and Recommendations

In this final section we conclude by reflecting on the messages that have emerged from our review in light of the four aims for BBC Children in Need's overall scoping study to inform a proposed '*Disabled Children and Young People Friendship and Fun Programme*'.

The review has presented a wealth of research and other evidence that highlights the need for a range of provision for disabled children and young people that enables them to experience fun and friendship, particularly outside of structured, targeted provision. There is a scarcity of provision, both targeted at particular groups and inclusive provision accessible to disabled children and young people, and perhaps associated with this a scarcity of research that establishes clearly favoured or preferable models. This review has explored the policy agenda that might contribute to opportunities for fun and friendship for disabled children and young people. We have seen how there is focus upon play for children, and despite an emerging agenda around opportunities for young people, less clarity about what might be provided and about how inclusive or accessible this might be to disabled young people. Across the regions of the UK, we know that there will be a variety of provision within and across local authority areas. Therefore we suggest that rather than being prescriptive about the schemes that BBC Children in Need should prioritise within the forthcoming grants programme, a set of themes emerge that provide the context for considering grant applications and could inform the parameters or themes of the programme itself.

6.1 Aims and Recommendations

Aim 1*: To assist BBC Children in Need in clarifying the focus and activity of the future proactive programme.*

We suggest that BBC Children in Need focus upon provision for older children and young people, aged from 12 years upwards, as there is a sustained policy focus upon younger children and play provision.

Rather than be prescriptive about models of best practice, we suggest that BBC Children in Need develop a set of themes to inform their programme and grant-making decisions, building on the recommendations within this section. Capacity should exist within the programme for locally defined proposals linked to local context.

There is a history of short-term and vulnerable funding for services for disabled children and young people. To achieve change longer-term funding should be considered so that projects are able to demonstrate effectiveness, enable learning and participation, and to enable learning to influence local policy and practice.

Building on this recommendation, in order for projects to work effectively locally to share learning and influence change, funding should enable, and the programme encourage, staff to network, contribute to partnerships and engage with local policy and practice structures

Aim 2: *To generate a clear understanding of what activities work in building friendships and creating socialising opportunities for disabled children and young people.*

There is a lack of evidence about different models of providing opportunities for fun and friendship for disabled children and young people. According to the context of local provision, but also individual and family preferences, both targeted and inclusive provision present positive opportunities. Local need will vary and grant applications should clearly address the local policy context and provide evidence of local need.

Enabling schemes, or those that support children and young people in accessing mainstream activity, and which work to address barriers in order that inclusion can be maintained, appear to offer potential for flexible approaches to achieving inclusive experiences for disabled children and young people in their everyday lives.

> ***Aim 3:*** *To identify what gaps exist in current provision that could be addressed by the BBC Children in Need programme.*

Although local need will vary, a strong message emerges from the review about the lack of opportunities for teenage disabled young people to take part in both the structured and spontaneous activities that are central to the development of friendship and the socialising that their non-disabled peers take for granted.

We suggest that BBC Children in Need focus upon provision that supports access to mainstream activities and opportunities, particularly for disabled young people and older children.

School and the school holidays present particular issues for disabled young people, who can rely on school for friendship opportunities but who can experience barriers in maintaining and developing friendships outside of school. An out-of-school focus therefore appears entirely appropriate for a BBC Children in Need programme.

A key gap in provision for disabled young people is inclusive mainstream provision; BBC Children in Need should support grant applications that are explicit about the way in which they will work to address barriers in their local areas so that sustainable inclusion is achieved.

Enabling provision has potential to address the gaps identified by this review. Enabling provision would work with parents to enable them to support their children as well as working with the young people themselves, taking a family focus and building upon strengths.

> ***Aim 4:*** *To develop a programme that is informed and supported by those who will benefit and those already working to meet their needs.*

As local need will vary, it is important that assumptions about what disabled children, young people and their families need or prefer should be avoided – the review has demonstrated the complexity of the issues involved, and this complexity is an important driver for engaging those who may use the services in the design of the services. Grant applications should be clear about the ways in which participation or consultation has been undertaken and how it will be supported in an ongoing fashion throughout the length of grant support.

Grant applications should clearly address the local policy context and provide evidence of local need and evidence of need should be rooted in the perspectives of disabled children and young people. There may be particular minority groups in some areas that require additional support. The perspectives of minority groups should be included within any local mapping of need.

There are a range of techniques for working with disabled children and young people to achieve participation and empowerment. Key to successful involvement is honesty about limits and capacity so that there is clarity about when participation can be achieved or when consultation is a more appropriate framework.

Finally, this review has demonstrated the difficulty in understanding the complex networks and maps of provision that exist at a local and community level, where disabled children, young people and their families live their lives. Academic literature reviewed in our study has been an important source for understanding issues and experiences for disabled children and young people, and for the services that work with them. Yet much of the most insightful material has come from the 'grey' literature: reports and publications from voluntary and community sector groups and campaigning organisations. In establishing models of practice, such sources can lack the independent rigour or commissioned research and evaluation (which itself has significant resource implications). In an international context, this is even more apparent with limits provided by the lack of English language material from non-English speaking countries, but also the difficulty of understanding international policy and practice. We therefore have two suggestions for the development of an evidence base in this area in the longer term. First, for BBC Children in Need to ensure that successful grant awards include a commitment to undertake research and evaluation and to contribute to learning. And second, for an international review of practice to be supported so that learning from different contexts can be collated and the learning promoted within the UK, but also internationally.

Appendix I

Methods

The review commissioned by Children in Need was a focused review, rather than a systematic review, that is intended to inform future developments. The literature review was undertaken in a systematic way, beginning with searches of academic databases of published, peer-reviewed, literature. We prioritised research evidence, but these databases also contain theoretical and analytical pieces that often draw on research. We searched the CSA Social Sciences Gateway, which includes 25 separate databases of academic social science research. We also searched the British Education Index (BEI), a database of education research, which we hoped would be informative about any messages from educational support and provision for disabled children and young people, and PsychInfo, a database of psychological research that we thought may contain relevant material about the needs of disabled children and young people.

The review is concerned with informing the work of Children in Need that supports fun and friendship for disabled children. We therefore used a range of search terms around 'fun', 'friendship', 'leisure', 'play', 'sport', 'socialising', 'peers', 'relationships' in combination with terms relating to 'disabled', 'disability', 'children' and 'young people'.

We also searched 'grey literature'[2] through online searches using the terms outlined above, to explore this broader range of material. As well as using search tools to search the web in general, we searched the websites of a range of government departments and VCS organisations. These were:

Action for leisure, AFASIC, Arthritis Care, ASBAH (Association for Spina Bifida and Hydrocephalus), Audit Commission, Barnardo's, British Council of Deaf People (BCODP), Big Lottery Fund (BLF), British Deaf Association, British Institute for Learning Disabilities, Centre for Accessible Environment, Commission for Architecture and the Built Environment (Cabe), Children First Programme, Children's Play Council, Council for Disabled Children, Children's Society, Contact a Family, Daycare Trust, Department for Children, Schools and Families (DCSF), Department of Local Government and Communities (DLGC), Family Fund, Fairplay for Children, Handsel Trust, JRF, Kids, Mencap, No time for us, One for Us, Play England, National Children's Home (NCH), National Youth Agency, National Society for the Prevention of Cruelty to Children (NSPCC), Parents for Inclusion, Playworks Partnership, Playsafe, Royal National Institute of Blind People (RNIB), SCOPE, Save the Children, National Evaluation of Sure Start, National Evaluation of the Children's Fund, Thrive, Values into Action, Young Minds, 4 Children Whizz-Kidz.

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[2] 'Grey' literature is published literature but is not peer reviewed and comes from a range of sources, for example voluntary and community sector groups or government reports. It often contains or reports on research, analysis and argument based on evidence. Because it is not published within peer-reviewed academic sources, grey literature does not appear within the searches of those databases.

This ‘grey literature’ proved to be the most fruitful in providing findings from work with disabled children and young people (and their families) to explore issues around fun and friendship, both as part of everyday life and as a feature of provision and practice. This literature was also essential in providing an understanding of existing policy focusing upon disabled children and young people, but also children and young people more broadly so that we can understand the extent to which this is inclusive of disabled children and young people. This understanding is essential to identifying the context within which any possible BBC Children in Need programme will operate, including any gaps that it may address.

The final complementary element of our strategy was to draw on the expert knowledge and networks of members of the study team. This knowledge informed our search terms and search strategy, but also highlighted particular pieces or research that contained insights for our overall themes. E-based networks – discussion groups and forums – that members of our networks are themselves active within, were used to invite comments from practitioners, service users and families about their experience of effective provision for fun and friendship. Where service providers cited their own practice, they were asked to provide any evidence to support this. Unfortunately, in almost all incidences they were unable to provide research evidence, reflecting a broader theme to emerge from the review. These responses are included in a short section following the findings from the literature review. The themes that emerged from the broad range of literature we explored are included in Section 3.

Appendix II

E-Forums and Networks

We invited members of e-forums to contact us with their perspectives on the focus of the scoping study, and contributions are included alongside material from the review in Section 3. The forums were: Autism Forum, for adults and children; Deaf Forum; Special Educational Needs Educators Forum; SLD Forum, for professionals working with learners with severe, profound and multiple learning difficulties; and, the Visual Impairment Forum. We received 25 responses, 23 of which were from professionals.

Professionals highlighted a range of provision they worked with, delivered or were aware of locally. This ranged from clubs for deaf children, sports for children with learning disabilities, after-school provision for disabled young people and their parents, mixed playschemes and enabling or support schemes. Professionals working in these schemes consistently highlighted the lack of sustainable and ongoing funding and the precarious nature of these services as a result. Centrally, whatever the focus of the service or activity they highlighted and the rationale for providing it, all highlighted the simple fact of it existing provided for opportunities for fun and friendship that would not otherwise exist and that this was highly valued by children, young people and families. Activities provide opportunities to mix with peers or with other families, regardless of the activity or a focus upon disability, particular impairments or were mixed and inclusive.

The parents who contributed highlighted: how living outside of the immediate school area meant a lack of opportunities for friendship, compounded by a lack of family car or accessible public or community transport; and, how an autistic boy lacked the enabling support he would like in order to spend time with friends, make trips into town independent of his family and access other everyday activities with a total reliance on (scarce) organised activities. Both parents highlighted the difficulties for these teenagers moving on from provision for younger people and children.

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