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DISABILITY
RESEARCH REVIEW 2

Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities



Centre for Excellence and Outcomes in Children and Young People's Services

The Centre for Excellence and Outcomes in Children and Young People's Services (C4EO) identifies and coordinates local, regional and national evidence of 'what works', to create a single and comprehensive picture of effective practice in delivering children's services. Using this information, C4EO offers support to local authorities and their Children's trust partners, working with them to improve outcomes for children, young people and their families.

It is focusing its work on eight national themes identified in Every Child Matters.

These are:

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- Disability
- Vulnerable Children (particularly children in care)
- Child Poverty
- Safeguarding
- Schools and Communities
- Youth
- Families, Parents and Carers.

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The Centre is also supported by a number of strategic partners, including the Improvement and Development Agency, the Family and Parenting Institute, the National Youth Agency and the Institute of Education.

There is close and ongoing cooperation with the Association of Directors of Children's Services, the Local Government Association, the NHS Confederation, the Children's Services Network, the Society of Local Authority Chief Executives, Ofsted and the regional Government Offices.

C4EO is funded by the Department for Children, Schools and Families.

Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities

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1. Summary

This review examines the evidence on how services can improve disabled children and young people's access to inclusive and positive activities and the impact this can have on their wellbeing. It also identifies the most promising directions for future research and development. Positive activities are defined as leisure-time activities outside of school hours and taking place in, or being delivered by, children's centres, extended services, youth services, school-based extra-curricular activities, play and leisure services, sports and recreation services, and the arts.

The review was carried out by the Social Policy Research Unit, York University on behalf of the Centre for Excellence and Outcomes in Children and Young People's Services (C4EO). Strategic decision-makers in children's trusts may find it helpful to read this review in conjunction with the complementary Progress Map Summary.

Two other C4EO reviews on disabled children are also available on the C4EO website. These focus on improving outcomes for disabled children through early years interventions and providing differentiated services. C4EO will use the main messages from the three reviews to underpin our knowledge-sharing and capacity-building work with children's trusts, and through them the full range of professions and agencies working with disabled children and their families. This review will be followed by a full knowledge review, which will incorporate examples of validated local practice along with stakeholder and client views.

1.1 Key research messages

- Disabled children and young people appear to have very limited opportunities to access positive activities in their local areas.
- Disabled children, young people and their families want more and different things to do so that they can choose where and how they spend their free time.
- Participating in positive activities is associated with positive outcomes in terms of children's health, experiences of enjoyment and achievement and community participation.
- At the same time, disabled children and young people report that bullying or fear or bullying spoils their experiences of, or stops them accessing, inclusive activities or using local leisure and recreation facilities.
- Achieving inclusion for disabled children requires planning, resources and the active involvement of skilled staff.
- There is scope for children's centres, extended schools and youth services to become more inclusive. Examining service delivery alongside best practice examples would be of benefit.
- There is variability in how services have interpreted what inclusion means and this has led to different modes of service delivery, some of which are not genuinely inclusive.

- Disabled children and young people value provision which is designed to facilitate disabled children's participation in activities and interaction between disabled and non-disabled children. However, they also value provision for disabled children or young people only.
- Supporting the participation of disabled children and young people in positive activities requires much more than making a service inclusive.
- The provision of information about positive activities needs to be improved and some families will need active support to identify and join positive activities provided.
- Opportunities to access positive activities need to be provided in inclusive settings and in 'disability only' groups. The most appropriate setting will differ according to children and young people's own preferences, the nature of the child's impairment, and the type of activity.

1.2 Implications from the research for service improvement

- Existing services need to examine whether the services they believe to be inclusive are truly inclusive, and whether they are meeting the requirements of the Disability Discrimination Acts (GB. Statutes 1995, 2005).
- Inclusive services need to be properly resourced in terms of the skills of the staff working in these settings, staff numbers and the physical environment.
- In terms of play services, at least, staff need to assume an active role in facilitating play and interaction between disabled and non-disabled children, *and* between disabled children. All staff working in such settings should have these skills.
- The numbers of disabled children and young people participating in or accessing positive activities available in their locality should be monitored.
- There is a need to conduct 'access audits' of generic play, leisure, sport, arts and cultural facilities to ensure that they are inclusive.
- Staff working in mainstream play, leisure and recreation facilities should be trained in disability awareness. These services or settings should operate a zero tolerance of bullying policy and actively work to ensure this is adhered to, paying particular attention to preventing bullying directed at disabled children and young people using their facilities.
- An information strategy should be developed that brings together local agencies and embraces the statutory, private and third sectors. This will enable disabled children, young people and their families to access and participate in the full range of universal and specialist services available to them.
- There should be opportunities for disabled children and young people to participate in both integrated and segregated positive activities, with decisions about the more appropriate settings being informed by individual preferences and the best available evidence.
- Limited exposure to non-disabled children's play interferes with disabled children's social development, particularly in terms of their understanding of peer culture. This can make it difficult for them to integrate in inclusive settings. Providing opportunities to

play and interact in inclusive play and leisure settings throughout childhood will help to ameliorate this difficulty.

- Efforts need to be made to improve access to sport outside of school for disabled children and young people.
- Consultation activities regarding the development of services which provide positive activities need to involve or represent all groups of disabled children and young people.
- All groups of disabled children and young people should be supported to actively participate in the development and evaluation of the services that they receive.

1.3 What does the research show?

Access

- The available evidence suggests that inclusive practice is more likely to be found in children's centres than extended schools and youth services. It seems that there have been increases in the numbers of disabled children using out-of-school clubs and play schemes and in inclusive practice in these settings. However, parents of primary school-aged disabled children in mainstream schools are most likely to report that extended school provision does not meet their needs.
- There is some evidence that disabled children and young people are less likely to be accessing out-of-school clubs and activities. Evidence from the United States would suggest that fewer disabled children and young people are likely to be engaging in positive activities compared to their non-disabled peers, and that the range of activities participated in is smaller.

Impact on outcomes

- There is some evidence that participating in positive activities impacts positively on disabled children's outcomes in terms of physical and psychological wellbeing.
- Using inclusive services and mainstream community facilities can be a negative experience for disabled children and young people because of the negative attitudes and behaviours of peer group users, staff and members of the public.
- Taking part in positive activities can be an important source of enjoyment for disabled children and young people. It would appear that the social aspects of doing a positive activity can be as, or even more, important as the activity itself.
- Playing and interacting in inclusive play and leisure settings helps disabled children's social development, particularly in terms of their understanding of peer culture. It ameliorates the effect of limited exposure to non-disabled children's play, which can make it difficult for children to integrate in inclusive settings.
- The opportunity to experience success has been identified as a further potential outcome of participating in positive activities. More specifically, positive activities can allow disabled children and young people to learn and develop skills, both those specific to an activity (for example, a particular sport) but also more generic life skills.

- Positive activities can also provide a means by which disabled children can make a positive contribution to their local communities. There is evidence that inclusive positive activities help to promote disabled children and young people's sense of belonging to their local community.

What works?

Using the findings from a number of studies it is also possible to identify what the current evidence tells us about the way inclusive services should be resourced, structured and delivered. Inclusive services tend to:

- develop a workforce which is skilled in a number of areas including communication, facilitating inclusive play, disability equality and knowledge of individual children's needs and abilities
- have a shared responsibility for supporting inclusion, as opposed to a single member of staff assuming that role
- create a physical environment that is physically accessible and that takes into account the need to provide for quiet and busy or active spaces
- offer a range of inclusive activities, including taster sessions
- support families and/or children to identify and use services
- address transport issues, for example by providing door-to-door support.

Providing opportunities for disabled children and young people to participate in both integrated and segregated positive activities, with decisions about the more appropriate settings being informed by individual preferences and the best available evidence, is also important.

1.4 What's missing from the evidence base?

- The evidence base is limited in terms of the number of studies, their scope and their quality. Further high-quality research in this area is to be welcomed.
- There is an absence of any detailed knowledge of the out-of-school lives of disabled children and young people, and the extent to which they have opportunities to participate in positive activities.
- There are very few rigorous evaluations of the impact of taking part in positive activities and/or using inclusive services on disabled children and young people's lives.
- To date, research has not properly explored the experiences of children and young people with profound and multiple learning difficulties, and of some groups of children and young people with autistic spectrum disorders.

2. Purpose and scope of the review

The purpose of this review is to investigate the evidence base on improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities. C4EO will use the knowledge review to underpin the support it is providing to children's trusts to help them improve service delivery, and ultimately outcomes for children and young people.

This review builds on a scoping study which assessed the nature and strength of the evidence base and provided an initial overview of trends in the literature aims. The review aims to provide:

- the best research evidence from the UK – and where relevant from abroad – on what works in improving services and outcomes for children and young people
- the best quantitative data on a thematic priority with which to establish baselines and assess progress in improving outcomes.

(Please see Appendices one and two for details of how literature was identified and assessed.)

The review will be followed by a full knowledge review, which will incorporate:

- the best validated local experience and practice regarding the strategies and interventions that have already proved to be the most powerful in helping services improve outcomes

This is one of three reviews about child disability. The others focus on providing early interventions and differentiated services to disabled children.

2.1 Review questions and definitions

The review looks at four questions, which were set by the C4EO Theme Advisory Group (TAG), a group of experts in disability policy, research and practice. These were:

- What evidence is there of practice in children's centres, extended schools and youth services that fully includes disabled children and young people?
- What do disabled children and young people think about the positive activities on offer (including access to physical activities) in their area, and how can their awareness of activities on offer be increased?
- What support is needed for children and young people to access inclusive activities?
- What evidence is there that improving access to positive activities improves the wellbeing of disabled children and young people?

The review covers all disabled children and young people, but excluded literature where:

- mental health problems were the disabled child's primary diagnosis

- children with attention deficit hyperactivity disorder (ADHD) were considered
- learning difficulties or disabilities were mentioned solely in relation to education (dyslexia, for example).

The following definitions were agreed by the Thematic Advisory Group:

For the purposes of this study, the research team adopted the definition of '**disability**' given in the Disability Discrimination Act 1995: 'a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities' (GB. Statutes 1995).

References to **positive activities** covered leisure-time activities outside of school hours and taking place in, or being delivered by, children's centres, extended services, youth services, school-based extra-curricular activities, play and leisure services, sports and recreation services, and the arts. Specific activities included sports and physical activities, performing and creative arts, courses and other learning-related activities (outside of school hours), visits to cinema, theatre and events, museums, galleries and places of interest, youth groups and other activities.

The term '**outcomes**' is interpreted broadly in relation to the five Every Child Matters outcomes: Be Healthy, Stay Safe, Enjoy and Achieve, Make a Positive Contribution and Achieve Economic Wellbeing.

While there may be a perception that there is a common understanding of '**inclusion**' in terms of what it means for disabled children and young people, in reality it is interpreted in different ways and can happen at different levels. Thus inclusive services can be interpreted as:

- *pseudo-inclusion*: mainstream provision which accepts disabled children and young people, but there is no or little evidence of resourcing or active work to support their participation in activities and social integration
- *active inclusion*: provision which is designed and resourced to facilitate disabled children's participation in activities and interaction between disabled and non-disabled children
- *opportunity inclusion*: provision for disabled children or young people only but which allows them the opportunity to take part in or experience the same activities and opportunities as non-disabled children.

Research pertaining to all these definitions or interpretations of inclusion was included in the review. However, care has been taken to explore the impact of these different interpretations of inclusion on services and disabled children and young people's experiences and outcomes. A similar approach was taken to research about positive activities. Some positive activities may be 'inclusive' in terms of a shared service, but other positive activities are separate or 'segregated' for disabled children.

3. Policy context

It is widely accepted that social exclusion is a common experience of disabled children and young people and their families. These CYP face social and environmental barriers to participating in opportunities and experiences which non-disabled children and families take for granted. Sometimes, additional support is required to enable disabled children and young people to experience the everyday experiences of childhood and adolescence. The right to engage in play and recreation is a human right and one, it has been argued, that most defines what childhood is (UN Convention on the Rights of the Child). It is essential, therefore, that generic policy activity and consequent developments in services around child care, play and leisure, sport and recreation, and youth services incorporate and respond to the needs and desires of disabled children and young people and their families.

Feeling healthy, having fun, enjoying, experiencing success and learning new skills are key features of the Every Child Matters outcomes framework (DfES 2003). Play and recreation, and having opportunities to take part in hobbies, arts, sporting or cultural activities, clearly provide a means by which these outcomes can be achieved, and this is reflected in Government policy.

Services for children, young people and their families have changed, or are changing as a result of the Every Child Matters programme. Children's centres, extended schools and youth services are central delivery mechanisms to support positive outcomes for children and young people. The Government's vision, set out in 2004, is that by 2010 every community in England will have a Sure Start children's centre (DfES 2004). The following year, the Government published its plans for extended schools (DfES 2005a) which, again, were seen as playing a key role in ensuring that children and young people achieve positive outcomes.

Local authorities are also responding to the requirements of the Childcare Act 2006 (England and Wales. Statutes 2006). This has placed requirements on local authorities to improve the outcomes, and reduce the inequalities of outcomes, of all pre-school children. It has also placed new duties on local authorities in terms of the extending the availability of childcare for working age parents. For older children this is likely to include positive activities. The Act also requires local authorities to provide information in accessible formats to parents, children and young people on the full ranges of local facilities. These requirements are therefore relevant to the provision of positive activities and out-of-school services for disabled children and young people.

The Government is committed to improving access to play and positive activities for all children and young people. The Children's Plan set out clear policies on play, puts forward a national play strategy, and was accompanied by a not insubstantial investment in play services (DCSF 2008).

Government attention has also focused on older children and teenagers with the publication of the Ten-year Youth Strategy, which sets out a strategy to transform leisure-time opportunities, activities and support services for young people in England (HM Treasury and DCSF 2007a). This builds on earlier policy documents for youth services

(DfES 2005b, 2006b) in which the importance of participating in sports, constructive activities in clubs, groups or classes and volunteering was emphasised, and the following national standards for young people's access to positive activities were set out (DfES 2005b):

- two hours per week of sporting activity
- two hours per week of other positive activities in clubs, youth groups or classes
- opportunities to contribute to their communities through volunteering
- a wide range of other recreational, cultural, sporting and enriching experiences
- a range of safe and enjoyable places in which to spend time.

The Disability Discrimination Act (GB. Statutes 2005) is another important lever for change in terms of improving disabled children and young people's access to services and facilities in their local communities. The Act places a duty on all public bodies to promote equality of opportunity for disabled people and to remove barriers to participation.

As well as being of key importance to general children's policy, the questions posed by this review are highly relevant to other policy areas. Recent Government policy on promoting a healthy weight is also focusing attention on children's physical activities and the way they spend their out-of-school time (HM Government 2008). Daily physical activity is part of the National Indicator set. Earlier guidance on promoting physical activity among children highlighted the need to "recognise and prioritise" physical activity opportunities for disabled children and young people (DoH 2005 p 13).

In addition, two key activity areas within Aiming High for Disabled Children (HM Treasury and DfES 2007b) – short breaks and individual budgets – are concerned with children and young people's everyday lives and, specifically, how children and young people have opportunities, or can be enabled, to take part in activities of their own choice, and which are enjoyable and enriching. An understanding of what is known about how best to achieve this will enable local policy implementation and service development to make changes which, hopefully, will make positive differences in the lives of disabled children, young people and their families.

In summary, there are currently a wide range of policy initiatives and developments that either require or provide opportunities for improving access to inclusive and positive activities by disabled children and young people. The publication of this review is therefore very timely and, in presenting the best available evidence, an important resource to those involved in implementing policy and overseeing change at a local level.

4. Are children's centres, extended schools and youth services fully including disabled children and young people?

Children's centres, extended schools and youth services are central delivery mechanisms in Government, to support positive outcomes for children and young people. This section of the review looks at how fully they are currently including disabled children and young people.

Key messages

- Evidence from Sure Start shows inclusive provision is possible; however, increasing the quality of early years provision is not necessarily associated with similar improvements in inclusive practice and provision
- Inclusive practice is more likely in after school clubs/ play schemes than activities / facilities provided by leisure and sports centres
- Services are interpreting inclusion in different ways. Sometimes 'inclusive services' are in fact not inclusive.
- More attention needs to be paid to inclusion by youth services.
- Inclusive practice is more likely to be found in out of school clubs / play schemes than extra-curricular activities.

4.1 Youth services

There is virtually no information available on the extent to which youth services are inclusive, nor the numbers of disabled young people accessing youth services.

Every Disabled Child Matters (EDCM)'s (2006) analysis of a sample of local authorities' Children and Young People' Plans (CYPP) found that only five out of 20 CYPPs referred to disabled young people in their plans for youth services. Where CYPPs did refer to disabled young people, they referred to policy development work or reports of existing arrangements, rather than to new activities. Bradford *et al's* (2004) research for the National Association of Clubs for Young People reports that just seven per cent of its users are 'registered disabled'.

An important part of youth service reform are the Empowering Young People Pilots (EYPPs). These ran from October 2007 to March 2009 in nine local authorities and aimed to encourage disadvantaged young people¹ to take part in positive activities of their

¹ Disadvantaged young people are defined by EYPP as young people in care and/or eligible for free school meals, or subgroups within this group. However, some local authorities also specifically include young disabled people (defined as those with special educational needs or learning difficulties and/or disabilities) within their target groups (Beilby *et al* 2008).

choice. Funding was provided, which removed the financial barriers often encountered by young people travelling to, accessing or attending an activity.

An evaluation of these pilots has been conducted, and interim findings showed that among the disabled young people living in the EYPP pilot areas were less likely to have participated in a range of activities than respondents with non-limiting illnesses or no disabilities. (Hewton *et al* 2008). These activities included sporting activities, performing and/or creative arts, courses or learning-related activities and having been to the cinema or theatre.

Information about the impact of EYPP on disabled young people's participation in positive activities should be available later this year. At this stage, however, there is very little information about disability-specific issues encountered by the pilot sites.

4.2 Extended schools

The evidence provided by evaluations of extended schools is generally extremely limited in terms of what it tells us about practice relating to ensuring the inclusion of disabled children and young people (for example, Cummings *et al* 2004, 2006). However, the most recently completed study, which surveyed over 3,600 schools and a randomly selected sample of families (Wallace *et al* 2009), does report that parents of primary school-aged children with special educational needs were least likely to feel their needs are being met by current activities and childcare provision. This research also found that extended school provision is less likely to be used in special schools compared to mainstream schools.

A regional evaluation of extended schools across 10 local education authorities (East Together and Sure Start 2005) provides further evidence on the inclusion of disabled children. It suggests the extent of inclusive practice within extended schools varies, depending on the type of scheme or activity. Thus, while all schools reported that all children were welcome to join extra-curricular activities (with the majority being physically accessible), developing more appropriate and accessible extra-curricular activities for disabled children and young people was seen not as a priority. More progress appeared to have been made in inclusive practice terms of out of school clubs and play schemes, with clubs actively addressing this issue, either by providing specialist and/or inclusive schemes/sessions. Secondary analysis of after-school and holiday child care schemes across England and Wales registered with the Kids' Clubs Network in 1996/97 found that, at that time, inclusive practice was decreasing (Smith and Barker 2000). The evidence presented here suggests that trend has been reversed and that, over the past 10 or so years, inclusive practice in out-of-school clubs and play schemes has increased.

4.3 Children's centres

National and regional evaluations of Sure Start activities provide some evidence of work by children's centres to ensure inclusive service provision. However, evidence regarding the national picture on inclusive practices within children's centres was not identified.

An investigation into SSLPs² in twelve local authorities identified as working innovatively in terms of inclusive practice and provision (Pinney 2007) reports that increased availability of inclusive activities/sessions, alterations to the built environment, improved staff skills, and flexible staffing and funding arrangements, had enabled these services to be better equipped “for inclusion and participation by children with special needs and disabilities and their families” (p 25). Examples of inclusive practice given in the report include: inclusive crèche and play sessions, home-based learning, skilled childminders and outreach to support children’s inclusion in the setting of their parents’ choice. This suggests that, at least in some areas, the service development strategies and activities of children’s centres are addressing inclusion of disabled children and their families. At the same time, the report notes that increased early years provision – even high-quality provision – did not necessarily mean an increase in inclusive provision.

4.4 Further evidence

There is further evidence on inclusive play and leisure provision which is not located within specific evaluations of children’s centres, Extended School of Youth Matters, but is relevant nonetheless.

Inclusive play and leisure provision

Differing interpretations of inclusion was an issue identified by Ludvigsen *et al* (2005) in their evaluation of the Better Play Programme. This was a programme which funded 225 play projects across England between 2001 and 2005. Ninety-four of the projects were inclusive play projects. The evaluation of these projects, through a survey of all inclusive projects followed by a detailed exploration of eight case study sites, revealed a number of different ‘interpretations’ and approaches to inclusive provision:

- *Provision together*: here play provision was offered to disabled and non-disabled children during the same session. Within this, there were conflicting views in terms of the type of support or service provided, either it consisted of:
 - disabled children accessing or accommodated within mainstream provision but without additional support/resources/planning to facilitate participation of disabled children and interaction with non-disabled children, or
 - play provision which was designed and adequately resourced to allow participation by disabled children.
- *Separate provision*: here disabled children were being provided with the same play opportunities as non-disabled children, but at different times or in different venues.

The ‘separate but the same opportunities’ approach was much less common and presented by providers as provision which would then lead to integration of the two groups. However, it should be noted that this was not achieved during the period of the research.

² Sure Start Local Programmes were set up to provide integrated support to young children and families living in many of England’s most disadvantaged communities. ‘Special needs’ was one of five core services which SSLPs were required to deliver.

Practice regarding inclusive play and leisure activities across England was mapped in 2005 by the English Federation of Disability Sport (Kelly 2005). A lack of comprehensive information at a local authority level of inclusive sport and leisure provision was noted. And, whilst examples of apparent good practice³ in play and holiday schemes were identified, such practice was not found to be comprehensive either within or across local authorities.

Follow-up case work in six local authorities provides some more detailed information about inclusive play and leisure provision in one region, though this needs to be treated with caution due to poor response rates to the postal survey used in the research. However, the findings do agree with those of Ludvigsen *et al* (2005) in terms of varied interpretations of 'inclusion' with consequent impacts on service provision. However, unlike Ludvigsen *et al* (2005), Kelly did find instances where 'separate provision' had developed or evolved into 'provision together'.

Murray's research on disabled teenagers' experiences of accessing inclusive leisure identified a further, essential, element to a definition of inclusion, making the point that the test of whether leisure services are truly inclusive is whether they allow a young person to pursue their own leisure interest (Murray 2002). The author concluded that there was "little evidence" of statutory agencies providing the individual support required to enable this to happen.

There is some evidence from Kelly's (2005) survey that 'provision together', rather than 'separate provision' is more likely to be found in after-school clubs and holiday play-schemes than activities provided by leisure and sport centres. However, sometimes separate sports provision was the outcome of enthusiasm for a particular sport among disabled people (for example, wheelchair basketball). Kelly also reports that separate provision was sometimes being scheduled into school hours, thus becoming a school activity as opposed to a leisure opportunity. Finally, qualitative evidence from focus groups with parents suggest that there may be more opportunities for disabled children to access holiday play schemes than after-school clubs, and that the fewest opportunities for participation were experienced by children with the most complex or profound needs.

³ It is not clear how judgements about good practice were made, and on what evidence.

5. What do disabled children and young people think about the positive activities on offer in their area?

This section of the review looks at disabled children and young people's views on the positive activities on offer in their area. In assessing this evidence, we have included research evidence on the type of positive activities disabled children and young people take part in locally, what they enjoy about these positive activities and what they find difficult. See Appendix 1 for further discussion of the evidence base.

Key messages

- Children and young people value the social aspects of taking part in positive activities.
- Disabled children and young people are less likely to be taking part in positive activities than their non-disabled counterparts.
- Children and young people with learning difficulties, autism and multiple impairments are least likely to be participating in positive activities.
- Disabled children and young people want more choice in the positive activity opportunities available to them; this is especially the case for older children and teenagers.
- Supportive staff with good disability awareness, accessible provision and affordable activities can facilitate disabled children and young people participating in positive activities.
- Raising children, young people and families' awareness of positive activities on offer is important. Information needs to be accessible and available in a range of formats. For some children, taster sessions are the only effective way of providing information about an activity.

5.1 Levels of participation in positive activities

There is very little robust national data about the out-of-school lives of disabled children and young people, including their participation in positive activities.

The most significant dataset comes from Finch *et al's* (2001) national survey of over two thousand disabled children and young people about their sporting activities, which also looked more widely at participation in non-school clubs and activities. Their data was compared to a previous survey of non-disabled young people and revealed that disabled young people were less likely than non-disabled young people to be:

- a member of a sports club outside of school, compared to non-disabled young people (12% versus 46%)
- participating in Girl Guides or Boy Scouts (11% vs 25%)
- a member of a youth club (8% vs 20%)

- a member of a church or religious club (4% vs 7%).

Meanwhile, Wallace *et al* (2009) found that children attending special schools were less likely than children attending mainstream schools to be using schools for supervised activities and clubs. Only 36 per cent of pupils at special schools used them for supervised activities and clubs, as opposed to 51 per cent in primary schools and 46 per cent in secondary schools.

PricewaterhouseCoopers' (2006) investigation for the Department for Education and Skills (DfES) into the market for positive activities among young people drew on existing datasets and qualitative work with young people and practitioners in six local authorities. It concluded that disabled young people were less likely to be participating in positive activities. It also reports that there is evidence that, in terms of providing positive activities, disabled young people were perceived by practitioners as a hard-to-reach group who presented additional challenges to service providers.

These findings concur with those of research conducted in other countries. For example, a large scale survey conducted in the United States (Wagner *et al* 2003) found that disabled children and young people are less likely to be participating in positive activities than their non-disabled peers. Wagner *et al* (2003) also found that levels of participation in positive activities were associated with types of impairment of disability, with children and young people with learning difficulties, autism or multiple disabilities being the least likely to be participating in positive activities.

5.2 What disabled young people enjoy about positive activities

The value young disabled people attach to play and leisure activities which enable them to maintain existing friendships and develop new ones is commonly reported in research and appears to be an important and valued aspect of participating in positive activities (Aitchison 2000; EDCM 2008; Keil *et al* 2001; Ludvigsen *et al* 2005; Murray 2002; Petrie *et al* 2007; Thompson *et al* 2000; Turner 2003).

In Murray's (2002) exploration of disabled teenagers' experience of access to inclusive leisure, many attributed positive value to the existence of segregated clubs and holiday schemes. This was because they were a place where teenagers built friendships and were sometimes the main source of friendship if the young people were socially isolated at mainstream school.

Aitchison (2000) reports that this social component of activities influenced leisure time preferences among the fifteen young people with cerebral palsy participating in her research. Thus, organised social and leisure clubs were valued more than formal activities at leisure or sports centres. Aitchison notes that the social opportunities and benefits of participating in positive activities do not receive strong emphasis within policies on promoting positive activities among young people. However, it is clear that, for disabled young people at least, this can be an important factor which will affect whether or not they participate in positive activities, and what activities they choose.

5.3 Barriers and facilitators to accessing positive activities

While the literature focuses on the barriers to participation, it is possible to infer potential facilitators from the evidence. These facilitators are:

- giving disabled children and young people access to a wide range of activities.
- providing opportunities to take part in positive activities both alongside their non-disabled peers but also just with other disabled children and young people.
- using buildings and facilities that are accessible.
- in mainstream and community settings, having trained staff who have good disability awareness and positive attitudes towards disabled people.
- ensuring that activities are affordable.
- providing families with multi-agency, multi-sector information about the positive activities available to disabled children and young people.

The barriers to participation are explored in more detail below.

Young disabled people and their parents recognise that their own, or their child's disabilities, sometimes make participation in a positive activity too difficult. The blind and partially sighted young people in Keil *et al*'s study (2001) cited their level of vision as the most common reason for not taking part in physical activities. Kelly (2005) found that parents of children with complex needs were realistic about how these needs often limited inclusion, because certain games required too high a level of dexterity or coordination. Furthermore, Lewis *et al* (2007) note that there are 'generic' reasons for disabled young people's lack of participation in activities which are not necessarily related directly to their disability. These include not wanting to take part, being shy, lacking confidence, preferring home-based activities, and changes in childminder arrangements. Nevertheless many of the studies in this review frequently note other barriers to participation: these are detailed below.

A lack of opportunity

Disabled children, young people and their families want more and different things to do so that they can choose where and how they spend their free time (EDCM 2007a and b, 2008; Keil *et al* 2001; Kelly 2005; Petrie and Poland 1998; Petrie *et al* 2007; Turner 2003).

Turner's (2003) consultation with 105 disabled children in Wales about the services they use reports that some young people felt they were missing out on a social life because there were few things to do in their area. This was especially the case for older young people who did not want to attend play schemes and clubs. Some spoke of not having a choice of activities, and not being able to attend activities with their friends. Choice was also important to the parents who took part in Kelly's (2005) study of sport, play and leisure facilities in six local authorities in southeast England. They wanted their children to have a choice of both inclusive and 'separate' provision locally. Separate provision, however, did not mean different provision but similar provision specifically developed for disabled children. Petrie *et al* (2007) found that some disabled children would have liked the chance to compete in sports events with children with similar abilities to their own.

Robust evidence on the lack of provision for young disabled people is provided by Keil *et al*'s (2001) study exploring the lives of blind and partially sighted children out of school. They found that the fifth most commonly reported thing (and reported by one in ten research participants) that would make life better for this group was more leisure facilities. A greater proportion wanted activities specifically for blind and partially sighted children and young people than inclusive activities.

Inaccessible provision

Various studies report on the inaccessibility of generic play, sport, and leisure facilities (Keil *et al* 2001; Ludvigsen *et al* 2005; Petrie *et al* 2007; Shelley 2002; Widdows 1997) and arts and culture venues (Shelley 2002; Mencap 2008). Access issues could be with respect to accessing the building or the lack of inclusive facilities (parking, toilets and changing facilities).

Staff in mainstream settings

Within mainstream facilities and venues, poor disability awareness on the part of staff was frequently cited as a barrier to participation for disabled young people in positive activities (EDCM 2008; Keil *et al* 2001; Kelly 2005; Ludvigsen *et al* 2005; Petrie and Poland 1998; Petrie *et al* 2007; Turner 2003). Parental concerns about staff skills regarding the support needs of disabled children and young people have been identified as a barrier to children undertaking positive activities in mainstream settings (Kelly, 2005). In addition, there is evidence of disabled children and young people being excluded from mainstream positive activities, or their level of participation constrained, due to misinformed staff (Keil *et al* 2001; Petrie *et al* 2007).

Interestingly, in Keil *et al*'s study (2001), trained staff was cited as the single most important thing that would make life easier for blind and partially sighted young people. Similarly, in Petrie *et al*'s (2007) study of young people with physical disabilities and sensory impairments reported a desire to be part of the mainstream experience, but also the need for greater understanding of their needs on the part of service providers.

Bullying and negative attitudes

Disabled children and young people report being bullied in inclusive and mainstream leisure and recreation settings (Mencap 2007). Public attitudes are identified by young disabled people as a barrier to participating in positive activities (EDCM 2008; Keil *et al* 2001; Mencap 2008).

Similarly, parents describe how discrimination and negative attitudes from staff and members of the public can make the experience of attending inclusive leisure facilities or mainstream arts and culture venues uncomfortable or distressing for disabled children and young people and their families (Widdows 1997; Mencap 2008; Shelley, 2002; Keil *et al* 2001).

Financial costs

Finally, the cost of taking part in positive activities is a difficulty reported by some families (for example, Finch *et al* 2001; Keil *et al* 2001).

5.4 How can families' awareness of positive activities on offer in their area be increased?

Receiving relevant information is the first step towards accessing positive activities for disabled young people. However, the evidence identified by this review suggests that families often struggle to find out what positive activities are on offer in their area because information is lacking, misleading or fragmented. It can also be inaccessible to disabled children and young people.

A lack of information

Several studies report that lack of information is a frequently reported barrier to disabled children and young people accessing leisure and sporting opportunities. This can be because families or young people themselves are unaware of local provision and therefore do not use it (Shelley 2002; Keil *et al* 2001; Thompson *et al* 2000; Audit Commission 2003; Turner 2003; Kelly 2005; Murray 2002; Petrie *et al* 2007). Alternatively, it can be because the information available does not provide sufficient detail on how their child's needs can be met in that setting. Here, this could be in terms of practical issues associated with using a facility or venue (for example, parking, toilets/changing facilities, arrangements to avoid queuing) (Mencap 2008; Murray 2002), about the skills and qualifications of staff (Kelly 2005), and/or a lack of clarity as to whether a generic service is inclusive (Petrie *et al* 2007).

Barriers to being informed

A number of barriers to receiving information about positive activities taking place locally have been identified by research and consultation exercises. These include:

- lack of routine, proactive information provision by local authorities (Kelly 2005; Petrie *et al* 2007, Turner 2003)
- lack of clarity within local authorities regarding roles and responsibilities for providing information to families (Kelly 2005)
- fragmentation of information provision (Kelly 2005; Audit Commission 2003)
- information provision restricted to existing users only with no system or strategy for how other families (non-service users) could receive information (Kelly 2005; Murray 2002)
- non-specialist provision not indicating whether or not the service is inclusive (Petrie *et al* 2007; Kelly 2005).

Meeting children and young people's and parents' information needs

Information provision to families with disabled children, and to children and young people themselves is well known to be problematic (for example Mitchell and Sloper 2002). We know from other research on meeting families' information needs that they prefer a 'one-stop shop' approach whereby information can be accessed from a central point.

It is also important that the information provided is accessible, and a range of formats is therefore necessary in order that all children, young people and their families have information which they can use. Disabled young people taking part in consultation

exercises for Every Disabled Child Matters (EDCM 2007a, 2008) requested that information be provided in written and pictorial forms, as well as spoken information. Turner's (2003) consultation work in Wales similarly identified the need to use different mediums to pass on information. Turner also notes that the language used is as important as the medium; she gives the example that children and young people do not use the word 'service', 'staff' or 'professionals', but instead tend to refer to staff as their friends or, for example, 'the lady who does....'.

A clear message from three of the studies is that written or visual information alone is sometimes not sufficient for a child or young person or a parent to decide whether or not a service or facility is for them. Sometimes trying out a sport or activity on a couple of occasions or visiting a service or attraction and having one or more 'taster' sessions are critical parts of the information-gathering process and are necessary steps before a decision about whether or not to use a service or pursue an activity can be made (Kelly 2005; Murray 2002; Mencap 2008).

6. What support is needed for children and young people to access inclusive activities?

In this section we identify the support that disabled children and young people need to access inclusive activities. We have taken a broad view of what might be helpful in understanding the support disabled children and young people may need to access inclusive activities and, in particular, have included what is understood about the barriers to inclusion as well as what research tells us about what supports inclusion.

How robust and transferable these research findings are varies enormously across this collection of evidence. In addition, there are significant gaps in the coverage within these types of evidence in terms of age, type of impairment or disability, and type of provision or facility. See Appendix one for further discussion of the evidence base.

Key messages

- A skilled and knowledgeable workforce working proactively to support inclusion – in activities and social interactions – is essential to inclusive practice.
- Families may need support and encouragement to access an inclusive activity.
- In mainstream community settings and venues, provision needs to be disability **and** family friendly.

6.1 Facilitators and barriers to participation in ‘inclusive activities’

A very wide range of factors have been identified as hindering or supporting participation in inclusive activities – see Box 1. This clearly illustrates that, while very important, improving participation in inclusive activities requires more than addressing service-specific barriers to inclusion.

Box 1: Factors affecting participation in inclusive activities**Factors essential to inclusive practice and inclusive services**

- Good workforce skills and knowledge
- all staff working pro-actively to support and facilitate inclusion
- offering activities which support and facilitate inclusion
- tailored support which meets the needs of participants
- support to the service from health professionals
- continuity of staff and venue.

Issues for disabled children, young people and their families

- Cost
- parents' support needs
- having someone to go with (or not)
- perceptions of own competence and physical abilities
- social skills
- transport.

6.2 Key aspects of the service**Workforce skills and knowledge**

A lack of staff skills was perceived to be a key barrier to developing or extending inclusive services (Thompson *et al* 2000; Mohay and Reid 2006; East Together and Sure Start 2005).

A number of skill areas have been identified by researchers, including:

- staff disability and inclusion aware (Pinney 2007)
- inclusive play techniques (Ludvigsen *et al* 2005; McIntyre 2007)
- skills that allow informed risk-taking, which allowed for rich experiences (Petrie 2000)
- behaviour management skills (Petrie 2000)
- administering medication (Thompson *et al* 2000; Petrie *et al* 2007)
- toileting and other self-care activities (Thompson *et al* 2000)
- knowledge of impairments, disabilities and health conditions (Thompson *et al* 2000)
- awareness of *each* child's developmental stage (Hanson *et al* 1998).

Petrie (2000) report that staff without training in these areas were disadvantaged. It would also appear to be important that *all* staff are adequately trained (Hanson *et al* 1998; Petrie *et al* 2007). Parents will avoid services or facilities perceived to have unhelpful or unsupportive staff (King *et al* 2006).

Staff working proactively

A number of qualitative studies have identified the role of staff in facilitating inclusion – this was in both ‘inclusive’ and ‘segregated’ settings. Three key roles have been identified:

- providing, fostering or modifying activities in which all children can participate (Hanson *et al* 1998; Petrie 2000; McIntyre 2007)
- interpreting disabled children’s behaviour and/or verbalisations and/or social overtures for non-disabled children and correcting non-disabled children when they ‘misinterpret’ disabled children’s behaviour/misbehaviour (Hanson *et al* 1998)
- supporting and facilitating friendships between disabled and non-disabled children and young people and between disabled children and young people (Murray 2002; McIntyre 2007).

The nature of the activity

The nature of the activity within a setting can facilitate or act as a barrier to disabled and non-disabled children playing together (for example, Ludvigsen *et al* 2005; McIntyre 2007). Nabors *et al*’s (1999) rigorous observational study of children aged from two to five with and without special educational needs in playground settings found that disabled and non-disabled children were 20 times more likely to be observed doing low-demand activities together (those involving gross motor skills, for example using the playhouse, outdoor play equipment, running/chasing) than complex activities (for example the use of art materials or small manipulative toys, and water or sand play). It is also important to remember that, especially among older children and young people, individual preferences will determine whether or not a child or young person takes part in an activity (King *et al* 2006).

The availability of tailored support

Some children will require higher than usual levels of support and a small minority will need one-to-one support from a member of staff to access a play or leisure service (inclusive, mainstream or specialist) and to participate in activities taking place there (Ludvigsen *et al* 2005; Shelley 2002; Lewis *et al* 2007; Petrie *et al* 2007; Murray 2002). Murray (2002) reported that the level of support might not be high but needs to be constantly available. Parents are often the people who are supporting their children’s participation in mainstream activities (Kleinert *et al* 2007; Aitchison 2000), which suggests that children without parents who are able or willing to play this role will need to access that support in some other way. Murray (2002) also notes highlights the need for communication support (for example, someone who can interpret and/or assist the child/young people with their communication aid), the absence of which can act as a barrier to participating in ordinary leisure pursuits.

Physical access

It is likely that adjustments and adaptations in the physical environment will be required in order to give disabled children access to more activities. This is especially the case where a service is changing from being a mainstream to an inclusive service (Thompson *et al* 2000; Ludvigsen *et al* 2005; Pinney 2007). However, even segregated positive activities were sometimes reported to be inaccessible to some groups of users (Audit Commission 2003; Petrie *et al* 2007). Finch *et al*'s (2001) national survey of sport participation reports that physically inaccessible buildings, or lack of appropriate equipment or amenities within the venue, are barriers to participating in out-of-school sport that are particularly likely to be experienced by children and young people with physical impairments and self-care needs.

It should be noted that parents' perceptions of physical access to a venue (which might not match reality) are sufficient to prevent a family accessing a facility (King *et al* 2006), and again reiterates the importance of providing accurate and relevant information regarding this.

Support to the service from health professionals

Service providers identify the need for support from health professionals to enable them to deliver inclusive services (Mohay and Reid 2006). In a national evaluation of extended schools, staff working in extended mainstream schools reported wanting more support from speech and language therapists, disability or special needs professionals and school nurses, with these additional staff support needs being more likely to be reported by mainstream primary schools (Wallace *et al* 2009).

Continuity of staff and venue

A couple of studies report that parents and staff believe that continuity of staff and the venue at which an activity takes place can be important factors to ensuring a child continues to use a service (Petrie *et al* 2007).

6.3 Aspects of service provision that inhibit access for children, young people and families

Cost

Levels of family income are associated with levels of participation in positive activities. Evidence from a very robust US study showed that young people from wealthier households were significantly more likely to have taken part in extra-curricular activities, and particularly volunteer or community service activities, compared to lower-income groups (Wagner *et al* 2003).

Murray's in-depth qualitative research with over 100 disabled young people identified a lack of money as being a barrier to enjoying positive activities. None of Murray's participants were financially independent and were therefore reliant on their benefits or family for money.

Parents' support needs

The extent to which a family typically take part in social and recreational activities has been shown to influence a disabled child and young person's participation in leisure and recreation (King *et al* 2006). This suggests that some families will require more information and support to facilitate a child or young person's access to activities which the family would not have considered engaging in.

Other studies have identified the need to support children and families as they seek to identify activities to participate in. This may be in terms of providing information (see previous section), matching a child to a service or activities, facilitating taster visits to a service or activities, and/or liaising with the activity/service regarding the child's needs or requirements (Pinney 2007; Kelly 2005; Petrie *et al* 2007)

Alternatively, parents may need to be supported to allow their child to use the scheme (Ludvigsen *et al* 2005). Trust in a service may need to be built up, especially where families had had negative experiences of mainstream play activities in the past (Buttimer and Tierney 2005; Ludvigsen *et al* 2005).

Not having 'anyone to go with'

A number of studies flagged up how not having 'someone to go with' (this could either be a friend or a formal 'buddy') to an activity could be a barrier to a disabled child or young person using an inclusive service or to taking part in a positive activity (Turner 2003; Shelley 2002; Buttimer and Tierney 2005; Petrie *et al* 2007; Finch *et al* 2000). Finch *et al* found that this was more likely to be perceived as a barrier by older rather than younger children.

Perceptions of competence and physical abilities

A perceived lack of competence to do an activity and perceived poor physical abilities have been identified as a barrier to participating in team sports (King *et al* 2006; Taub and Greer 2000). Similarly, parents of older teenagers identified that not knowing how to do a leisure activity or play a sport was a barrier to their child participating in leisure and recreational activities (Buttimer and Tierney 2005).

Social skills

Two studies that used observational methods (Hanson *et al* 1998; Petrie 2000) reported that disabled children's lack of social skills and/or experience and/or 'developmental maturity to interpret the rules of peer culture' acted as barrier to inclusive play. Petrie (2000) refers to Kampman's (1997) notion of disabled children in special schools not having experienced the 'play apprenticeship' which children in mainstream schools acquire, resulting in them being unaware of the cultural forms and unspoken rules of non-disabled children's play.

Transport

Many families find they have to travel out of their local area to find suitable facilities or activities for their child (Shelley 2002). Some play and leisure schemes report parents find

accessing a scheme difficult because of the cost of transport or difficulties using public transport with their child (Thompson *et al* 2000; Ludvigsen *et al* 2005; Buttmer and Tierney 2005). Transport, including the inflexibility of school transport services, was also been identified as a barrier to accessing extended school activities (Pinney 2007; East Together and Sure Start 2005; Petrie *et al* 2007) and mainstream leisure services (Petrie *et al* 2007). In addition, some parents participating in Shelley's (2002) survey of out-of-school activities reported that lack of supervised transport was a barrier to their child participating in such activities. Murray (2002) reports that young people perceived public transport as 'unwelcoming' and limited in that it did not provide door-to-door transport.

6.4 Supporting access to and use of community facilities or venues

A small number of studies have looked specifically at access to and use of community facilities or venues.

Poor amenities or equipment or physical inaccessibility acted as barriers to families using such facilities. For example, low water temperature and unsuitable play equipment meant that families could not use local parks and swimming pools (Widdows 1997; Shelley 2002). Negative attitudes and a lack of support from staff also put families off using such places or were the reason for an unpleasant or unhappy outing (Widdows 1997; Shelley 2002).

Mencap (2008) report the only study identified by this review that specifically explored families' experiences of visiting arts and cultural events. A qualitative research project with six families with children with a range of impairments revealed the range of barriers which families can encounter when making such trips:

- car parking at a venue could be difficult, particularly if it is not possible to pre-book parking
- procedures for accessing the building could be confusing and complicated and served to draw attention to the child/young person
- a lack of seating in museums and galleries, and in lobby areas generally, could be a problem
- wheelchairs not provided by venues
- physical barriers restricted the views of children in wheelchairs
- the lack of sufficient numbers of accessible toilets and toilets which allow the family to stay together
- inadequate changing facilities, especially for older children
- queuing can be very difficult for some children
- the attitudes of some staff and members of the public can make children anxious and spoil the outing
- poor signage.

Finally, families described the dilemma of paying high ticket prices to an event or attraction when there was the risk that their child may not be able to cope with it or enjoy it, to such a degree that the visit has to be curtailed. Many of these barriers were also identified by Every Disabled Child Matters' consultation exercises with disabled children and young people and parents about changes they would like to see in their or their children's lives (EDCM 2007a and b, 2008). Participants in these projects also noted the importance of consultation with families to improve access and 'use-ability' of venues.

7. Does improving access to positive activities improve the wellbeing of disabled children and young people?

This section looks at whether improving access to positive activities improves disabled children and young people's wellbeing.

Key messages

- Participating in positive activities can have positive outcomes for children and young people's physical and psychological well-being.
- Positive activities can be a source of enjoyment and offer opportunities for experiencing success and learning new skills.
- The setting is important – taking part in positive activities in integrated settings *can* be a negative experience.

7.1 Physical wellbeing

There is some evidence that participating in positive activities improves physical health and functioning and improves emotional wellbeing. Here the evidence base pertains particularly to participation in sport.

Here sport has been found to be associated with improvements in fitness level, coordination, mobility, muscle strength and general fitness levels among children and young people with physical impairments (Aitchison, 2000; Cairney et al., 2005; Darrah *et al* 1999; Fragala-Pinkham *et al* 2006; Kristen *et al* 2002, 2003; Goodwin *et al* 2004; Taub and Greer 2000).

Petrie's qualitative evaluations of play services (Petrie and Poland 1998; Petrie 2000) describe the physical benefits to children of spending time in a place where space is less restricted and thus allowing greater freedom of movement and development of physical abilities.

7.2 Psychological wellbeing

Some studies have explored the impact of positive activities on aspects of psychological wellbeing.

The emotional or psychological benefits of participating in sport or other physical activities include children and young people feeling better about their appearance (Darrah *et al* 1999) and positive changes in self-identity (Goodwin *et al* 2004; Groff and Kleiber 2001), self-confidence (Lewis *et al* 2007; Kristen *et al* 2003) and beliefs about their abilities and potential (Taub and Greer 2000).

However, research has also identified factors which might moderate the positive benefits on psychological wellbeing of participating in positive activities. First, positive outcomes

are dependent on appropriate and sensitive support being provided in inclusive settings (Kelly 2005). Negative experiences such as poor staff or public attitudes, active exclusion, or bullying, all of which may be experienced when accessing inclusive positive activities, can threaten wellbeing, as set out in sections 5 and 6 (Murray 2002; Mencap 2007).

The type of activity and whether or not participation takes place in inclusive or 'segregated' settings or groups also appears to be an important factor in determining outcomes of participation. Research with young people with learning disabilities found that complex activities requiring a specific sports skill plus additional skills (such as team work or the need to respond to a rapidly changing situation) can lead to decreased self-esteem or experiences of failure, or can serve to draw attention to relatively poorer abilities. This effect was found to be exacerbated if the young person was taking part in 'complex or high-demand sports' or in events where disabled and non-disabled young people were participating (Ninot *et al* 2000). Taub and Greer (2000)'s research with children and young people with physical impairments also found that participation in an inclusive setting could be disheartening and lead to feelings of inadequacy, a loss of confidence and negative effects on self-esteem.

In contrast, a number of qualitative studies of children and young people's experiences of segregated positive activities all report a positive impact on self-reported self-confidence, based either on the accounts of the children and young people themselves and/or their parents (Kristen *et al* 2002, 2003; Murray 2002; Goodwin and Staples 2005).

7.3 Belonging

A number of small-scale exploratory qualitative studies have found children and young people reporting a sense of belonging or acceptance through participating in both segregated and integrated positive activities. These included, for example:

- wheelchair dance for children with spina bifida (Goodwin *et al* 2004)
- adapted sports programmes for young people with physical impairments (Groff and Kleiber 2001; Kristen *et al* 2002, 2003)
- inclusive sports/physical activities (Kristen *et al* 2003).

7.4 Enjoyment

Not surprisingly, enjoyment is a strong and consistent theme in research that has explored the outcomes of participating in positive activities. This refers to both liking the activity and having fun. This has been found across a wide range of positive activities including: participating in disability sports both at a competitive level (Martin 2006; Martin and Smith 2002) and in community settings (Kristen *et al* 2002, 2003); activities which take place in extended schools, particularly primary schools (Wallace *et al* 2009) and inclusive play and leisure services (Kelly 2005). A couple of qualitative studies also highlight the ways in which taking part in physical positive activities could be exciting (Kristen *et al* 2003) and provide opportunities for experiencing 'risky' activities such as climbing or riding a bicycle (Petrie and Poland 1998).

As well as enjoying the physical aspects of a sport, the evidence suggests that the social aspects of participating also contribute significantly to the experience of fun and enjoyment (Martin and Smith 2002). Some researchers have made the important distinction of the fun gained through social interaction (for example, Whitehurst's (2007) small-scale but in-depth evaluation of the outcomes of an inclusive drama project) and the fun gained through friendships experienced and shared during participation in a positive activity (for example Martin and Smith 2002), noting that either or both may be experienced.

7.5 Social outcomes

The social aspect of taking part in positive activities is a recurrent theme in the research evidence. Wagner *et al's* (2003) analysis of a national US dataset of over 9,000 young people aged 13 to 16 with a range of impairments found that young people who participated in extracurricular activities had more active friendships (as demonstrated by visits, phone calls and emails to friends, and invitations to social activities) than those who did not. What is not clear from this research is whether participation in extracurricular activities results in more active friendships or whether factors that increase the likelihood of having active friendships also make it more likely for a young person to participate in extracurricular activities. Keil *et al's* (2001) survey on the leisure lives of children and young people with visual impairments also found an association between having friends and joining in after-school activities.

The social outcomes of participating in segregated positive activities over a sustained period were explored by Martin and Smith's (2002) international research with 150 disabled athletes aged nine to 18. They concluded that participation in sport had the potential to enhance wellbeing by providing an opportunity to experience the positive benefits of friendship such as loyalty and intimacy. In-depth research with young people attending an adapted sports programme in the US (Groff and Kleiber 2001) also identified social interaction as supporting positive outcomes in terms of young people's self-identity.

Murray's (2002) and Goodwin and Staples's (2005) qualitative research with disabled young people participating in segregated positive activities found that being a member of a segregated leisure group allowed the development of relationships with peers with similar impairments, and that these relationships could be an important source of emotional support around shared experiences.

Looking at the research evidence on the perceived social benefits of participating in inclusive positive activities suggests, these *may* differ from those potentially experienced through participating in segregated positive activities. In terms of inclusive play projects for young children, parents and staff report the social benefits of playing and mixing with non-disabled children in the local community, as opposed to friendship development (Ludvigsen *et al* 2005; Hanson *et al* 1998). Similar themes are found regarding positive activities for older children (Widdows 1997; Whitehurst 2007). However, this difference may be spurious and the product of the types of activities researched and the research question.

Indeed, Kristen *et al* (2003) conclude from their qualitative evaluation of a specialist sports programme delivered in community sports clubs that, in an inclusive setting, a shared activity/interest can provide a starting point for friendship to develop friendships with both

disabled and non-disabled peers. Similarly, Taub and Greer's (2000) exploration of twenty disabled children and young people's experiences of integrated physical activities in and out of school identified strengthening social ties as a major outcome of participating in physical activities (both segregated and integrated), with the activity providing the opportunity for interaction and context for shared experiences and the development of relationships.

7.6 Experiences of success

In addition to fun, participating in positive activities was also identified as being a means by which disabled children and young people experience success. This was identified by research into children and young people's experiences of (and parents' observations of their child's responses to) adapted sports programmes (Kristen *et al* 2002, 2003)) as well as physical activities in a range of settings (Taub and Greer 2000).

7.7 Skills and learning

A number of pieces of research identify the acquisition of new skills as a positive benefit of participating in positive activities (in all cases, sports or other physical activities). In some instances the research explored specific areas of sports skill acquisition to test the effectiveness of a training programme or mode of delivering training. Thus, Ninot *et al* (2000) found attending a training programme in swimming or basketball had a significant impact on the sports skills of adolescents with learning difficulties. Other projects which have sought disabled children and young people's views of the perceived outcomes of taking part in sport or other physical activities consistently report the development of skills or increased competence as a positive outcome (Groff and Kleiber 2001; Kristen *et al* 2002, 2003). The nature of the activity impacted on the skills acquired or developed. They ranged from skills to participate in a specific activity to more general independence or life skills, gained for example through attending a residential outdoor sports camp (Goodwin and Staples 2005); simple decision-making skills developed through attending a play scheme with a range of activities on offer (Petrie and Poland 1998; Petrie 2000); sportsmanship (Fenning *et al* 2000); and, in inclusive settings, social skills (Petrie and Poland 1998; Taub and Greer 2000).

7.8 Community-based experiences and participation

Having the same access to opportunities and activities as non-disabled children and being part of the local community has been identified as an important outcome by disabled children and young people and their parents (Sloper *et al* 2009 forthcoming).

Research on the child and parent-reported outcomes of participation in inclusive positive activities (Widdows 1997; Petrie 2000; Dunn *et al* 2004; Kelly 2005; Ludvigsen *et al* 2005) and segregated activities in community settings (Kristen *et al* 2003; Fragala-Pinkham *et al* 2006) suggests that these can be a means by which disabled children and young people feel part of the local community.

In addition, positive activities – whether segregated or inclusive, and whether taking place in community or segregated settings – provided the opportunities to participate in activities enjoyed by non-disabled children. Indeed, sometimes a segregated activity and setting can sometimes be the best way to provide this. For example, Murray (2002) observed the

difficulties some young people with learning difficulties experience making friends with their peers (disabled or non-disabled) and noted, from the basis of her qualitative evidence, that a segregated setting appeared to be most conducive to development of friendships with peers. Findings reported earlier about the potential for negative impacts on psychological wellbeing of participating in positive activities in inclusive settings (here the evidence is currently restricted to sporting activities) also supports the notion that segregated activities can be the most appropriate way of experiencing positive activities (see for example Ninot *et al* 2000; Taub and Greer 2000).

7.9 Concluding comments

The evidence reviewed here points to the significant potential that participation in positive activities can have on outcomes for disabled children and young people. At the same time it is clear that great care needs to be taken when planning the provision of opportunities for positive activities. For some activities, and/or for some groups of disabled children and young people, separate provision is required in order to support positive outcomes. Providing choice and careful planning, in consultation with disabled children, young people and their families representing the full range of impairments, is therefore necessary

8. Conclusions and main messages

This review has focused on inclusive practice within services provided by children's centres, extended schools and youth services. It has also examined the evidence on positive activities, both in terms of disabled children and young people's experiences of positive activities currently provided, and the impact of positive activities on outcomes.

It is important to make clear that these inclusive services and positive activities are different. Positive activities can be delivered in integrated and segregated settings: the emphasis is on the activity as opposed to the setting. Inclusive services are, instead a description of a particular way of delivering an integrated service. However services use varying definitions of 'inclusive practice'.

8.1 The current state of inclusive practice in children's centres, extended schools and youth services

The evidence available suggests that inclusive practice is more likely to be found in children's centres than extended schools and youth services. However, it would not appear that inclusive practice has been an integral feature of the increase in the volume, and sometimes quality, of early years services.

It seems that there have been increases in the numbers of disabled children using out-of-school clubs and play schemes, and in the extent of inclusive practice in these settings. However, parents of primary school-aged disabled children in mainstream schools are most likely to report that extended school provision does not meet their needs.

In terms of youth services and their role in supporting young people to participate in positive activities, the evidence suggests that disabled young people are less likely to be participating in positive activities than their non-disabled peers. At a strategic level, it would appear that local authority youth services need to give greater consideration to disability and inclusion issues.

There is also evidence from wider research on play and leisure services that there are differences in the way inclusion is being interpreted by services and this, naturally, affects the sorts of services being provided. Three different interpretations of inclusive practice have been identified:

- *pseudo-inclusion*: mainstream provision which accepts disabled children and young people, but there is no or little evidence of resourcing or active work to support their participation in activities and social integration
- *active inclusion*: provision which is designed and resourced to facilitate disabled children's participation in activities and interaction between disabled and non-disabled children
- *opportunity inclusion*: provision for disabled children or young people only, but which allows them the opportunity to take part in or experience the same activities and opportunities as non-disabled children.

'Pseudo-inclusion' is not inclusive practice, and it is a cause of concern that some service providers believe that they are providing inclusive services merely by allowing disabled children and young people to use a service together. Research with disabled children and young people suggests that 'active inclusion' and 'opportunity inclusion' are both important and valued, though they fulfil different functions. 'Opportunity inclusion' may, in some cases, lead to the development of an 'active inclusion' service or children or young people moving to use such a service. However, sometimes 'opportunity inclusion' is entirely appropriate and should not be regarded as 'second-best' to services which are actively inclusive.

8.2 Disabled children and young people's participation in positive activities

Very little is known, at a national level, about the out-of-school lives of disabled children and young people. There is limited evidence that disabled children and young people are less likely to be accessing out-of-school clubs and activities. Evidence from the United States would suggest that fewer disabled children and young people are likely to be engaging in positive activities than their non-disabled peers, and that the range of activities participated in is smaller. Certain groups are less likely to be participating in positive activities, particularly children and young people with learning difficulties, autism, or multiple impairments.

8.3 Disabled children and young people's experiences of positive activities

A key benefit and motivator to taking part in positive activities is the opportunity it provides for friendship and social interaction. However, accessing positive activities can be difficult when presented with limited choice and opportunities. Included within this notion of choice is the desire to have the choice between engaging in an inclusive positive activity or a 'segregated' activity; both types of provision were valued.

Accessing generic sports and leisure provision can be difficult, both in terms of physical access to buildings and the sorts of equipment and facilities provided at a venue. The knowledge and disability awareness of staff at such centres has been consistently identified by research as a key factor to enabling participation and positive experiences.

The evidence suggests that families typically find identifying local opportunities to take part in positive activities difficult. This is particularly the case if they have not previously accessed a service or activity and/or are not users of other services. Information about inclusive provision within generic facilities or services also needs to be improved. A lack of a joined-up information provision strategy (that is, one that works across all relevant services/providers) is a barrier to keeping families informed about local opportunities to participate in positive activities.

In line with previous research, the importance of providing information about positive activities in a range of formats and in accessible and appropriate language has been identified. In addition, there is evidence to suggest that some disabled children and young people may need to actually experience an activity, on one or more occasions, before they or their parents can decide whether or not to pursue the activity.

8.4 Barriers to enjoying inclusive opportunities and activities

The evidence reviewed suggests that factors associated with the inclusion of disabled children in mainstream activities and their participation in opportunities and activities associated with childhood and adolescence are multiple and complex, and extend beyond the features of a particular service.

A family's own predisposition to participate in social and recreational activities, and an individual child's preferences, influence how disabled children and young people spend their out of school time. In addition, children's perceptions of their own knowledge of, and ability to do, a certain activity influence whether or not they participate in it. There are also differences in the way that families perceive barriers to their child participating in an activity, with the impact of barriers to participation increasing with the increased severity of the child's impairments. Family income is another barrier to accessing mainstream and community leisure services. This includes both the costs of the service and transport costs.

A number of pieces of research have also highlighted the need to support and develop disabled children's social skills in order for them to be able to fully participate in inclusive activities. Children in special schools have little exposure to the cultural forms and unspoken rules of non-disabled children's play, and, not unexpectedly, can struggle in inclusive settings.

8.5 Hallmarks of inclusive services

The evidence tells us about the way that services should be resourced, structured and delivered in order to be inclusive.

First, staff need to play an active role in supporting inclusion – both in activities and in interactions – with disabled and non-disabled peers. This requires a workforce which is skilled in a number of areas including facilitating inclusive play, disability awareness and knowledge of individual children's needs and abilities. In addition, it appears to be important that there is a shared responsibility for supporting inclusion, as opposed to a single member of staff assuming that role. However, there do need to be sufficient numbers of staff to provide one-to-one support, if needed.

Second, the service or setting needs to be inclusive, both in terms of the activities offered as and the physical environment, with the latter taking account of the need to provide for quiet and busy or active spaces, as well as being physically accessible.

Third, families and/or children may need support to identify and/or join a club or use a service. Parents, especially where the child has more severe impairments, will need to be confident that the service can properly support their child. Some families need help identifying the best club or activity for their child, and the service may need information and advice too. Finally, as with any child or teenager, some disabled children and young people find joining something new or starting a new activity difficult and will need support at that stage.

At a more practical level, services need to address transport issues. A lack of 'door to door' transport, either through school transport services or public transport, is a key barrier to participation in out of school opportunities and activities.

8.6 Positive activities and disabled children's outcomes

There is evidence that participating in positive activities impacts on disabled children's outcomes though the evidence base is somewhat limited

Being healthy

Studies of physically disabled children participating in sport (both separate and integrated) suggest that participating in sport, or physiotherapy-type programmes in community sports facilities, has positive effects on physical strength and functioning and general physical health and development.

Similarly, and again the evidence is mainly restricted to physically disabled children, participating in sport and leisure activities impacts on psychological wellbeing. Here, however, there is evidence that the setting (separate or integrated) and type of sport can affect whether psychological wellbeing outcomes are positive or negative. Doing physically complex team sports in integrated settings can lead to a decrease in self-esteem and a sense of inadequacy. There is no evidence of a similar effect from participating in sport and other positive activities in segregated settings.

Enjoyment and friendship

Taking part in positive activities can be an important source of enjoyment for disabled children and young people. It would appear that the social aspects of doing a positive activity can be as, or even more, important as the activity itself. Indeed, meeting social needs appears to be more of a priority in terms of disabled children and young people's leisure time than having the opportunity to do a positive activity *per se*. However, positive activities are a means by which this can be achieved, and the current (and limited) body of evidence suggests that segregated positive activities may be more likely to address disabled children and young people's desired social outcomes than integrated positive activities.

Achieving

The opportunity to experience success has been identified as a further potential outcome of participating in positive activities. More specifically, positive activities can allow disabled children and young people to learn and develop skills, both those specific to an activity (for example, a particular sport) but also more generic life skills.

Participating

Finally, positive activities can also provide a means by which disabled children can make a positive contribution to their local communities. There is evidence that inclusive positive activities help to promote disabled children and young people's sense of belonging to their local community.

8.7 Implications for local, regional and national services

Our analysis of the evidence has a number of implications for services, as listed below:

- Existing services need to examine whether the services they believe to be inclusive are truly inclusive.
- Inclusive services need to be properly resourced in terms of the skills of the staff working in these settings, staff numbers and the physical environment.
- There do appear to be movements in the right direction in terms of inclusive practice in children's centres and extended schools. However, the available evidence suggests that youth services need to look carefully at this issue in terms of current practice and strategic planning.
- In terms of play services, at least, staff need to assume an active role in facilitating play and interaction between disabled and non-disabled children, and between disabled children. All staff working in such settings should have such skills.
- Local authorities should seek to monitor and audit the numbers of disabled children and young people participating in or accessing the range of positive activities available in their locality.
- Local authorities should conduct 'access audits' of generic play, leisure, sport, arts and cultural facilities and venues, looking at issues of: quality of information provided regarding measures to ensure the facility is 'inclusive'; public transport access; parking; physical access; safety; personal care and toilet facilities; and the skills of staff working in these settings. These audits should involve disabled children, young people and parents and represent the range of impairments. The audits should be used to inform remedial work in venues or facilities and be used as a basis of information provided to families.
- A cross-agency and cross-sector information provision strategy encompassing generic and specialist services providing any type of positive activity should be developed which identifies a route by which all disabled children, young people and their families will receive information about local positive activities.
- A system for offering taster sessions at venues and services which provide positive activities should be established.
- Segregated positive activities can be very positive settings for disabled children and young people, and, in some cases, are more appropriate than inclusive settings. There should, therefore, be opportunities for disabled children and young people to participate in both integrated and segregated positive activities, with decisions about the more appropriate settings being informed by individual preferences and the best available evidence.
- A key motivation for participating in positive activities is the opportunity for socialising and friendship. This should be taken into account when planning the types of positive activities which will be provided.
- Increasing disabled children and young people's involvement in positive activities requires attention to factors beyond the specific service or activity. Families may need support to identify and access a service or activity, especially if they do not tend to

participate in such activities. Children and young people may also need help with joining a new club or activity.

- Services need to consider their location and whether they are easily accessible by public transport.
- Limited exposure to non-disabled children's play interferes with disabled children's social development, particularly in terms of their understanding of peer culture. This can make it difficult for them to integrate in inclusive settings. Providing opportunities to play and interact in inclusive play and leisure settings throughout childhood will help to ameliorate this difficulty.
- There is evidence from research conducted in other countries that participation in sport out of school has a positive effect on children and young people's outcomes. Levels of participation in sport out of school by disabled children and young people in England are considerably lower than for their non-disabled peers. Given these positive effects, efforts clearly need to be made to improve access to sport out of school for disabled children and young people.
- The evidence suggests there may be differences between groups of disabled children and young people in terms of what are the most beneficial and appropriate settings and activities. In addition, individual preferences play an important role on whether or not disabled children and young people participate in activities which are on offer. It is therefore important that consultation activities regarding the development of services that provide positive activities involve or represent all groups of disabled children and young people.

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Data annexe

Introduction and availability of data

The main focus of this priority is ‘improving the wellbeing of disabled children and young people (up to age 25) through improving access to positive activities: extended services, youth work, inclusive play and leisure opportunities, sports and the arts’.

Currently, no survey is specifically designed to collect data on the whole population of disabled children and young people. Some data is available at a national level about the prevalence of disability among children, though the most comprehensive population estimate (from the 2001 Census) is now dated (ONS 2008). Data on the prevalence of disability by some of the demographic characteristics of children (such as age, gender and ethnicity) is also available, though the coverage is not comprehensive; data in the Annual Schools’ Census records disability only in terms of primary and secondary needs for those young people in the educational system with identified special educational needs, for example.

The range of data on the social and living circumstances of disabled children and their families is more limited than data on prevalence, but is available in a number of published datasets, including the 2001 Census and the Family Resources Survey. However, many of the sources of data on disabled children are limited by factors such as population coverage, age of children, geography and place of residence. Some datasets provide a breakdown of disability data by age, but this data tends to be aggregated in different ways, with the most common age breakdown being for children from birth to four years, then five to 15 (or 17) years. Some datasets aggregate all data for children into one group of children and young people under 18 years of age only. In other cases, data is aggregated for those over 16, but it is not always possible to identify those aged under 25. The General Household Survey, for example, aggregates data from the age of 16 to 44 years. Of particular relevance to this theme is one of the National Indicators: ‘to measure and drive improved participation of young people in positive activities’ (National Indicator 110). As part of the process to provide indicator data, attempts are being made to collect such participation information more systematically (through, for example, the Client Caseload Information System). At present, however, publicly available data on the participation of young people in positive activities (both disabled and non-disabled young people) remains very limited. This relates partly to issues around definitions (both of disability and of positive activities) and partly to the lack of comprehensive or recent surveys. The Sport England Disability Survey, for instance, provides some useful comparative data on the sporting activities in which disabled young people participate, but publicly available data relates to a survey conducted in 2000; more recent data has not yet been tracked down. This data annexe presents further discussion about the data currently available on disabled children and young people up to the age of 25 years. It provides:

- a summary of the search strategy for identifying data
- an overview of the nature and scope of the data that was found, with a brief commentary on the quality of this data and any gaps that have been identified

- some examples of the type of charts and diagrams that could be produced, showing, for example, comparisons between national and regional data on disabled children.

A summary table of the data sources of readily available, published data for disabled children and young people at a national, regional and/or local authority level is produced in Appendix 3.

Data search strategy

There are a number of archival databases in the UK, such as the National Digital Archive of Datasets (NDAD) and the UK Data Archive, some of which have services that facilitate searching or access to macro- and micro-datasets (including Economic and Social Data Service International). Even so, searching for current and recently published data cannot yet be conducted in the same way as searching for published research findings. Access to newly published data is not supported by comprehensive searchable databases in the same way that literature searches are supported.

Data for this data annexe was obtained by a combination of search methods including obtaining online access to known government publications (such as the Statistical First Releases from the Department for Children, Schools and Families (DCSF); access to data published by the Office for National Statistics, the Department of Health and other government departments; data published by the National Health Service and other national, regional and local bodies; and online searches following leads emerging from these publications, research funding council summaries and other literature searches. It should be noted that links to statistical sources that were live at the time of searching might not be live at the time of publication.

Nature and scope of the data

Two recent studies have contributed significantly to an awareness of the range and scope of data availability on disabled children and their families. Read *et al* (2007a) identified a range of cross-sectional surveys, panel and longitudinal studies, administrative data sources for health, education and children's social services, as well as what she called 'sentinel' condition data sources (such as the UK Collaborative Cerebral Palsy Register), that provided data on the prevalence of disability. Mooney *et al* (2008) provided a critical commentary on the nature of the data included in such datasets for the DCSF. In addition to these two source documents, we have identified a number of other surveys (such as the Youth Cohort Study, which also includes Wales), research studies (including the national Evaluation of Sure Start) and administrative datasets that include some indication of the prevalence of disability among children and young people.

Although there appear to be a number of sources of data about the apparent prevalence of disability among children and young people at both national and local level, it is difficult to obtain an accurate estimate of overall numbers of children and young people in England with disabilities. This is partly because of the wide variation in definitions of disability used by the collectors and collators of that data and partly because of the ways in which data are collected. While national cross-sectional surveys provide estimates of prevalence, no single administrative dataset collects data specifically on childhood disability.

Read *et al* (2007b) identified four main definitions of childhood disability used by data collectors:

- Definitions derived from the *Disability Discrimination Act (DDA) 1995* (GB. Statutes 1995), which includes children whose impairments and conditions result in significant difficulties with daily activities. These definitions are used by the Department for Work and Pensions for surveys such as the Labour Force Survey(LFS) and the Family Resources Survey(FRS), but are not used by the DCSF for the collection of data on special educational needs(SEN) and were not included in the 2001 Census.
- Definitions based on **limiting longstanding illness**, disability or infirmity(LLSI), used in the 2001 Census but with no sub-classification data (by specific disability).
- Definitions based on **longstanding illness**, disability or infirmity (LSI), which can capture a wide range of health conditions of varying severity, but which do not give any indication of the extent of impairment.
- Definitions based on **specific impairments** (such as visual impairment) or on specific support needs (such as special educational needs), which do not provide an overview of all disabled children.

A further issue for this data scoping study is raised by the purpose for which data is collected, which can limit the scope and extent of data collection, and/or its ability to be used for comparative or trend analysis:

Population Census data, while comprehensive (an estimated 96 per cent of the UK population), is infrequent (every 10 years), and uses 'limiting longstanding illness' without sub-classifications.

DCSF administrative data, collected through the Schools' Census, is comprehensive in including all children and young people in compulsory education from Foundation Stage to Key Stage 4. Data on disability, however, is confined to a classification of primary and secondary need under the SEN variable. It is likely, therefore, that the census underestimates the prevalence of disability. In the one area where we have found comparable national data – that of visual impairment – DCSF figures for England for 2007–08 recorded 8,080 children and young people of school age with a visual impairment as their primary SEN, while a further 940 were recorded as having multi-sensory impairment. A survey of Visual Impairment Services in England for the same period, based on an extrapolation of the data from 77 per cent of all English local authorities, suggested that the total figure of children and young people of school age with some form of visual impairment was nearly two-and-a-half times greater (21,946 children up to age 16).

Local authorities' administrative data on disability is collected as part of their statutory requirement under the *Children's Act 1989*, and uses the definitions in that act. The voluntary nature of registration data and the different criteria applied for registration between local authorities means that the data is not a good indicator of prevalence, however. Similarly, until October 2008, the data collected for the Children in Need (CIN) Census provided an indication of the number of disabled children who received social care during the defined Census week but did not cover all disabled children known to the social services or in the local authority area. The 2008-09 CIN Census collection covers the period October 2008 to March 2009 while, from April 2009, the data collections will cover the entire financial year.

Cross-sectional surveys (such as the Family Resources Survey) are generally seen as providing the best estimate of disability at any one time, but are often limited in terms of the amount of analysis that can be undertaken, because the data is not linked to the development stage of the child, or the sample size is too small, or because they include only children and young people in particular family circumstances. Such surveys vary, too, in their definition of disability. While the Labour Force Survey (LFS) and the Family Resources Survey (FRS) are DDA-related (and also use limiting longstanding illness (LLSI) and/or longstanding illness (LSI)), the Health Survey for England, the Survey of English Housing and the General Household Survey are not, primarily using variations of 'LLSI or LSI or 'sentinel' data recording.

Longitudinal panel studies (such as the Families and Children Study, the British Household Panel Survey, the Longitudinal Study of Young People in England and the Millennium Cohort Study) while able to track trends over time, may suffer from attrition and are not as good as cross-sectional surveys for providing information on prevalence. The same issues of defining disability apply to them as to the cross-sectional surveys; the Longitudinal Study of Young People in England, for example, is the only survey to include DDA-related questions (and has done so from 2007).

Data collected by **Primary Care Trusts** (such as records of disability collected on Child Health Computer Systems, or through the General Practice Research Database) tend to be related to the codes from the International Classification of Diseases (ICD).

'**Sentinel**' data can provide a reliable source of data on children with specific disabilities or known support needs, but registration can be voluntary: (as in the case of the Register for Deaf and Hard of Hearing, for example); dependent on family circumstances (such as the Family Fund Trust); or dependent on reporting by paediatricians (the UK Collaborative Cerebral Palsy Register) or other non-familial source. It is not always clear, therefore, whether population coverage is comprehensive.

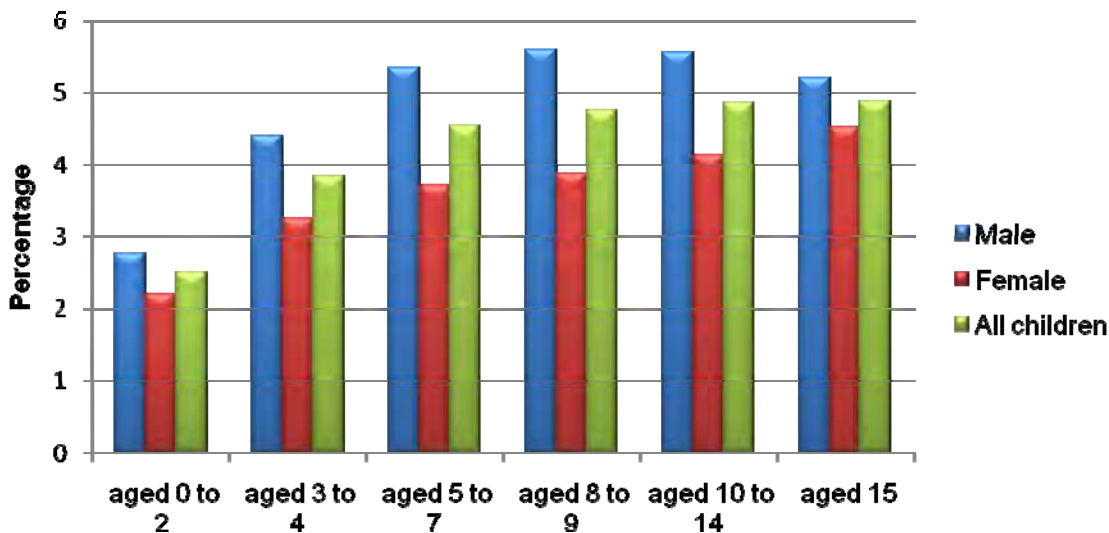
Examples of charts showing trends and regional data

Exemplar 1 Data on prevalence of disability (by age, by sex, by ethnicity and by household tenure)

Data from the 2001 Population Census provides some indication of children aged from birth to 15 years old with a limiting longstanding illness (LLSI) (see Figure 1), by age, by sex and by ethnicity, although the aggregations for each variable are different. The age and sex categories provide information on children from birth to 2, 3 to 4, 5 to 7, 8 to 9, 10 to 14, and age 15; the ethnicity category aggregates data for children and young people up to age 15; while the category for household tenure is divided up to include children from birth to 4, 5 to 9 and 10 to 15 years old.

Figure 1 provides an overview of the percentage of the population of children from birth to 15 years old who were recorded as having a LLSI in 2001. The data referred to the general health of the child over the 12 months prior to Census day (29 April 2001). In each age category, the proportion of male children reported as having a limiting longstanding illness was greater than the proportion of female children with such an illness/disability.

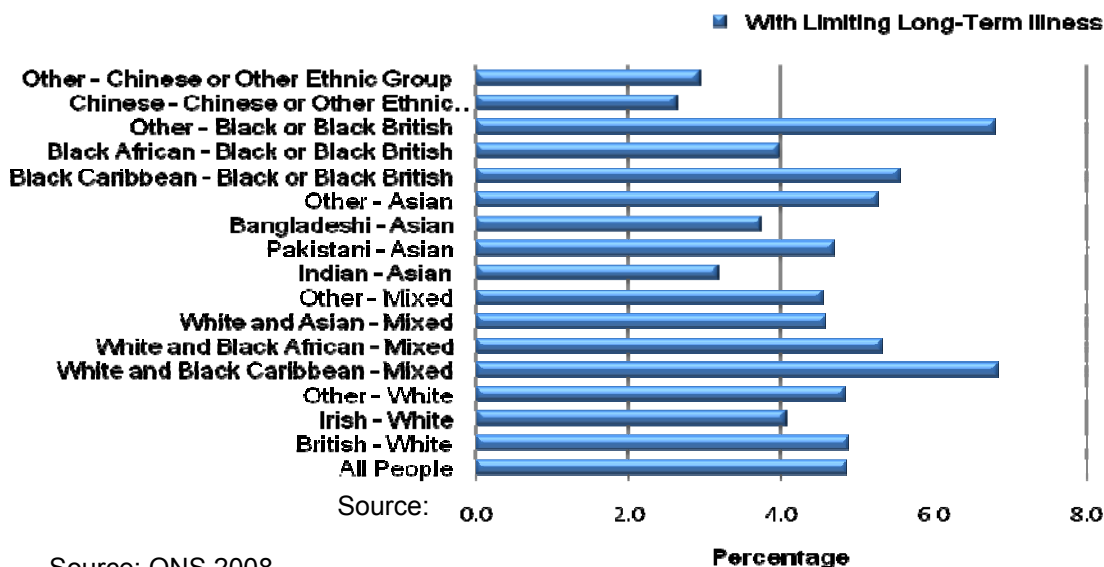
Figure 1 All children with a limiting longstanding illness (LLSI): Population Census 2001; by sex



Source: ONS 2008

The proportions of children with an LLSI appear to be greatest among those from a Black or Black British background and from a mixed race White and Black Caribbean background (see Figure 2) and lowest among those from a Chinese background.

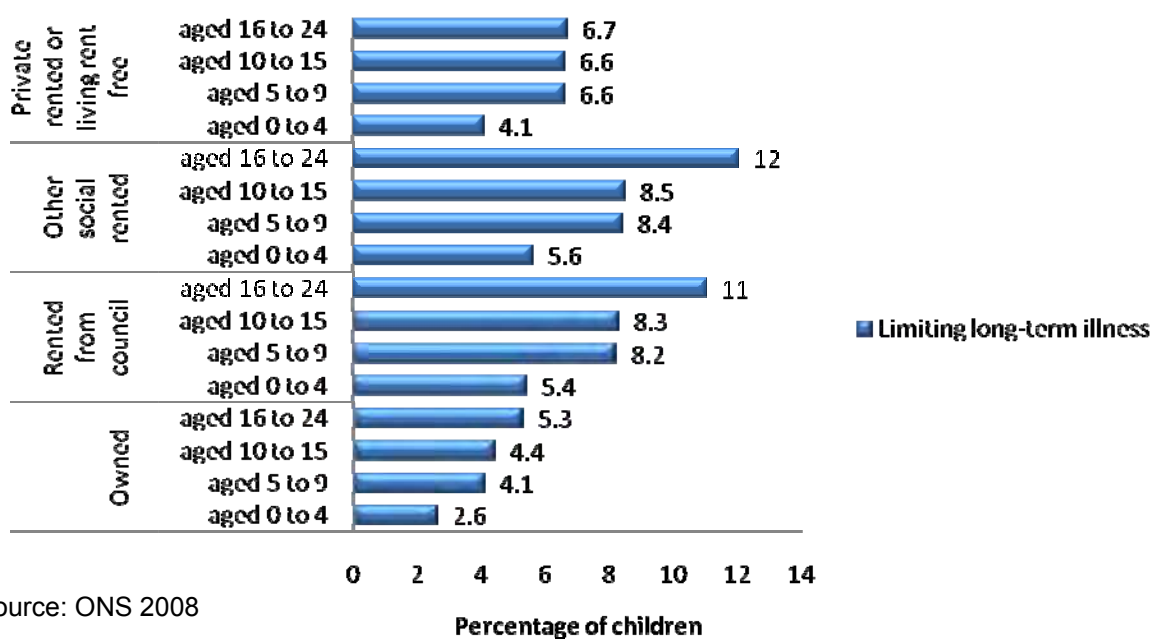
Figure 2 All children with a limiting longstanding illness (LLSI) up to age 15: Population Census 2001; by ethnicity



Source: ONS 2008

The proportions of children with an LLSI also appear to be greatest – across all age groups – among those living in social rented accommodation (whether council-owned or other social ownership) and lowest among those living in owner-occupier properties (see Figure 3).

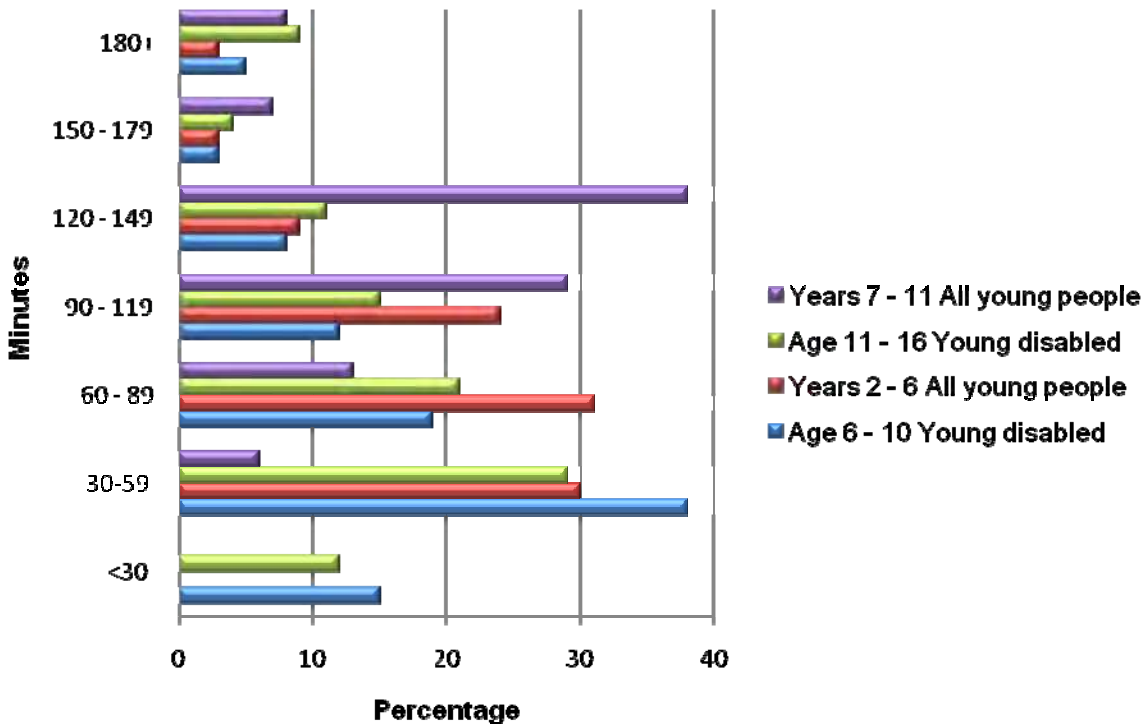
Figure 3 All children with a limiting longstanding illness (LLSI) up to age 24: Population Census 2001; by household tenure



Exemplar 2 Participation in positive activities

Comprehensive data on participation in positive activities is currently lacking both for non-disabled and disabled children, so assessing progress in promoting wellbeing for disabled children and young people through positive activities is challenging. Data from an early Sports England survey of around 2,000 disabled children with an LLSI (as identified using the Canadian developed Health Utilities Index) in English schools in 2000 was compared with an earlier comparable survey of around 2,500 non-disabled children carried out in the previous year. The authors concluded that 'Clearly disability per se is not a barrier to taking part in sport. However, both the overall rate of participation and the frequency with which children and young people with a disability take part in sport is lower than for young people in general'. Figure 4 suggests that the length of time spent on sport in school was markedly lower for young disabled pupils compared with their peers. The Office for National Statistics (ONS) suggests that the lack of parity in participation is not primarily school-based but is due more to 'lower levels of participation compared to the general population of the same age, outside of school'. Lack of money, health condition and unsuitability of local sports facilities to accommodate the child/young person's disability were the main barriers cited (in the survey of Young People with a Disability & Sport carried out in 2000) to participating in sporting activities outside of school.

Figure 4 Average time per week in PE lessons: reported by young disabled in 2000 and by the overall population of young people in 1999; by primary and secondary age groups⁴



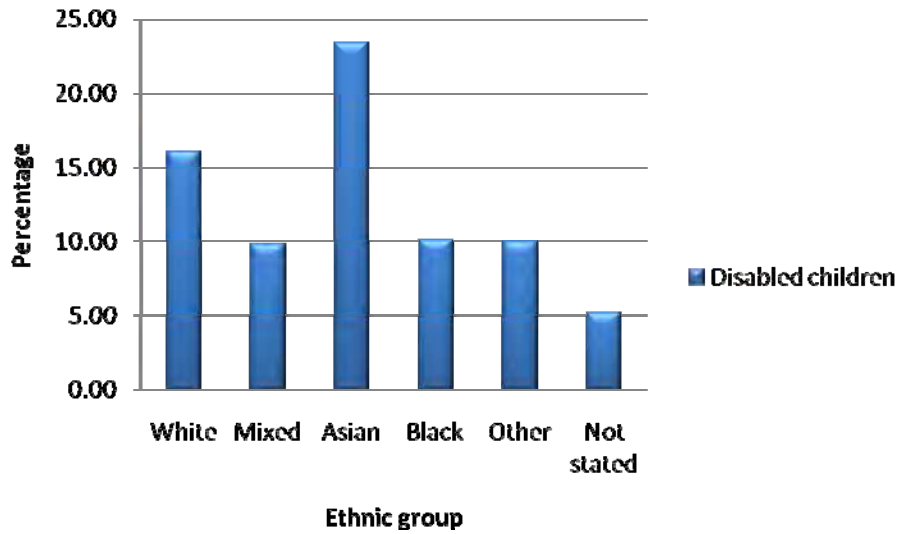
Source: Sport England 2001

Exemplar 3 Access to services

The Children in Need Census 2005 (DCSF 2006) provided an indication of the numbers of children in need (both non-disabled and disabled) accessing social care during a single week. The majority (85 per cent) of those accessing a service in the Census Week in February 2005 had no disability. Of those who had, a higher proportion of the Asian children in need accessing a service had a disability (2,100 out of 9,000) than was the case for any other ethnic group (see Figure 5).

⁴ The scoping study does not include specific lessons; the data published by Sport England, however, provides clearer participation data for in-school activity than out-of-school activity, which is primarily reported in terms of popularity of individual sports.

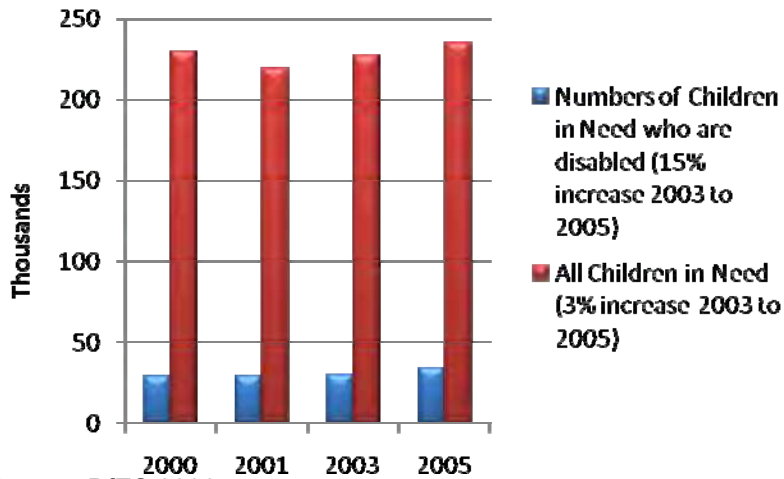
Figure 5 Access to Local Authority Social Services' Children and Families Teams by disabled children in need: by ethnicity



Source: DfES 2006a

As Figure 6 illustrates, between 2003 and 2005 the overall numbers of children in need and their families/carers that accessed a service from Local Authority Social Services' Children and Families Teams during the annual Census Week increased by three per cent; the numbers of disabled children and families/carers accessing the service increased by 15 per cent over the same time period.

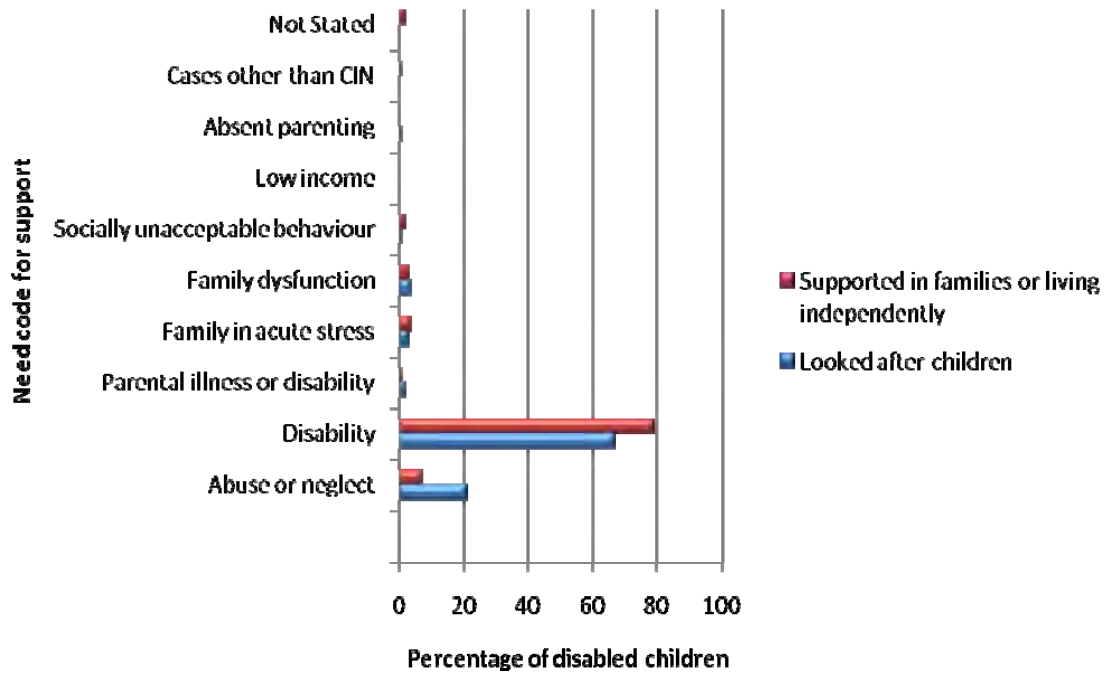
Figure 6 Access to Local Authority Social Services' Children and Families Teams by Children in Need: 2000 to 2005.



Source: DfES 2006a

Reasons for accessing the service (whether for looked after children or those living with families or independently) appear to relate predominantly to a disability (see Figure 7), but a notable proportion accessed the Local Authority Social Services' Children and Families Teams because of issues related to abuse or neglect or to specific family issues (dysfunction or acute stress).

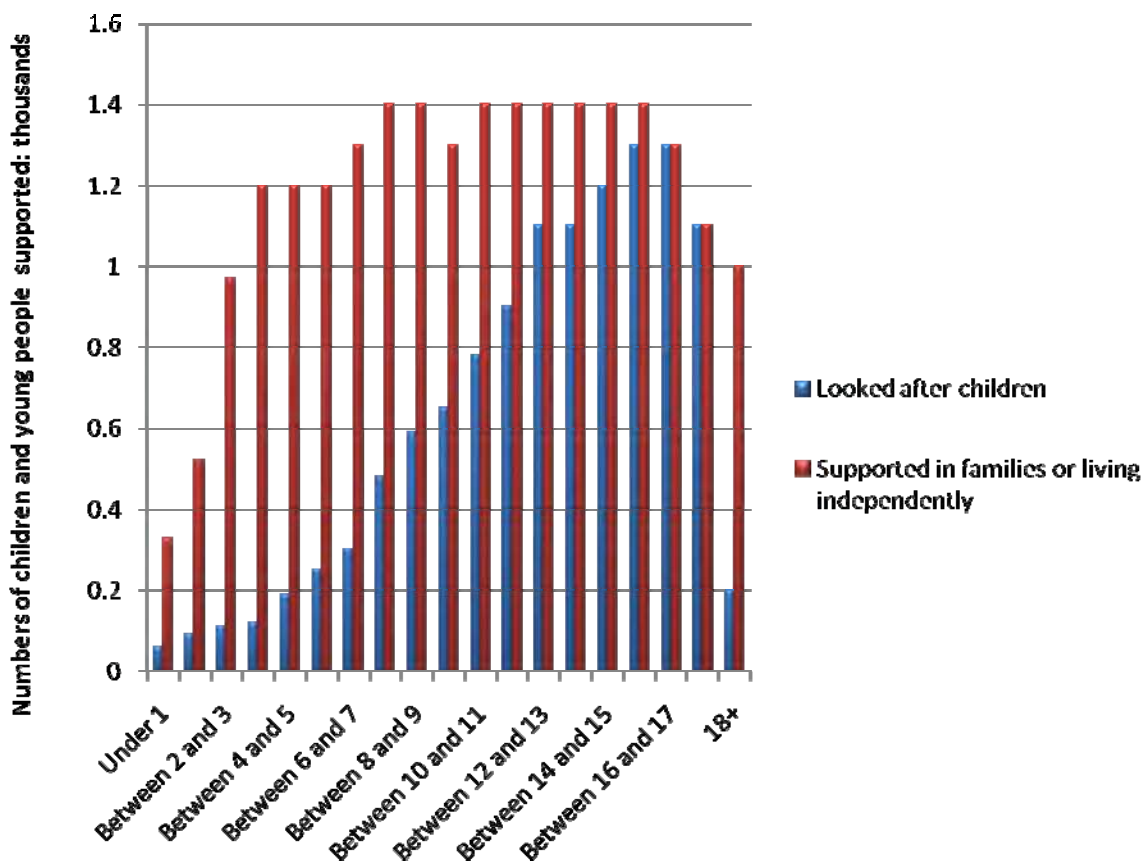
Figure 7 Access to Local Authority Social Services' Children and Families Teams by Children in Need: by reason for access



Source: DfES 2006a

A total of 34,100 disabled children from birth to 18 years old and over received support during the week of the Children in Need Census in February 2005, with the numbers receiving support increasing with the age of the child and varying according to family circumstance (see Figure 8). For children between the ages of eight and 16 supported by their families (or living independently), the numbers of disabled children and their families accessing social care support during Census Week in February 2005 were fairly similar (around 14,000 in each age cohort). The story for children and young people who were looked after children shows a different trend, with increasing numbers accessing support until age 16, possibly reflecting greater numbers of looked after children in older age groups. Most evident from Figure 8 are the limited numbers of looked after children accessing support at age 18+, when fewer children would be looked after children.

Figure 8 Access to Local Authority Social Services' Children and Families Teams by Children in Need: by age



Source: DfES 2006a

In summary

At present, no single national dataset is able to provide definitive insights into the impact of positive activities on the wellbeing of disabled children and young people up to the age of 25. An exploration of existing data suggests that there is a need for greater clarity or agreement of definition of childhood disability across all data collection exercises; even where 'limited longstanding illness' was adopted as the definition, the basis for the designation varied.

The main issue for this priority, however, is the lack of current data related to positive activities, not just for those with disabilities, but for all children and young people. Moreover, the relationship between activities and outcomes is not clearly documented, although the cost of providing activities is sometimes recorded. National, population level datasets provide useful monitoring data (how many disabled children access services in Census Week, for instance) that can be tracked over time, but do not provide evaluative information on the impact of a specific activity or service provision.

Some relevant data may be found in particular administrative datasets (including the largely voluntary sentinel datasets) and targeted cross-sectional and longitudinal panel studies (albeit with the caveats noted in the section on the nature and scope of the data).

- Administrative data, such as the DCSF National Pupil Dataset, can be accessed (with permission) by the data team and outcomes for disabled children can be explored using the 'sensitive' data collated for children with special educational needs. This would give an insight into trends in certain measurable outcomes (primarily attendance and attainment) over time, but would not provide insights into the impact of specific interventions unless the interventions were specifically recorded on a database that could be matched to the administrative data.
- Older archived data from cross-sectional and longitudinal panel studies can be accessed by the data team, but such access takes time and, in some cases, requires explicit permissions from data owners and controllers. Newer data from cross-sectional and longitudinal panel studies may not be accessible to the team, although, in some cases, particular analyses could be commissioned from the data owners and controllers.
- Sentinel datasets are not all anonymous and so are not readily accessible to the data team. It is thought that they are unlikely to include any data of relevance to this theme.

Appendix 1: Assessment of the evidence base

This section provides an overview of the evidential basis of the review.

The initial searches generated 617 titles, and the scoping team considered that 246 titles were potentially relevant to the research questions. The review team re-assessed these titles for potential inclusion against the original criteria and identified 97 as potentially relevant. Of these 97 titles, the team were able to retrieve 89 papers for more detailed evaluation. By scanning the reference sections of these papers, a further 84 potentially relevant papers were identified, of which the team were able to retrieve 80. The reviewers also identified a further three papers from other sources. From the total of 172 papers retrieved for further evaluation, 54 papers representing 52 studies were deemed relevant for inclusion in the review. The relevant studies identified provided evidence relating to one or more of the research questions and were reports of research and consultations, which drew upon a range of methodological approaches.

In conducting the review, care has been taken to distinguish between those research findings that have a stronger or weaker evidential base. A major consideration has been the design of the research and the extent to which the findings can be generalised.

Limitations of the evidence base

- The lack of research conducted in England, thus requiring the reviewers to include research conducted in other countries, where cultural differences and different patterns of service provision impose limitations on the ability to generalise their findings to this country.
- Disabled children and young people are not a homogeneous group and there is evidence that the type of impairment is associated with experiences of services, leisure and recreation preferences, and the sorts of support needed to access inclusive services and take part in positive activities. However, the current evidence base does not reflect that breadth and therefore it is often only possible to draw tentative conclusions, which may only be relevant to particular groups of disabled children and young people.
- The most robust evidence on patterns of use of inclusive services and access to positive activities is limited in the depth of information it provides concerning disabled children and young people.
- The most robust research on the factors associated with the use of inclusive services and participation in positive activities has all been carried out in other countries.
- Qualitative research provides a different, but essential set of evidence, which typically provides richer data and allows explanations for the findings from quantitative research to be developed. The qualitative research identified for this review was limited because it focused only on a limited range of groups of disabled children and young people. In addition, the majority of studies did not provide adequate information about their research methods, making it impossible to draw firm conclusions about the quality of the research.
- In the absence of research which was highly relevant to the review question, it has been necessary to include studies where the main research questions were different to those of this review but which yielded some relevant data. Similarly, findings from

consultation exercises were also included which, if better-quality research evidence were available, would not have been included because of design and/or methodological weaknesses.

Given these apparent weaknesses in the evidence base, great care was taken to identify evidence which corroborated or disagreed with findings from individual studies.

The types of evidence included in the review

The types of evidence and numbers of studies used for each review question are outlined below.

What evidence is there of practice in children's centres, extended schools and youth services in fully including disabled children and young people?

Fifteen studies were included in this part of the review including: national and regional evaluations of policy implementation related to children's centres, extended schools, youth services and play programmes; national survey of participation in sport by disabled children and young people; analysis of local authorities' plans and policies; national-level data reported by voluntary sector organisations about the population using their service; national-level mapping of sport and leisure provision for disabled children and young people; qualitative research on disabled children and young people's experiences of using inclusive play and leisure services.

What young people think about positive activities on offer in their area and how can their awareness of activities on offer be increased?

Nineteen studies were included in this part of the review, including: quantitative studies which explored patterns of participation in extracurricular activity, problems associated with local leisure facilities, the perceptions and usage of extended services in schools, and life outside the classroom; qualitative studies which focused exclusively on the leisure experiences of families with disabled children; qualitative studies which explored the leisure experiences of disabled children as part of a wider study of their lives; national consultations which explored the leisure experiences of disabled children as part of a wider study of their lives; qualitative studies which focused on 'inclusive' leisure; mixed-method studies which focused on 'inclusive' leisure.

What support do disabled children and young people need to access inclusive activities?

Thirty-one studies were included for this question and covered the following areas: quantitative studies of factors associated with participation in positive activities; observational studies of play in inclusive play settings; qualitative studies of stakeholders' experiences of specific inclusive services. These included: inclusive play projects; Sure Start Local Programmes (SSLPs); extended schools and out-of-school services; studies of providers' experiences; surveys and qualitative studies of families' general experiences of accessing and participating in inclusive, mainstream and/or segregated play, leisure, recreation and other positive activities; surveys and qualitative studies of families' experiences of using mainstream facilities and venues.

What evidence is there that improving access to positive activities improves the wellbeing of disabled children and young people?

Twenty-four studies (reported in 26 papers) provided evidence for this question. They included the following types of research: quantitative evaluations of the impact of specific positive activities on one or more outcomes for disabled children and young people; quantitative evaluations of the impact on participating in positive activities on one or more outcomes for disabled children and young people; qualitative research of the impact of positive activities on the lives of disabled children and young people as perceived by the children and young people themselves, or their parents; quantitative research on the benefits of participating in positive activities as perceived by children, young people and/or their parents; qualitative research into providers' views on the impact of specific or positive activities generally on disabled children and young people; qualitative research with children, young people and their parents about their everyday lives.

Appendix 2: Review and scoping study processes, search results and parameters

Review methods

This main review builds on an earlier [scoping study](#) (Bielby *et al* 2009), which used a broad range of sources to identify relevant material, including searches of bibliographic databases, web searches, current research and recommendations from the TAG.

The study began by establishing key questions to be addressed and determining the parameters for identifying material relevant to the study topic. These parameters were used to identify exclusion and inclusion criteria.

The study used a broad range of sources to identify relevant material:

- searches of bibliographic databases (containing literature of education, social science, psychology, social care, and health)
- web searches
- recommendations from the Thematic Advisory Group
- ‘reference harvesting’ (following up items cited in other documents identified in the review).

Searches were carried out using the above sources of information. The search results were screened to remove duplicates and material that did not fit within the parameters. (Details of the search strategy can be found in Appendix X.)

The review team used a ‘best evidence’ approach to select literature of the greatest relevance and quality for the review. This entailed identifying:

1. The items of greatest relevance to the review questions.
2. The items that came closest to providing an ideal design to answer the review questions.
3. The quality of the research methods and reporting.

The team reviewed all priority items and summarised their findings in relation to the review questions. The reviewer also assessed the quality of the evidence in each case. In judging the quality of the studies, the review team was guided by principles established to assess quantitative research (Farrington *et al* 2002) and qualitative studies (Spencer *et al* 2003).

On 20 per cent of the summaries, quality assurance checks were carried out by a member of the team who had not been involved in the original assessment.

Strengths of the review

- Identifying the best available evidence from research and national datasets to inform specific questions.
- Comprehensive and documented searching for relevant information.
- An analysis of the strength and quality of the evidence.
- Systematic data extraction.

Limitations of the review

- The short time in which the review was carried out, which limited the ability of the team to extend and develop the evidence base.
- It was not possible to adopt all of the processes expected of an extended systematic review.
- The review was limited to English-speaking countries only.
- The inclusion, due to the lack of any other evidence, of quite weak evidence, typically from consultation exercises.

Scoping study process

The first stage in the scoping study process was for the Theme Lead to set the key review questions and search parameters and agree them with the National Foundation for Educational Research (NFER) scoping team (see Appendix 1 for the full set of parameters). The list of databases and sources to be searched was also agreed with the Theme Lead. Sets of keywords were selected from the British Education Index (BEI) and were supplemented with free text phrases. The keywords comprised an age group set covering a range of terms describing children and young people; a set of terms relating to disability to ensure retrieval of documents pertaining specifically to disabled children and young people; and sets of terms relating to each category of positive activities: extended services, youth work, inclusive play and leisure opportunities, sports and the arts. The keywords were adhered to as far as possible for all bibliographic databases, with closest alternatives selected where necessary. Web-based databases were searched using a more limited number of terms enabling a simultaneous search across the three priority areas within the disability theme.

A list of websites considered relevant to the search was compiled by the NFER team and supplemented by key organisations identified in the National Children's Bureau (NCB) organisations database, the British Education Internet Resource Catalogue (BEIRC) and by others identified in the course of the bibliographic database searches. Current research was specifically searched for in the CERUKplus (education and children's services research) database, in the Research Register for Social Care and on the websites of key organisations. Members of the Theme Advisory Group (TAG) were invited to suggest relevant documents, networks and websites.

The next stage in the process was to carry out searching across the specified databases. The database and web searches were conducted by information specialists. Owing to the

spread of database holdings across consortium member institutions, the database searching tasks were divided between NFER, the Social Care Institute for Excellence (SCIE) and the NCB, whose information specialists worked in close consultation to ensure consistency. Initial screening was done at this stage to ensure that the results conformed to the search parameters. The records selected from the searches were then loaded into the EPPI-Reviewer database, duplicates were removed and missing abstracts sourced. The scoping team members used information from the abstract and/or the full document to assess the relevance of each piece of literature in addressing the key questions for the review. They also noted the characteristics of the text, such as the type of literature, country of origin and relevance to the review question. A 15 per cent sample was selected at random and checked for accuracy by another member of staff.

The numbers of items found by the initial search, and subsequently selected, can be found in the following table. The three columns represent:

- items found in the initial searches
- items selected for further consideration (that is those complying with the search parameters after the removal of duplicates)
- items considered relevant to the study by a researcher who had read the abstract and/or accessed the full document.

Table 1. Overview of searches

Source	Items found ⁵	Items selected for consideration	Items identified as relevant to this study
Databases			
Applied Social Sciences Index and Abstracts (ASSIA)	37	37	5
British Education Index (BEI)	36	12	5
ChildData	737	326	123
MEDLINE	46	43	8
PsycINFO	63	62	9
Internet databases/portals			
British Education Internet Resource Catalogue (BEIRC)	81	2*	n/a
CERUKplus	175	1	1
NHS EED	24	0	0

⁵ Where n/a is indicated, this is because these resources were browsed rather than searched

Research in Practice	6	0	0
Research Register for Social Care	105	4	1
Social Care Online	872	45	29
TAG recommendations (including texts and organisations)	87	87	65

Search strategy

This section provides information on the keywords and search strategy for each database and web source searched as part of the scoping study. The searches were conducted by information specialists at various organisations, as follows:

- British Education Index (BEI), British Education Internet Resource Catalogue (BEIRC), CERUKplus, Making Research Count, NHS EED, Research in Practice, Research Register for Social Care, and Social Care Online were searched at NFER
- Applied Social Sciences Index and Abstracts (ASSIA), MEDLINE and PsycINFO were searched at SCIE
- ChildData was searched at the NCB.

All searches were limited to publication years 1995–2008, in English language only.

A brief description of each of the databases searched, together with the keywords used in the searches, are outlined below. The search strategy for each database reflects the differences in database structure and vocabulary.

The following conventions have been used: (ft) denotes that free-text search terms were used, * denotes a truncation of terms; and (+NT) denotes that narrower subject terms have been included (where available).

Applied Social Sciences Index and Abstracts (ASSIA)

(searched via CSA Illumina 20/10/08)

ASSIA is an index of articles from over 500 international English language social science journals.

- #1 child ren (+NT)
- #2 young people (+NT)
- #3 adolescents (+NT)
- #4 #1 or #2 or #3
- #5 disability (+NT)
- #6 #4 and #5
- #7 extended school* (ft) or extended school day (ft)
- #8 out of school care
- #9 breakfast club* (ft) or after school club* (ft)
- #10 extra curricular activit*
- #11 children's centre (ft) or children's center (ft)
- #12 youth clubs
- #13 youth work (ft) or youth cent* (ft) or youth group* (ft)
- #14 cultural activ*
- #15 exerci se (+NT)
- #16 art or dancing or literature or music or performing arts
- #17 leisu re (+NT)
- #18 leisure (ft) or play (ft) or sport (ft)
- #19 #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17
or #18
- #20 #6 and #19

British Education Index (BEI)

(searched via Dialog 27/10/08)

BEI provides information on research, policy and practice in education and training in the UK. Sources include over 300 journals, mostly published in the UK, plus other material including reports, series and conference papers.

Children set

- #1 infants
- #2 under fives (ft)
- #3 children (+NT)
- #4 preschool children
- #5 young children
- #6 nursery school pupils
- #7 kindergarten children
- #8 primary school pupils
- #9 secondary school pupils
- #10 further education students
- #11 higher education students (ft)
- #12 adolesc ents
- #13 young adults
- #14 youth
- #15 young people (ft)

#16 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16

Disabled children and YP set

#17 disab*

#18 disabilities

#19 disabled children (ft)

#20 disabled students (ft)

#21 disabled young people (ft)

#22 disabled adolescents (ft)

#23 intellectual impairment (ft)

#24 learning disabilities

#25 learning difficult* (ft)

#26 learning disorders (ft)

#27 mental disorders

#28 mental retardation

#29 inclusion (ft)

#30 inclusive education (ft)

#31 #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30

#32 #16 and #31

Extended services set

#33 extended services (ft)

#34 extended schools (ft)

#35 extended school day

#36 before school care (ft)

#37 breakfast club* (ft)

#38 after school care (ft)

#39 after school club* (ft)

#40 out of school care (ft)

#41 extracurricular activities

#42 childrens centres (ft)

#43 childrens centers (ft)

#44 childcare pilot (ft)

#45 childcare (ft)

#46 child care (ft)

#47 #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46

Youth work set

#48 youth work (ft)

#49 youth clubs

#50 youth groups (ft)

#51 youth programmes

#52 youth service

#53 youth services (ft)

#54 youth opportunities

#55 #48 or #49 or #50 or #51 or #52 or #53 or #54

Sports set

#56 sports

#57 sport (ft)

#58 sports coach(ft)

#59 #56 or #57 or #58

Play, leisure, recreation and short breaks set

#60 play

#61 play centres

#62 play groups

#63 play therapy

#64 playgrounds

#66 playground activities

#67 recreation

#68 recreational activities

#69 leisure (ft)

#70 leisure activities (ft)

#71 short breaks (ft)

#72 short break services (ft)

#73 field trips

#74 school visits

#75 vacations

#76 holidays

#77 outdoor pursuits

#78 adventure education

#79 #60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69 or #70 or #71
or #72 or #73 or #74 or #75 or #76 or #77 or #78

Arts set

#80 arts

#81 art

#82 dance

#83 drama

#84 music

#85 art activities

#86 cultural activities

#87 #80 or #81 or #82 or #83 or #84 or #85 or #86

#88 #47 or #55 or #59 or #79 or #87

#89 #32 and #88

British Education Internet Resource Catalogue (BEIRC)

(searched 20/10/08)

The British Education Internet Resource catalogue is a freely accessible database of information about professionally evaluated and described internet sites which support educational research, policy and practice.

#1 disabilities or learning disabilities or mental retardation

CERUKplus

(searched 10/10/08)

The CERUKplus database provides access to information about current and recently completed research, PhD level work and practitioner research in the field of education and children's services.

#1 disab* (ft)

ChildData

(searched 28/10/08)

ChildData is the National Children's Bureau database, containing details of around 35,000 books, reports and journal articles about children and young people.

Children set

#1 infants

#2 under twos

#3 under fives (ft)

#4 under eights

#5 children (+NT)

#6 preschool children

#7 young children (ft)

#8 nursery school pupils (ft)

#9 kindergarten children

#10 primary school pupils (ft)

#11 primary school age

#12 secondary school pupils (ft)

#13 further education students (ft)

#14 higher education students (ft)

#15 adolescents

#16 young adults

#17 youth (ft)

#18 young people (ft)

#19 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18

Disabled children and YP set

#20 disab*

#21 disabled children (ft)

#22 disabled students

#23 disabled young people (ft)

#24 disabled adolescents (ft)

#25 intellectual impairment (ft)

#26 learning disabilities (ft)

#27 learning difficulties

#28 learning disorders (ft)

#29 mental disorders

#30 mental retardation (ft)

#31 mental disability

#32 physical disability

#33 multiple disabilities

#34 inclusion

#35 inclusive education

#36 #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35

Extended services set

#37 extended services (ft)

#38 extended schools

#39 extended school day (ft)

#40 before school care (ft)

#41 breakfast club*

#42 after school care

#43 after school club* (ft)

#44 out of school care

#45 extracurricular activities (ft)

#46 childrens centres

#47 childrens centers (ft)

#48 childcare pilot (ft)

#49 childcare (ft)

#50 child care (ft)

#51 extended day

#52 child care services

#53 day care

#54 early childhood services

#55 #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54

Sports set

- #56 sports
- #57 sport (ft)
- #58 sports coach* (ft)
- #59 physical education
- #60 physical fitness
- #61 #56 or #57 or #58 or #59 or #60

Youth work set

- #62 youth work
- #63 youth clubs
- #64 youth groups (ft)
- #65 youth programmes (ft)
- #66 youth service (ft)
- #67 youth services (ft)
- #68 youth opportunities (ft)
- #69 youth societies
- #70 #62 or #63 or #64 or #65 or #66 or #67 or #68 or #69

Play, leisure, recreation and short breaks set

- #71 play
- #72 play centres (ft)
- #73 play groups
- #74 play therapy
- #75 playgrounds
- #76 playground activities (ft)
- #77 recreation
- #78 recreational activities (ft)
- #79 leisure
- #80 leisure activities (ft)
- #81 short breaks (ft)
- #82 short break services (ft)
- #83 field trips (ft)
- #84 school visits (ft)
- #85 vacations (ft)
- #86 holidays
- #87 outdoor pursuits (ft)
- #88 outdoor play
- #89 outdoor games
- #90 adventure education (ft)
- #91 adventure playgrounds
- #92 activities
- #93 #71 or #72 or #73 or #74 or #75 or #76 or #77 or #78 or #79 or #80 or #81 or #82 or #83 or #84 or #85 or #86 or #87 or #88 or #89 or #90 or #91 or #92

Arts set

- #94 arts
- #95 art (ft)
- #96 dance
- #97 drama
- #98 music
- #99 art activities (ft)
- #100 cultural activities (ft)
- #101 #94 or #95 or #96 or #97 or #98 or #99 or #100
- #102 #55 or #61 or #70 or #93 or #101
- #103 #19 and #36 and #10

Making Research Count

(browsed 27/10/08)

Making Research Count is a collaborative national research dissemination network based regionally in the social work departments of nine UK universities. The following documents available on the national Making Research Count website

(www.uea.ac.uk/menu/acad_depts/swk/MRC_web/public_html/) were browsed for relevant items:

- Research News Summer 2008 (this is the first edition of this newsletter)
- Quality Protects Research (QPR) briefings (numbers 1 to 9)
- Every Child Matters (ECM) research and practice briefings (numbers 10 to 16).

MEDLINE

(searched via Ovid SP 14/10/08)

MEDLINE is the primary source of international literature on biomedicine and healthcare.

- #1 child, preschool
- #2 young adult* (ft)
- #3 young people (ft)
- #4 young person (ft)
- #5 infant
- #6 students
- #7 youth (ft)
- #8 #1 or #2 or #3 or #4 or #5 or #6 or #7
- #9 disabled persons (+NT)
- #10 mental disorders diagnosed in childhood (+NT)
- #11 physical disab* (ft)
- #12 early intervention (education)
- #13 mental retardation (+NT)
- #14 hearing disorders or vision disorders
- #15 #9 or #10 or #11 or #12 or #13 or #14
- #16 extended school (ft) or extended school day (ft)
- #17 before school care (ft) or after school care (ft)

- #18 breakfast club* (ft) or after school club* (ft)
- #19 extracurricular activit* (ft)
- #20 children's cent* (ft)
- #21 youth work (ft) or youth club* (ft) or youth group* (ft) or youth program* (ft) or youth activit* (ft)
- #22 cultural activit* (ft)
- #23 exercise (+NT)
- #24 leisure pursuits (+NT)
- #25 outdoor pursuits (ft)
- #26 art or drama or music
- #27 #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26
- #28 #8 and #15 and #27

NHS EED

(searched via CRD 21/10/08)

NHS EED contains over 7000 abstracts of quality-assessed economic evaluations.

- #1 disabled children (ft)
- #2 disabled young people (ft)
- #3 disabled and sport (ft)
- #4 disabled and leisure (ft)
- #5 disabled and extended services (ft)

PsycINFO

(searched via Ovid SP 28/10/08)

PsycINFO contains more than 2.5 million records on psychological and behavioural science.

- #1 child* (ft)
- #2 adolescen* (ft)
- #3 young adult* (ft)
- #4 young person (ft)
- #5 young people (ft)
- #6 youth (ft)
- #7 #1 or #2 or #3 or #4 or #5 or #6
- #8 disabilities (+NT)
- #9 #7 and #8
- #10 extended school (ft) or extended school day (ft)
- #11 before school care (ft) or after school care (ft)
- #12 breakfast club* (ft) or after school club* (ft)
- #13 extracurricular activit* (ft)
- #14 children's cent* (ft)
- #15 youth work (ft) or youth club* (ft) or youth group* (ft) or youth program* (ft) or youth service* (ft)
- #16 cultural activit* (ft)
- #17 exercise (+NT)
- #18 leisure pursuits (+NT)

- #19 outdoor pursuits (ft)
- #20 art or drama or music
- #21 #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20
- #22 #9 and #21

Research in Practice

(searched and browsed 10/10/08)

Research in Practice is the largest children and families research implementation project in England and Wales. It is a department of the Dartington Hall Trust run in collaboration with the Association of Directors of Children's Services, the University of Sheffield and a network of over 100 participating agencies in the UK.

EvidenceBank database:

- #1 disability (topic filter)
- #2 disabled children (ft)
- #3 disabled youth (ft)
- #4 disabled young people (ft)

The publications database was also searched but contained the same hits as the EvidenceBank. The publications section of the site was also browsed.

Research Register for Social Care (RRSC)

(searched 10/10/08)

The RRSC provides access to information about ongoing and completed social care research that has been subject to independent ethical and scientific review.

- #1 disabled people (kw)
- #2 disabled children (ft)
- #3 disabled youth (ft) or disabled young people (ft) or disabled adolescents (ft)
- #4 disabled students (ft)
- #5 learning disabilities (kw) or physical disabilities (kw)

Social Care Online

(searched 10/10/08)

Social Care Online is the Social Care Institute for Excellence (SCIE) database covering an extensive range of information and research on all aspects of social care. Content is drawn from a range of sources including journal articles, websites, research reviews, legislation and government documents and service-user knowledge.

- #1 disab* (ft) and extended s* (ft)
- #2 disab* (ft) and youth (ft)
- #3 disab* (ft) and sport (ft)
- #5 disab* (ft) and leisure (ft)
- #6 disab* (ft) and recreation not leisure (ft)
- #7 disab* (ft) and play (ft) not leisure (ft) not recreation (ft) not sport (ft)
- #8 disab* (ft) and short breaks (ft)
- #9 disab* (ft) and arts (ft)

#10 disab* (ft) and transition (ft)

#11 disab* (ft) and child care (kw)

Organisations

A list of key organisations was approved by the Theme Advisory Group (see following table). The list, which primarily included the group's specific recommendations, was supplemented by some additional organisations considered relevant by the NFER team. These additional organisations were identified in the NCB organisations database, the BEIRC and through initial 'Google' searches.

Organisation	URL	Records selected
4Children	www.4children.org.uk/	2
Aiming High for Disabled Children	www.everychildmatters.gov.uk/socialcare/ahdc/	6
Barnardo's	www.barnardos.org.uk	2
British Institute of Learning Disabilities	www.bild.org.uk/	0
Cabinet Office	www.cabinetoffice.gov.uk/	1
CanChild	www.canchild.ca	2
Cedar Foundation	www.cedar-foundation.org/	1
Children's Play Information Service (National Children's Bureau)	www.ncb.org.uk/Page.asp?originx6812in_1832991054480z44q6370913124	4
Clubs for Young People	www.clubsforyoungpeople.org.uk	1
Council for Disabled Children (CDC)	www.ncb.org.uk/Page.asp?sve=785	4
Early Support Programme	www.direct.gov.uk/en/CaringForSomeone/CaringForADisabledChild/DG_10027494	0
English Federation of Disability Sports (found via Sports England)	www.efds.co.uk/	2
Every Disabled Child Matters	www.edcm.org.uk	0
I CAN	www.ican.org.uk/	0
Joseph Rowntree Foundation	www.jrf.org.uk	8
KIDS	www.kids.org.uk/	5
National Deaf Children's Society	www.ndcs.org.uk	0
Disability Archive UK	www.leeds.ac.uk/disability-studies/archiveuk	0
National Youth Agency	www.nya.org.uk/	3
Norah Fry Research Centre (Bristol)	www.bristol.ac.uk/norahfry	4
Shared Care Network	www.sharedcarenetwork.org.uk/index.jsp	2
Sparcle Project (Newcastle University)	www.ncl.ac.uk/sparcle/	1
Sport England	www.sportengland.org/	0
Social Policy Research Unit (University of York)	www.york.ac.uk/inst/spru/	2
Strathclyde University (Kirsten Stalker)	www.strath.ac.uk/eps/staff/stalker-kirstenprof/	0

Thomas Coram Research Unit (Institute of Education)	http://ioewebserver.ioe.ac.uk/ioe/cms/get.asp?cid=470	2
Together for Children	www.childrens-centres.org/default.aspx	0
Transition Information Network	www.transitioninforonetwork.org.uk	0
Youth Sport Trust	www.youthsporttrust.org/page/home-welcome/index.html	0

Key texts

The Theme Advisory Group provided a list of recommended texts which were located at the start of the searching process and are listed in the search parameters (Appendix 1).

Search parameters

1. C4EO Theme

Disability.

2. Priority

Improving the wellbeing of disabled children and young people through improving access to positive activities; extended services, youth work, inclusive play and leisure opportunities, sports and the arts.

3. Context for this priority

Lack of access to mainstream services alongside non-disabled peers exacerbates social exclusion for disabled children and young people and this can have long-term and intractable consequences. It also denies them opportunities for enjoyment, achievement and development that these settings afford. There is a lot of policy and service development activity around childcare, play and youth services which needs to take on board and respond to the need for inclusivity. This priority also relates to innovations in terms of short breaks' provision and supporting transitions to adulthood, both of which are key priorities for Aiming High.

4. Main review questions to be addressed in this scoping study (no more than five; preferably fewer)

1. What evidence is there of practice in children's centres/extended schools/youth services fully including disabled children and young people?
2. What do disabled children and young people think about the positive activities on offer (including access to physical activities) in their area, and what activities do they want to do?
3. What support is needed for children and young people to access inclusive activities?
4. What evidence is there that improving access to positive activities improves the wellbeing of disabled children and young people?

5. Which cross-cutting issues should be included?

(Child poverty: equality and diversity; disability; workforce development; change management; leadership; learning organisations)?

As with priority 1, we need to be careful to look for any evidence of success for young people at the more complex ends of the spectrum.

Please specify the review questions for cross-cutting issues in this scope.

6. Definitions for any terms used in the review questions.

7. What will be the likely geographical scope of the searches?

(Work conducted in/including the following countries)

England only	<input type="checkbox"/>
UK only	<input type="checkbox"/>
Europe only	<input type="checkbox"/>
All countries (English language)	<input checked="" type="checkbox"/>

8. Age range for children and young people:

0-25

9. Literature search dates
Start year

1995

10. Suggestions for key words to be used for searching the literature.

11. Suggestions for websites, databases, networks and experts to be searched or included as key sources.

- Early Support Databank
- Prime Minister's Policy Unit (information on children's trusts and what makes a difference to outcomes for disabled children)

- Julie Hathaway – KIDS
- Inclusion/leisure – Pippa Murray – JRF reports; Pat Petrie, TCRU; Jenny Morris; Bryony's chapter, SPRU's work for Sport England (maybe they have replicated it again?)
- Short breaks – Shared Care UK; Norah Fry Research Centre, University of Bristol; Kirsten Stalker – Strathclyde University
- Barriers to participation: SPARCLE project (Allan Colver, University of Newcastle)
- KIDS
- Play England
- Sport England
- Youth Sport Trust
- National Youth Agency
- 4Children
- National Deaf Children's Society
- I CAN

Websites that will be searched:

Organisation

Suggested by

4Children

TAG

Aiming High for Disabled Children

NFER

Barnardo's

NFER

Cabinet Office

TAG

Cedar Foundation

NFER

Children's Play Information Service

NCB

Clubs for Young People

NFER

Council for Disabled Children

NFER

Early Support Programme

TAG

Every Disabled Child Matters

NFER

I CAN

TAG

Joseph Rowntree Foundation

TAG

KIDS

TAG

National Deaf Children's Society

TAG

NCB disabled children's publication list

NFER

Norah Fry Research Centre (Bristol)

TAG

National Youth Agency

TAG

Shared Care UK

TAG

Sparcle Project (Newcastle University)

TAG

Sport England

TAG

Social Policy Research Unit (York)

TAG

Strathclyde University (Kirsten Stalker)

TAG

Thomas Coram Research Unit

TAG

Together for Children

NFER

Transition Information Network

NFER

Youth Sport Trust

TAG

12. Any key texts/books/seminal works that you wish to see included?

- Dunn, K., Moore, M. and Murray, P (2004) *Developing accessible play space. A good practice guide*, London: Office of the Deputy Prime Minister.
- Every Disabled Child Matters (2006) *Off the radar: how local authority plans fail disabled children*, London: Every Disabled Child Matters (available at www.edcm.org.uk/pdfs/edcm_offtheradar_fullreport.pdf, accessed 20 November 2008).
- Every Disabled Child Matters (2008) *Between a rock and a hard place: campaign briefing*, London: Every Disabled Child Matters (available at www.edcm.org.uk/pdfs/edcm_briefing_rock.pdf, accessed 20 November).
- Every Disabled Child Matters (2008) *Going places*, London: Every Disabled Child Matters (available at www.edcm.org.uk/Page.asp?originx_5175bn_2888810122597t49o_20089184948s, accessed 20 November).
- Every Disabled Child Matters (2008) *If I could change one thing: children and young people's views*, London: Every Disabled Child Matters (available at www.edcm.org.uk/pdfs/if_i_could_change_childrens.pdf, accessed 20 November).
- John, A. and Wheway, R. (2004) *Can play, will play: disabled children and access to outdoor playgrounds*, London: National Playing Fields Association (available at: www.npfa.co.uk/downloads/can_play_will_play.pdf, accessed (20 November 2008).
- Murray, P. (2002) *Hello! Are you listening? Disabled teenagers' experience access to inclusive leisure*, York: Joseph Rowntree Foundation (available at: www.jrf.org.uk/bookshop/eBooks/1842630873.pdf, accessed 20 November 2008).
- NIACE report on the benefits of active play.
- Petrie, P., Storey, P. and Thompson, D. (2003) *Inclusive play: supporting provision for disabled children*, London: Institute of Education, University of London.
- Petrie, P., Knight, A., Zuurmond, M. and Potts, P. (2007) *On holiday! Policy and provision for disabled children and their families: report for DfES. Executive summary*, London: Thomas Coram Research Unit, Institute of Education, University of London.
- Play Pathfinders pilots (including those focusing on the value of 'short breaks')
- Shelley, P. (2002) *Everybody here: play and leisure for disabled children and young people. A Contact a Family survey of families' experiences in*

the UK, London: Contact a Family (available at www.cafamily.org.uk/pdfs/leisure.pdf, accessed 20 November 2008).

- Sport England (2001) *Disability survey 2000: survey of young people with a disability and sport*, London: Sport England (available at www.sportengland.org/disabled_young_people_2001_final_report.pdf, accessed 20 November 2008).
- Stobbs, P. (2008) *Extending inclusion: access for disabled children and young people to extended schools and children's centres: a development manual*, London: Council for Disabled Children (available at <http://publications.teachernet.gov.uk/eOrderingDownload/CDC-00186-2008.pdf>, accessed 20 November).

DATABASES: ASSIA; BEI; BEIRC; CERUKplus; ChildData; EEP; PsycINFO; Research in Practice; Social Care Online

13. Anything else that should be included or taken into account?

There are two issues covered in this priority: access to mainstream activities and access to positive activities which may not be mainstream.

Need to explore the interpretation of the five Every Child Matters outcomes for disabled children: what does this mean in practice?

Important to bear in mind parents' and children's self-definition of 'disability' and 'wellbeing'.

Important to include notions of family resilience.

Appendix 3: Relevant national indicators and data sources

Table 2 identifies the relevant national indicators and data sources relevant to the disability theme and its three priorities:

2.1 – Improving the wellbeing of disabled children (up to the age of eight) and their families through increasing the **quality and range of early interventions**.

2.2 – Improving the wellbeing of disabled children and young people (up to age 25) through **improving access to positive activities**: extended services, youth work, inclusive play and leisure activities, sports and the arts.

2.3 – Ensuring all disabled children and young people and their families receive **services which are sufficiently differentiated** to meet their diverse needs.

Table 2 National indicators and data sources, by Every Child Matters outcomes

Be healthy							
National Indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Links to data source (and comments about trend data)
N154	Services for disabled children	Children in Need Census	National, regional and local authority Data based on 0-17 year olds	Biannual	February 2005	February 2000	www.dcsf.gov.uk/rsgateway/DB/VOL/v000647/vweb02-2006.pdf Trend data available.
		Population Census (2001)	UK, regional and local authority	Every10years	2001	1801	www.nomisweb.co.uk/home/census2001.asp Trend data available
		People registered as blind/partially sighted, Information Centre (2006)	National, regional and local authority Data available on children aged 0-4 and 5-17 years	Every three years	2006	1982	www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/people-registered-as-blind-and-partially-sighted-triennial-2006-england Trend data available
		People registered as deaf or hard of hearing (March 2007), National Statistics/DH	National, regional and local authority Data based on 0-17 year olds	Every three years	2007	1989	www.ic.nhs.uk/webfiles/publications/Registdeaf2007/2006-07%20Deaf.pdf Trend data available
		NFER/RNIB survey of local authority visual impairment services	National (100 English local authorities and/or consortia) Data available on children aged 0-23 months, 24-35 months and 36-59 months	Ad hoc (1995, 2002, 2007)	2007	1995	www.rnib.org.uk/xpedio/groups/public/documents/code/public_rnib001971.hcsp No trend data available yet
		BMRB Social Research Childcare and Early Years Providers Surveys: Children's Centres (2007)	National data only	Ad hoc (1998, 2001, 2005, 2006, 2007)	2007	1998	www.dcsf.gov.uk/research/programmeofresearch/projectinformation.cfm?projectId=15516&resultspage=1 Trend data likely
		OPCS surveys of disability	Great Britain only	Ad hoc (between 1985 and 1988)	1988	1985	www.statistics.gov.uk/STATBASE/Product.asp?vlnk=8008&More=Y Trend data likely
		General Household Survey (2006)	Great Britain only Data available on children aged 0-4 and 5-17 years	Annual	2006	1971	www.statistics.gov.uk/StatBase/Product.asp?vlnk=5756 Trend data available

Improving access to positive and inclusive activities

Be healthy (cont)							
National Indicator (NI)	NI detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Links to data source (and comments about trend data)
		Family Resources Surveys (2005/6)	Great Britain and Northern Ireland, and regional data Data based on 0-17 year olds	Annual	2005/6	1979	www.data-archive.ac.uk/findingData/snDescription.asp?sn=5742 Trend data available
		Health of Children and Young People	UK	Ad hoc	2001	1953	www.statistics.gov.uk/cci/nugget.asp?id=795 www.statistics.gov.uk/Children/downloads/disability.pdf Trend data available
		Health Survey for England	England only	Annual	2006	1991	www.esds.ac.uk/government/hse/ In 2002, the survey focused on children, young people and maternal health. Trend data available

Stay safe							
National Indicator (NI)	NI Detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Links to data source (and comments about trend data)
NI69	Children who experience bullying	Youth Cohort Study and Longitudinal Study of Young People in England: Activities and experiences of 16 year olds: England 2007	National	Annual	2007	2004 (for LYSPE), and 1985 for YCS	www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml Trend data available

Improving access to positive and inclusive activities

Enjoy and achieve							
National Indicator (NI)	NI Detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Links to data source (and comments about trend data)
NI72-	Achievement of at least 78 points across the Early Years FS with at least 6 in each of the scales in PSED and CLL	Foundation Stage Profile	National, regional and local authority	Annual	2007/8	2003/4	www.dcsf.gov.uk/rsgateway/DB/SFR/s000812/index.shtml Secondary analysis required to explore attainment of students with SEN/ a disability Trend analysis may be possible for some years. However, the data collection changed in 2006/7, so data is not comparable for all years.
NI92	Narrowing the gap between the lowest achieving 20% in the Early Years FS Profile and the rest	Foundation Stage Profile	As above	As above	As above	As above	As above
NI104	The SEN/non-SEN gap – achieving Key Stage 2 English and Maths threshold	National Curriculum assessments, GCSE and equivalent attainment and post-16 attainment by pupil characteristics, in England 2006/7	National, regional and local authority	Annual	2007	2002	www.dcsf.gov.uk/rsgateway/DB/SFR/s000759/index.shtml Trend data available
NI105	The SEN/non-SEN gap – achieving 5 A*-C GCSEs including English and Maths	National Curriculum assessments, GCSE and equivalent attainment and post-16 attainment by pupil characteristics, in England 2006/7	As above	As above	As above	As above	As above
		Pupil Level Annual School Census (PLASC) and the SEN2 survey	National only Data on approximately eight million pupils in maintained schools age 2-18 years	Annual	2008	1984/5	www.dcsf.gov.uk/rsgateway/DB/SFR/s000794/index.shtml Trend data available

Positive contribution							
National Indicator (NI)	NI Detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Links to data source (and comments about trend data)
NI110	Young people's participation in positive activities	Health of Children and Young People (March 2004), ONS	See above (in 'Be healthy' section)	See above (in 'Be healthy' section)	See above (in 'Be healthy' section)	See above (in 'Be healthy' section)	See above (in 'Be healthy' section)

Economic wellbeing							
National Indicator (NI)	NI Detail	Data source (published information)	Scale (published information)	Frequency of data collection	Latest data collection	First data collection	Links to data source (and comments about trend data)
NI116	Proportion of children in poverty	Family Resources Survey (2005/6)	See above (in 'Be healthy' section)	See above (in 'Be healthy' section)	See above (in 'Be healthy' section)	See above (in 'Be healthy' section)	See above (in 'Be healthy' section)
NI117	16-18 year olds who are not in education, employment or training (NEET)	Youth Cohort Study (2007)	England and Wales only Data based on 19 year olds	Annual	2007	2004	www.dcsf.gov.uk/rsgateway/DB/SFR/s000760/index.shtml Trend data available

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Improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities

This review examines the evidence on how services can improve disabled children and young people's access to inclusive and positive activities and the impact this can have on their wellbeing. It also identifies the most promising directions for future research and development. The review was carried out by Barnardo's on behalf of the Centre for Excellence and Outcomes in Children and Young People's Services (C4EO). Strategic decision-makers working in Children's trusts may also find it helpful to read the progress map summary that complements this review.

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