

**DISABILITY**  
KNOWLEDGE REVIEW 2

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

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# 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 partners working with them, to improve outcomes for children, young people and their families.

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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.

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

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## Summary

This knowledge review tells us what works in improving access to positive and inclusive activities for disabled children and young people. It is based on a rapid review of the research literature involving systematic searching, analysis of key data, promising local practice examples and views from service users and providers. It summarises the best available evidence that will help service providers to improve services and, ultimately, outcomes for children, young people and their families.

The Social Policy Research Unit at York University carried out this review on behalf of the Centre for Excellence and Outcomes in Children and Young People's Services (C4EO). The National Foundation for Educational Research (NFER) conducted the data work.

## What did we find out?

### Key messages from our knowledge review

- Participating in positive activities is associated with positive outcomes in terms of children's health, experiences of enjoyment and achievement and community participation.
- 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. 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).
- Disabled children and young people report that negative attitudes spoil their experiences of, or stop them accessing, inclusive activities or using local leisure and recreation facilities. Staff working in these facilities should be trained in disability awareness. These services or settings should operate a zero tolerance of bullying policy and actively work to ensure that this is adhered to, paying particular attention to preventing bullying directed at disabled children and young people using their facilities.
- Disabled children and young people appear to have very limited opportunities to access positive activities in their local areas. They want more and different things to do so that they can choose where and how they spend their free time. Existing services need to monitor the numbers of disabled children and young people participating in or accessing positive activities in their locality.
- Achieving inclusion for disabled children requires planning, resources and the active involvement of skilled staff. There is a need to conduct 'access audits' of generic play, leisure, sport, arts and cultural facilities to ensure that they are inclusive. Issues such as the physical environment and transport need to be considered, as well as the workforce issues. Consultation activities regarding the development of services that provide positive activities need to involve or represent all groups of disabled children and young people.

- Disabled children and young people value provision that 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. 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.
- 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. An information strategy should be developed that brings together local agencies and embraces the statutory, private and third sectors. This strategy should refer to the 'core offer' from *Aiming high for disabled children* (HM Treasury and DCSF 2007b), which encompasses minimum standards on information and transparency. 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.
- 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.

## Who are the key stakeholders?

- disabled children and young people
- parents/carers of disabled children and young people
- providers and staff working in leisure and play settings, including children's centres, leisure centres, play and recreation facilities
- local authority children's and disability services, as well as other health and social care professionals who work with disabled children and young people
- universal providers such as youth services
- policy-makers.

## Their contributions are valuable in the process of improvement

- **Disabled children and young people** require access to a wide choice of leisure and play activities in supportive environments that are truly inclusive.
- **Parents and carers** of disabled children can act as advocates for their children and support them in their efforts to take part in activities that they enjoy. They are in a position to access information about services and interpret this information for their children.
- **Staff** working in leisure and play services, as well as the **providers** of those services, have a vital role to play in ensuring that disabled children and young people have equitable access to their facilities, are involved in planning and implementation of services and are treated positively and supported sufficiently in their use of those services.



- **Local authority services** are in a position to ensure that all their leisure and play services are inclusive and provide suitable access to disabled children and young people. They are able to make sure that information is provided to families with disabled children in suitable and easily accessible formats. They can also introduce auditing systems to guarantee that all their facilities are meeting the needs of disabled children and their families.
- **Policy-makers** are essential for providing the necessary drivers to encourage service providers to review their leisure and play provision for disabled children and young people and implement the necessary changes to make it accessible and inclusive.

## What data is available to inform the way forward?

Local and national datasets are publicly available on the prevalence of disability, including by background characteristics (such as age, gender and ethnicity). Meanwhile, the disabled children's services national indicator (NI54) measures parental experiences of services provided to disabled children, based on a national sample survey of parents. NI54 results became available from 2008–09. There are also datasets relating to the social and living circumstances of disabled children and their families. These datasets provide useful monitoring data that can be tracked over time, such as on the prevalence of disability.

Of particular relevance to this theme is national indicator 110: young people's participation in positive activities. At present, some publicly available data on the participation of young people in general in positive activities is available, for example in the Taking Part survey (DCMS 2009), the Department for Children, Schools and Families (now the Department for Education) TellUs survey (Chamberlain *et al* 2010), the Youth Cohort Study and the Longitudinal Study of Young People in England (DCSF 2008b). These datasets, however, presently only provide a breakdown of children and young people's engagement in positive activities by their disability status for a limited number of these activities.

[C4EO's interactive data site](#) enables local authority managers to evaluate their current position in relation to a range of key national indicators and to easily access publicly available comparative data on disabled children.

## 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.

## Knowledge review methods

This knowledge review is the culmination of an extensive knowledge-gathering process. It builds on a scoping study and research review, which are available on the [C4EO website](#).

Research literature was identified through systematic searches of relevant databases and websites, recommendations from our Theme Advisory Group and considering studies cited in identified literature ('reference harvesting'). The review team used a 'best evidence' approach to systematically select literature of the greatest relevance and quality to include in the review. This approach attempts to eliminate bias in the selection of literature, to ensure that the review's findings are as objective as possible.

Data contained within the data annexe was obtained by a combination of search methods but primarily by obtaining online access to known government publications and access to data published by the Office for National Statistics.

The review also contains examples of promising local practice sent in from the sector, which have been assessed by specialists in the field of child disability as part of an ongoing process to gather evidence-informed practice. C4EO knowledge reviews usually contain validated practice examples, but no practice examples have been validated in this area yet. Validated practice examples have strong outcomes evidence of impact on population groups, whereas promising practice mainly has qualitative outcome and output evidence, which refers to systems change. The full versions of all of the practice examples contained within this review, and those published since the review was written, are available on the [C4EO website](#)

Evidence was also gathered from service providers during discussion groups at C4EO knowledge workshops, while evidence from people who use services was collected via consultation with a small number of disabled children and young people and parents of disabled children and young people. People who use services and/or providers are contributors to many of the studies included within the review too.

# 1 Introduction

This review aims to draw out the key ‘what works?’ messages on improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities. It addresses four questions, which were set by the C4EO Theme Advisory Group, a group of experts in disability policy, research and practice. These questions are:

- 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?

Reviews on improving disabled children and young people’s wellbeing through early years interventions and ensuring that services are sufficiently differentiated are also available on the C4EO website

The reviews are based on:

- the best research evidence from the United Kingdom (UK) – and where relevant from abroad – on what works in improving services and outcomes for children and young people
- the best quantitative data with which to establish baselines and assess progress in improving outcomes
- the best validated local experience and practice on the strategies and interventions that have already proved to be the most powerful in helping services improve outcomes, and why this is so
- service user and provider views on ‘what works?’ in terms of improving services and outcomes.

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).

C4EO will use the reviews to underpin the support it provides to those providing children’s services to help them improve service delivery, and ultimately outcomes for children and young people.

## Definitions of key terms

The following definitions were agreed by the Theme Advisory Group.

For the purposes of this study, the research team adopted the definition of '**disability**' given in the *Disability Discrimination Act 1995* (GB. Statutes 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'.

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 the cinema, theatre and events, museums, galleries and places of interest, youth groups and other activities.

The term '**outcomes**' was 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 that 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 that 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 was 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.

## Types of evidence used

The research included in this review was identified through systematic searching of key databases, reference harvesting or recommendations from the Theme Advisory

Group. All research included was appraised to ensure that the evidence presented is the most robust available.

The review also contains examples of e presented is the mostice that have been gathered from the sector and assessed as having good potential to have a positive impact on outcomes for children and young people by specialists in disability. (See Appendix 5 for C4EO's promising local practice assessment criteria.)

Evidence was also gathered from service providers during discussion groups at C4EO knowledge workshops. Meanwhile, views of parents and carers were collected via a panel discussion and of children and young people through a group discussion conducted by the Council for Disabled Children and also through questionnaires and interview feedback conducted by the National Children's Bureau (see Appendix 6 for more details of the process).

Data contained within the data annexe was obtained by a combination of search methods but primarily by obtaining online access to known government publications and access to data published by the Office for National Statistics.

## Strengths and limitations of the review

**Strengths** of the review include 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 quality and strength of evidence; and guidance from an advisory group on the issues of greatest importance in disability research, policy and practice.

**Limitations** of the review include the very tight deadlines that the review had to meet, which limited the ability of the team to extend and develop the evidence base through reference harvesting and hand searching; and the fact that the review was limited to English-speaking countries.

## 2 Policy context

It should be noted that this Review was written before the new coalition government was elected in May 2010. It is widely accepted that social exclusion is a common experience of disabled children and young people and their families. These children and young people 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 (United Nations Convention on the Rights of the Child). It is essential, therefore, that generic policy activity and consequent developments in services around childcare, 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 (HM Treasury 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 former government's vision, set out in 2004, was that by 2010 every community in England would have a Sure Start children's centre (HM Treasury *et al* 2004). The following year, the same 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.

In *Aiming high for young people* (HM Treasury and DCSF 2007a), the former government set out a 10-year strategy to transform leisure-time opportunities, activities and support services for young people in England and in March 2010, the Department for Children, Schools and Families (now the Department for Education) published its draft *Quality standards for positive activities* (DCSF 2010a), which are aimed at commissioners and providers and will help them to ensure that provision is high quality and contributes to the achievement of the Every Child Matters 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 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 former government was committed to improving access to play and positive activities for all children and young people. The Children's Plan (DCSF 2007) set out clear policies on play, put forward a national *play strategy* (DCSF 2008) and was accompanied by a not insubstantial investment in play services.

The attention of the former government has also focused on older children and teenagers with the publication of the Ten-year Youth Strategy, which set 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, 2006a) 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 2005* (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.

At an international level, the UK signed up to the Convention on the Rights of Persons with Disabilities (CRPD) in February 2009. Article 30 of this convention focuses on participation in cultural life, recreation, leisure and sport and places a duty on 'States parties' to take appropriate measures 'to ensure that children with disabilities have equal access with other children to participation in play, recreation and leisure and sporting activities' (UNICEF Innocenti Research Centre 2007).

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 former 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 (DH 2005 p 13).

In addition, two key activity areas within *Aiming high for disabled children* (HM Treasury and DCSF 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. *The families and relationships Green Paper* (DCSF 2010b) published by the former government, announced that the Aiming High for Disabled Children programme would increase provision of short breaks for families with positive activities for disabled children. It also highlighted that, from 2009, all local authorities have been receiving funding to allow over 3,000 public play areas to be rebuilt or renewed to make them accessible to disabled children (DCSF 2010b). Two reports looking at the impact of short break provision on disabled children and young people and their families have also just been published by the Department for Children, Schools and Families (now the Department for Education) (Langer *et al* 2010; Robertson *et al* 2010).

In summary, there is 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 for those involved in implementing policy and overseeing change at a local level.



## 3 The evidence base

The evidence base for this review consists of three main sources:

- a literature review updating the research review (Beresford and Clarke 2009) with further published evidence as suggested by the Theme Advisory Group; in total, 70 sources were drawn on for this review
- [promising local practice](#) gathered from specialists in the disability sector and assessed by an expert panel as having a positive impact on children's outcomes
- stakeholder views gained through C4EO organised group discussions about key issues affecting disabled children and young people's access to positive and inclusive activities. This consultation exercise included parents, carers, disabled children and young people and, separately, local service providers.

The Theme Advisory Group recommended additional sources of evidence for inclusion in the literature review, which either helped to fill gaps identified in the previous research review (Beresford and Clarke 2009) or related to studies published after the review. These references were assessed by the review team for relevance and the resulting new references were incorporated into the review. In total, 16 new references were included.

### The original research 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 reassessed 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 on a range of methodological approaches.

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

### Limitations of the evidence base

- There was a lack of research conducted in England, which required 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 that was highly relevant to the review questions, it was necessary to include studies where the main research questions were different from 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 that 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; a national survey of participation in sport by disabled children and young people; an 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; and qualitative research on disabled children and young people's experiences of using inclusive play and leisure services.

## What do 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 that explored patterns of participation in extra-curricular activity, problems associated with local leisure facilities, the perceptions and usage of extended services in schools, and life outside the classroom; qualitative studies that focused exclusively on the leisure experiences of families with disabled children; qualitative studies that explored the leisure experiences of disabled children as part of a wider study of their lives; national consultations that explored the leisure experiences of disabled children as part of a wider study of their lives; qualitative studies that focused on 'inclusive' leisure; and mixed-method studies that 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; and 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; and 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 of 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; and qualitative research with children, young people and their parents about their everyday lives.

## 4 What do service users and providers tell us about what works?

The experiences of children and young people, parents and carers and those providing services to them add much to our knowledge of what works in relation to improving access to positive and inclusive activities through effective practice in services for disabled children and young people. Service users and providers contribute to much of the research evidence presented in subsequent sections. However, it is important to remember that this section is drawn from discussions with groups of stakeholders and is therefore reporting experiences and opinions rather than the research evidence on which the rest of the review is based.

The main messages that emerged from the consultation were:

- the need for greater clarity regarding the meaning of ‘inclusion’ and, ideally, a working definition that is agreed by disabled children and their families, policy-makers and service providers alike
- the importance of challenging attitudes towards disabled children and young people, those of both the general public and staff within leisure and play facilities
- the need for workforce development and training for staff working in play and leisure facilities
- the need to address a number of practical issues that are preventing children and young people from accessing the positive activities they would like to take part in – in particular, the lack of suitable transport facilities, provision of sufficient support and provision of easily accessible information about services that are available
- the need for greater choice of accessible activities, both segregated and non-segregated
- the need for service providers to review their play and leisure provision for disabled children and young people to make sure that it is inclusive and accessible
- the importance of involving disabled children and young people and their parents/carers in evaluating, planning and commissioning play and leisure services within their local community.

### Views from service users

#### Children and young people

Sixteen disabled children and young people gave their views on: the barriers that prevented them from accessing positive and inclusive activities; what changes might be made to increase their ability to access those activities; and their aspirations for getting involved. Many of their views reflect the findings of the research evidence discussed in the following sections.

The most significant **barriers** to accessing activities were:

- **Other people's attitudes**

The young people who were interviewed cited both the attitudes of staff in leisure facilities and those of the general public as being problematic. They felt that there was pressure on them to be grateful for help even when it was not welcome:

"They asked me what it felt like to be carried like a princess, little did they know that it actually made me feel excluded and lose my dignity." (young person)

They were also afraid of being bullied and made to feel different:

"Just because you talk funny, people think you are thick." (young person)

There was a feeling that a shift in attitudes was needed and that accessibility was not just about ramps and wide entrances but about the way disabled people were treated.

Those with communication requirements also felt less able to access services because of people's attitudes and inability to communicate with them:

"Everyone can communicate in some way, talking, touching, smiling, looking. People should take the time to communicate in whatever way suits us. Everyone needs this opportunity." (young person)

- **Lack of suitable transport**

Transport was seen as a major issue with regard to access to leisure activities. This included having to plan for journeys far in advance, high costs of fares and the attitudes of transport providers:

"It doesn't matter how good things are, if you can't get there in the first place, what's the point?" (young person)

Young people need to learn independence and this is true for those with disabilities as well as those without. If there is a lack of suitable transport to access leisure and social activities then disabled young people have to rely on their parents and/or carers if they are to take part in the activities they have chosen.

- **Lack of support**

The young people with whom the National Children's Bureau and the Council for Disabled Children consulted felt that there was also a lack of suitable support for them to access the activities of their choice. This was thought to be particularly the case for teenagers, who may want to go to things in the evenings or at weekends when formal support may not be available.

A number of ways in which children and young people's **access to positive activities might be improved** were suggested. These included:

- involving disabled children and young people in the evaluation and development of services
- increasing the number of accessible services for disabled children and young people
- increasing the amount of choice in relation to positive activities, both segregated and non-segregated
- improving the amount of information available to families about services and other play and leisure facilities and opportunities
- ensuring that services evaluate and review their provision to make sure that it is truly inclusive and accessible

The disabled young people felt that their opportunities to access leisure and positive activities were reduced because of their disability. They observed that there was a lot of talk about 'inclusion' but, in reality, services were usually segregated and young people rarely met in truly inclusive settings. There was scepticism among these young people about whether anything would actually change.

## Parents

Many of the themes brought up by parents in C4EO's Parents and Carers Panel (run by the Family and Parenting Institute) echoed those discussed in the children and young people's consultation.

Parents felt that there were a number of **barriers** that inhibited their children's access to positive and inclusive activities. These included:

- a lack of sufficient funding to provide fully inclusive services
- a lack of suitable support for children and young people to access positive activities, such as adequately trained staff and easily available information
- the cost of taking part in certain activities
- a lack of suitable/affordable transport, especially in rural areas
- not enough choice of activities that are both segregated and non-segregated.

Parents were asked about their views on local provision of positive and inclusive services for their children. There was a feeling that there was confusion over what 'inclusion' meant and that there should be an agreed definition that all services could work to. Some parents described services as "limited" in their area but some felt that things were beginning to improve. It was thought that parents needed to be proactive but that services should also have a 'can do' attitude towards providing inclusive services for disabled children and young people. Some parents felt that there was not enough access to inclusive sports facilities. There was also a feeling that those with 'hidden disabilities', such as autism, suffered from a lack of understanding. In one area, a recent consultation by the local authority on play and leisure facilities with parents and disabled children had been seen as successful. Various new initiatives had been planned as a result, such as the development of a social inclusion support team and additional weekend and evening activities.

Parents gave a number of suggestions for ways in which they could be supported to access positive activities for their disabled child. These included:

- making sure that staff in leisure facilities were fully trained to support disabled children and young people
- increasing awareness of disability issues
- increasing inclusive provision
- ensuring that provision of information about services is sufficient for parents and disabled children and young people, possibly considering the use of service directories
- improving transport services
- improving knowledge about how to support children and young people with complex and severe disabilities.

## Views from service providers

C4EO held seven regional workshops to discuss the findings from an earlier version of this review. Local service providers were asked to identify the key strategic issues for their areas in terms of the research evidence described in the previous review. They were also asked to discuss the opportunities or 'levers' available to them to make an impact.

## Key strategic issues

### **Workforce development**

Service providers felt that there was a lack of skills and confidence within the workforce and that there was an urgent need for training and awareness-raising in relation to disability issues concerning children and young people. They thought that it was partly a cultural issue and that 'hearts and minds' had to be engaged in order to effect change. The message needs to be that providing inclusive services for disabled children and young people is "everyone's business". They also considered the attitudes of the general public to be problematic.

### **Resources**

Service providers identified a lack of suitable funding sources as a barrier to improving services for disabled children and young people. They also expressed concerns about the sustainability of activities once the funding stream from Aiming High for Disabled Children had dried up.

### **Evaluation and monitoring**

Service providers thought that there was a need to monitor inclusiveness and outcomes in leisure and play services. The involvement of children and young people in the evaluation and planning of services would support this.

## Practical issues

Providers raised various practical issues that created barriers for disabled children and young people in relation to accessing services. These included the provision of suitable transport, the provision of suitable changing facilities in leisure settings and the provision of easily accessible information to families.

As with parents, service providers also noted the lack of understanding by some professionals in relation to the meaning of 'inclusion'. They also felt that there was a lack of clarity about the links between improved leisure and play opportunities and improved wellbeing of disabled children and young people.

## Opportunities and levers

The discussions highlighted a number of legislative and policy documents as being potentially useful in addressing the challenges facing service providers in relation to improving access to positive activities for disabled children and young people. These included:

- the ***Disability Discrimination Act 2005*** (GB. Statutes 2005), which could act as a lever for influencing training and awareness of staff
- the ***Aiming high for disabled children programme*** (HM Treasury and DCSF 2007a and b), which could provide some opportunities, such as the Parents' Forums and the chance to jointly commission with neighbouring local authorities
- the ***Children's Plan*** (DCSF 2007)
- **kite marks** and the new **national indicator (NI54)**, which looks at parental experiences of services for disabled children.

Providers also saw individual budgets as an opportunity for improving access to services. This facility would potentially enable children and young people to access the services that they want by using their funding to provide tailored support or transport. Another suggestion for improving transport services was to extend the 'taxi token' system, currently used by looked-after children, for disabled children and young people.

Service providers suggested linking in with the voluntary and community sector as another possible avenue for improving support for disabled children and young people to take part in positive activities. They suggested that parents could also be trained alongside providers to increase their influence and ability to improve services. Again, involving parents and children in planning and commissioning services was seen as important.



## 5 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 centrally driven models but locally delivered 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 that 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.

### 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' analysis of a sample of local authorities' Children and Young People' Plans (EDCM 2006) found that only five out of 20 Plans referred to disabled young people in their plans for youth services. Where Plans 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 7 per cent of its users are 'registered disabled'.

One initiative related to youth service reform was the Empowering Young People Pilots. These ran from October 2007 to March 2009 in nine local authorities and aimed to encourage disadvantaged young people<sup>1</sup> to take part in positive activities of their choice. Funding was provided, which removed the financial barriers often encountered by young people travelling to, accessing or attending an activity.

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<sup>1</sup> Disadvantaged young people are defined by Empowering Young People Pilots 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 (Bielby *et al* 2008).

Evaluations of these pilots have been conducted and interim findings showed that disabled young people living in the 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). The activities included sporting activities, performing and/or creative arts, courses or learning-related activities and going to the cinema or theatre. The final evaluation found that young people limited by a disability used their Empowering Young People Pilot funds less frequently than those without a disability. However, there was some evidence that the pilots may have helped some young people with limiting disabilities to participate more often in sporting activities than they had been able to prior to the scheme (Bielby *et al* 2010).

## 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), reported that parents of primary school-aged children with special educational needs were least likely to feel that their needs were being met by current activities and childcare provision. This research also found that extended school provision was less likely to be used in special schools compared to mainstream schools.

A regional evaluation of extended schools across 10 local authorities (East Together and Sure Start Project 2005) provides further evidence on the inclusion of disabled children. It suggests that 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 not seen as a priority. More progress appeared to have been made in inclusive practice terms in out-of-school clubs and play schemes, with clubs actively addressing this issue, by providing either specialist and/or inclusive schemes/sessions. Secondary analysis of after-school and holiday childcare 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 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.

## 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 Sure Start Local Programmes<sup>2</sup> in 12 local authorities identified as working innovatively in terms of inclusive practice and provision (Pinney 2007) reported 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 included: 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 noted that increased early years provision – even high-quality provision – did not necessarily mean an increase in inclusive provision.

## Further evidence

There is further evidence on inclusive play and leisure provision, which is not located within specific evaluations of children’s centres, extended schools or youth services 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 programme 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. It consisted of either:
  - 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 that 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.

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<sup>2</sup> 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 that Sure Start Local Programmes were required to deliver.

The 'separate but the same opportunities' approach was much less common and presented by providers as provision that 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.

McDowell and Fisk (2005) also encountered differences in parents' and providers' interpretations of the meaning of inclusion in their study looking at the needs of disabled children and young people in relation to accessing play and leisure activities in the East Midlands.

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, while examples of apparent good practice<sup>3</sup> in play and holiday schemes were identified, such practice was not found to be comprehensive either within or across local authorities.

Follow-up casework in six local authorities provides some more detailed information about inclusive play and leisure provision in one region, although 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'.

A consultation with stakeholders from eight local authorities exploring disabled children's participation in services (Council for Disabled Children 2009) found that respondents blamed their inability to make services more accessible and inclusive for disabled children and young people on a lack of resources to support universal participation structures.

Murray's (2002) 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. 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 reported 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 suggested that there may be more opportunities for disabled children to access holiday play schemes than after-

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

school clubs, and that the fewest opportunities for participation were experienced by children with the most complex or profound needs.

**Promising practice example: Developing inclusive holiday play provision**

*What is it?* The Play Development Team from the London Borough of Enfield was aware that disabled children were not accessing their holiday play provision scheme. They teamed up with the Joint Service for Disabled Children to develop a new play scheme that they hoped would become a model for future service development. In order to establish robust consultation processes, a Children and Young People's Panel was formed in order that young 'consultants' could contribute to the planning and evaluation of the service, and also future provision in Enfield.

*What does it do?* Initially, a pilot scheme consisting of six 'inclusive taster days' was run in which children from specialist play schemes were supported to take part in mainstream holiday activities. A number of issues were highlighted, which were then addressed before the full scheme was put in place. In total, 31 children took part in the first summer play scheme.

*Why is it different?* Disabled children and young people are supported to access inclusive, mainstream holiday play provision, which has been set up as a result of partnership working.

*What has it achieved?* Feedback from children and parents found that the scheme was successful in terms of the children's enjoyment and parents' satisfaction. Staff felt that there was a sense of 'joint ownership' between specialist and universal provision.

## 6 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 the 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.

### 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 2,000 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 per cent versus 46 per cent)
- participating in Girl Guides or Boy Scouts (11 per cent versus 25 per cent )
- a member of a youth club (8 per cent versus 20 per cent )

- a member of a church or religious club (4 per cent versus 7 per cent ).

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 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 reported 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. The Prime Minister's Strategy Unit's report on improving the life chances of disabled people found that although disabled young people saw maintaining an active leisure and social life as of primary importance to them, they did not feel that those involved in planning services felt the same way and did not feel that their views were always taken into account (Prime Minister's Strategy Unit *et al* 2005).

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 were 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 or disability, with children and young people with learning difficulties, autism or multiple disabilities being the least likely to be participating in positive activities.

## What disabled young people enjoy about positive activities

The value that young disabled people attach to play and leisure activities that 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; Thompson *et al* 2000; Keil *et al* 2001; Murray 2002; Turner 2003; Ludvigsen *et al* 2005; Petrie *et al* 2007; EDCM 2008).

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) reported that this social component of activities influenced leisure time preferences among the 15 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 noted 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.

## 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 and 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. Disabled children and young people from the Awaaz Project and their parents (Raghavan and Pawson 2009) expressed the view that the most significant barriers to them accessing leisure activities were concerns about safety, lack of suitable transport, lack of individual support and a lack of information. 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) noted that there were 'generic' reasons for disabled young people's lack of participation in activities, which are not necessarily related directly to their disability. These included 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 noted 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 (Petrie and Poland 1998; Keil *et al* 2001; Turner 2003; Kelly 2005; EDCM 2007a and b, 2008; Petrie *et al* 2007).



Turner's (2003) consultation with 105 disabled children in Wales about the services they use reported 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.

Contact a Family at some disabled children would have liked led children reported that over 70 per cent of respondents said that their children would have liked led children reported that over 70ents with children with similar abilities to their ow per cent reported that opportunities to enjoy play and leisure together as a family were poor or unsatisfactory (Bennett 2009). Families wanted more opportunities to enjoy leisure together and they also wanted real choice in the activities that they could take part in. ScopewanDisablism Audit, which surveyed 500 families with disabled children as well as 1,000 families without a disabled child, also reported that the majority (58 per cent) of families with a disabled child found it difficult to access leisure activities. This was in contrast to families without a disabled child, where 80 per cent found it easy to access leisure activities (Pyer and Bush 2009). McDowell and Fisk9).cess leisure activities (Pyer and Bush 2009).80uPyer and BushBushFisk9). per cent of families with disabled children reporting difficulties accessing clubs and leisure activities.

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 (Widdows 1997; Keil *et al* 2001; Shelley 2002; Ludvigsen *et al* 2005; Petrie *et al* 2007; Bennett 2009) 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).

### **Promising practice example: Disabled young people taking action to improve access to leisure centres**

*What is it?* Disabled young people in the Time 4 Change participation group at the Children's Society PACT project in the City of York felt that local leisure centres were not very inclusive or accessible to disabled young people. They decided to take action to improve the situation for themselves and their disabled peers.

*What does it do?* Nine disabled young people each visited three local leisure centres on four separate occasions in order to investigate their accessibility and inclusivity. They recorded their findings and produced a DVD and report for City of York Council, which included recommendations for action.

*Why is it different?* Disabled young people were enabled to take action to assess and improve leisure facilities in their local area.

*What has it achieved?* A year later the young people revisited the leisure centres to see if any improvements had been made. Almost all their recommendations had been put into place in two of the leisure centres. (The other one was due to be demolished and hence had not made improvements.) In particular, the young people found that staff attitudes had positively changed as a result of their

## **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 in positive activities for disabled young people (Petrie and Poland 1998; Keil *et al* 2001; Turner 2003; Kelly 2005; Ludvigsen *et al* 2005; Petrie *et al* 2007; EDCM 2008; Bennett 2009; Raghavan and Pawson 2009). Parental concerns about staff skills regarding the support needs of disabled children and young people were identified as a barrier to children undertaking positive activities in mainstream settings (Kelly 2005; McDowell and Fisk 2005). In addition, there was 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* (2001) study, 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, 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 (Keil *et al* 2001; EDCM 2008; Mencap 2008; Pyer and Bush 2009).

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; Keil *et al* 2001; Shelley 2002; McDowell and Fisk 2005; Mencap 2008).

## 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; Bennett 2009; Campbell-Hall *et al* 2009).

## 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 (Thompson *et al* 2000; Keil *et al* 2001; Murray 2002; Shelley 2002; Audit Commission 2003b; Turner 2003; Kelly 2005; Petrie *et al* 2007; Raghavan and Pawson 2009). 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) (Murray 2002; Mencap 2008), 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 (Turner 2003; Kelly 2005; Petrie *et al* 2007)
- lack of clarity within local authorities regarding roles and responsibilities for providing information to families (Kelly 2005)
- fragmentation of information provision (Audit Commission 2003b; Kelly 2005)

- information provision that is restricted to existing users only, with no system or strategy for how other families (non-service users) could receive information (Murray 2002; Kelly 2005)
- non-specialist provision not indicating whether or not the service is inclusive (Kelly 2005; Petrie *et al* 2007).

### **Promising practice example: Improving parents' ability to identify inclusive leisure and play services**

*What is it?* A Mencap report in 2001 found that there was very little in terms of inclusive play and leisure for disabled children and young people in Dudley in the West Midlands. In order to address this shortfall, Mencap, in partnership with Dudley Metropolitan Borough Council, introduced the *me2* kite mark award for inclusive children's settings.

*What does it do?* The *me2* award recognises, promotes and celebrates inclusive service provision for disabled children and young people. In order to achieve the award, play and leisure settings have to demonstrate their inclusiveness. The *me2* project also involves providing training to children and young people, empowering them to contribute their opinions effectively and be actively involved in running the project. They are involved in carrying out audits and giving the awards.

*Why is it different?* The *me2* project involves young people in assessing and evaluating services instead of relying on adult experts. Service providers have tangible evidence of their inclusive service provision and service users are well informed about suitable, inclusive leisure services in their area.

*What has it achieved?* The key outcome of the project is that parents, carers, children and young people are able to clearly identify which play, leisure and childcare providers meet set standards of inclusive practice. This means that they can make informed choices when looking for suitable play and leisure settings. At the time of writing, 22 settings have been awarded the *me2* kite mark in Dudley and another 30 are working towards the award.

## **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 (see, for example, Mitchell and Sloper 2002). We know from other research on meeting families' needs to children and young people themselves of inclusive practice, inclusive leisure services in their area.

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 that 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 orally. Turner's (2003) consultation work in Wales similarly identified the need to use different mediums to pass on information. Turner also noted that the language used is as important as the medium; she gave 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 (Murray 2002; Kelly 2005; Mencap 2008).

## 7 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 that 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.

### 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.

## Facilitators and barriers to participation in ‘inclusive activities’

A very wide range of factors has 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 proactively to support and facilitate inclusion
- offering activities that support and facilitate inclusion
- tailored support that 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.

## **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; East Together and Sure Start Project 2005; Mohay and Reid 2006).

A number of skill areas were identified by researchers, including:

- staff being disability and inclusion aware (Pinney 2007)
- inclusive play techniques (Ludvigsen *et al* 2005; McIntyre 2007)
- skills that enable informed risk-taking, which allow 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) reported 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 identified the role of staff in facilitating inclusion – this was in both ‘inclusive’ and ‘segregated’ settings. Three key roles were 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).

### **Promising practice example: Consulting with children and young people with complex communication needs**

*What is it?* Wolverhampton City Council was aware that there was little work being done to communicate with children and young people with severe learning needs about their likes and dislikes in relation to short-breaks provision. They aimed to set up a system that encouraged all disabled young people to be consulted and enabled them to participate in decision-making about the activities they were taking part in.

*What does it do?* Fifty disabled children and young people are in receipt of short breaks in Wolverhampton. All these children and young people have been consulted about their preferences using suitable communication methods for each individual child or young person and they all have personal profiles which record information such as their likes, dislikes and medication needs. They also all have photographic evidence of activities that they have taken part in and enjoyed.

*Why is it different?* Disabled children and young people in receipt of short breaks are being enabled to communicate their preferences for activities during short-breaks provision.

*What has it achieved?* The main benefit of the new system is that the young person is at the centre of the decision-making process. In addition, staff are better equipped to interpret the young person’s responses, behaviour and actions.



## 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* (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 (Murray 2002; Shelley 2002; Ludvigsen *et al* 2005; Lewis *et al* 2007; Petrie *et al* 2007). 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 (Aitchison 2000; McDowell and Fisk 2005; Kleinert *et al* 2007), 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 highlighted the need for communication support (for example, someone who can interpret and/or assist the child/young person with their communication aid), the absence of which can act as a barrier to participating in ordinary leisure pursuits.

### **Promising practice example: The use of volunteers to support disabled children when accessing short breaks**

*What is it?* Rochdale Metropolitan Borough Council's Children's Social Care Service wanted to support disabled children in Rochdale to enjoy and achieve by increasing their access to mainstream activities. It has introduced a 'befriending' scheme in which volunteers accompany disabled children and young people to activities of their choice. Volunteers are trained and have monthly group supervision meetings.

*What does it do?* The scheme was commenced in April 2009 and, at the time of writing, had recruited 11 volunteers who had then been linked with four children. A further three children were in the process of being introduced to the scheme.

*Why is it different?* The advantage of the befriending scheme is that it provides an alternative to traditional short-break provision as it does not require sanction via the Resource Allocation Panel. This means that children and parents can self-refer. 'Links' tend to take place on a weekly basis for two to three hours, which makes it a more frequent support to families than traditional services.

*What has it achieved?* The scheme has been successful in increasing the number of children receiving short-break support; all those on the scheme are in receipt of a short break for the first time.

## 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 2003b; Petrie *et al* 2007). Finch *et al*'s (2001) national survey of sport participation reported that physically inaccessible buildings, or lack of appropriate equipment or amenities within the venue, were barriers to participating in out-of-school sport, which were particularly likely to be experienced by children and young people with physical impairments and self-care needs. Yantzi *et al*' (2010) study on the suitability of playgrounds for disabled children found that many of the surfaces that make playgrounds safer for children without disabilities, such as sand, actually create difficulties for children with mobility impairments. Wooden borders around the edges of playgrounds also act as barriers and serve to make disabled children feel excluded (Yantzi *et al* 2010).

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

## 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 study in the United States 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 (2002) 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 takes 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 that 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 (Kelly 2005; Petrie *et al* 2007; Pinney 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 have had negative experiences of mainstream play activities in the past (Buttimer and Tierney 2005; Ludvigsen *et al* 2005).

### Not having 'someone to go with'

A number of studies flagged up how not having 'someone to go with' (this could be either 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 taking part in a positive activity (Finch *et al* 2000; Shelley 2002; Turner 2003; Buttimer and Tierney 2005; Petrie *et al* 2007; Finch *et al* 2000; Raghavan and Pawson 2009). Finch *et al* (2001) 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 were identified as barriers to participating in team sports (Taub and Greer

2000; King *et al* 2006). 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 that not knowing how to do a leisure activity or play a sport was a barrier to 'interpret the rules of peer culture' acted as barrier to inclusive play. Petrie (2000) referred to Kampmanma (1997) notion of disabled children in special schools not having experienced the leisure activity or play that children in mainstream schools acquire, resulting in them being unaware of the cultural forms and unspoken rules of non-disabled children rules of 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 that parents find accessing a scheme difficult because of the cost of transport or difficulties using public transport with their child (Thompson *et al* 2000; Buttimer and Tierney 2005; Ludvigsen *et al* 2005; McDowell and Fisk 2005). Transport, including the inflexibility of school transport services, has also been identified as a barrier to accessing extended school activities (East Together and Sure Start Project 2005; Petrie *et al* 2007; Pinney 2007), short breaks (Langer *et al* 2010) and mainstream leisure services (Prime Minister's Strategy Unit *et al* 2005; Petrie *et al* 2007; EdComms 2009). 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) reported that young people perceived public transport as 'unwelcoming' and limited in that it did not provide door-to-door transport. McGrath and Yeowart (2009), in their guide to supporting disabled young people in the transition to adulthood, emphasised that a lack of accessible and affordable transport can hinder the development of young people. door-to-door transport was a barrier to their child partici

The Disabled Children's Accessible and Affordable Daycare (DCATCH) pilot scheme, which has been set up in conjunction with the Aiming High for Disabled Children programme, aims to test out ways of achieving better access to childcare for disabled children and young people (Andrews 2009). One of the areas of activity is working towards developing more flexible transport arrangements to enable disabled children to access play and out-of-school activities more easily.

## Supporting access to and use of community facilities or venues

A small number of studies 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) reported on 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 that families can encounter when making such trips:

- Car parking at a venue can be difficult, particularly if it is not possible to pre-book parking.
- Procedures for accessing the building can be confusing and complicated and serve to draw attention to the child/young person.
- A lack of seating in museums and galleries, and in lobby areas generally, can be a problem.
- Wheelchairs may not be provided by venues.
- Physical barriers can restrict the views of children in wheelchairs.
- There may be a lack of sufficient numbers of accessible toilets and toilets that allow the family to stay together.
- Changing facilities may be inadequate, 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.
- There may be 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 had 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.

In conjunction with its *Services for disabled children* report (Audit Commission 2003b), the Audit Commission published a handbook for agencies and services to review their provision for disabled children (Audit Commission 2003a). It recommended that the handbook be used across agencies. This was because families felt that better coordination across professionals and agencies would make the biggest difference to the quality of their lives (Audit Commission 2003a). An online factsheet giving ideas and suggestions for accessing leisure services was also produced for families with a disabled child (aMAZE and Audit Commission 2003). McDowell and Fisk (2005) have also produced a Good Practice Guide and an audit tool for use by providers, which is based on their research into disabled children and young people's needs with regard to accessing play and leisure activities.

## 8 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.

### 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.

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 (Darrah *et al* 1999; Aitchison 2000; Taub and Greer 2000; Kristen *et al* 2002, 2003; Goodwin *et al* 2004; Cairney *et al* 2005; Fragala-Pinkham *et al* 2006).

Petrie's qualitative evaluations of play services (Petrie and Poland 1998; Petrie 2000) showed 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.

### 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 (Groff and Kleiber 2001; Goodwin *et al* 2004), self-confidence (Kristen *et al* 2003; Lewis *et al* 2007) and beliefs about their abilities and potential (Taub and Greer 2000).

However, research has also identified factors that might moderate the positive benefits on psychological wellbeing of participating in positive activities. First, positive outcomes are dependent on appropriate and sensitive support being

providing 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 appear to be important factors 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 teamwork 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's (2000) 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 reported a positive impact on self-reported self-confidence, based on the accounts of either the children and young people themselves and/or their parents (Kristen *et al* 2002, 2003; Murray 2002; Goodwin and Staples 2005).

## Belonging

A number of small-scale exploratory qualitative studies 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).

## 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 and Smith 2002; Martin 2006) and in community settings (Kristen *et al* 2002, 2003); activities that take place in extended schools, particularly primary schools (Wallace *et al* 2009); short-break activities (Langer *et al* 2010) 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 between 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.

## 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 dataset in the United States of over 9,000 young people aged 13 to 16 with a range of impairments found that young people who participated in extra-curricular 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 extra-curricular 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 extra-curricular 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 United States (Groff and Kleiber 2001) also identified social interaction as supporting positive outcomes in terms of young people's self-identity.

Langer *et al* (2010) reported that participation in short breaks had positive impacts on disabled children and young people in relation to developing and maintaining social relationships.

Murray's (2002) and Goodwin and Staples' (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.

The research evidence on the perceived social benefits of participating in inclusive positive activities suggests that 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 reported the social benefits of playing and mixing with non-disabled children in the local community, as opposed to friendship development (Hanson *et al* 1998; Ludvigsen *et al* 2005). Similar themes



were 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) concluded 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 friendships to develop with both disabled and non-disabled peers. Similarly, Taub and Greer's (2000) exploration of 20 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.

## 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).

## Skills and learning

A number of pieces of research identified 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 that attending a training programme in swimming or basketball had a significant impact on the sports skills of adolescents with learning difficulties. Other projects that sought disabled children and young people's views of the perceived outcomes of taking part in sport or other physical activities consistently reported 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).

## Community-based experiences and participation

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

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) suggested 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 experienced 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 the 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 support 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).

## 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.

## 9 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, in terms of both 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'.

### 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 that 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 that 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 and evidence from the parents and disabled children and young people who were consulted for this review suggest that ‘active inclusion’ and ‘opportunity inclusion’ are both important and valued, although they fulfil different functions. ‘Opportunity inclusion’ may, in some cases, lead to the development of an ‘active inclusion’ service or children and 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 that are actively inclusive.

## 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.

## Disabled children and young people’s experiences of positive activities

A key benefit of 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 and engaging in a ‘segregated’ activity; both types of provision were valued in the research reviewed.

Accessing generic sports and leisure provision can be difficult, in terms of both 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 have been consistently identified by research, and also by the parents and disabled children and young people who were consulted with for this review, as key factors in 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.

## 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/young person's preferences, influence how disabled children and young people spend their out-of-school time. In addition, children and young people'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.

## Hallmarks of inclusive services

The evidence tells us about the way in which services should be resourced, structured and delivered in order to be inclusive. The views of the parents, children and young people who were consulted with for this review, as well as those of the service providers, generally concurred with the evidence available.

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 that is skilled in a number of areas, including being able to facilitate inclusive play, being disability aware and having 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 needs to be sufficient numbers of staff to provide one-to-one support, if needed.

Second, the service or setting needs to be inclusive, in terms of both the activities offered 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 their 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, through either school transport services or public transport, is a key barrier to participation in out-of-school opportunities and activities.

## Positive activities and disabled children's outcomes

There is evidence that participating in positive activities impacts on disabled children's outcomes, although 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 to 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) and also more generic life skills.

## Participating

Finally, positive activities can also provide a means by which disabled children and young people 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.

## Implications for services

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

### **Overarching messages**

- There does 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.
- 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.
- 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.

### **Monitoring inclusion**

- Existing services need to examine whether the services they believe to be inclusive are truly inclusive.
- 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 that 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.

### Increasing participation

- The evidence suggests that 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 with regard to whether or not disabled children and young people participate in activities that 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.
- 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. This is part of the 'core offer' from the *Aiming high for disabled children* report (HM Treasury and DCSF 2007b), which acts as a key driver for the promotion and development of local services.
- 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.
- A system for offering taster sessions at venues and services which provide positive activities should be established.
- Services need to consider their location and whether they are easily accessible by public transport. Other transport options for enabling disabled children and young people to get to facilities may need to be considered.

### Nature of provision

- 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 that will be provided.
- 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 the positive effect of participation in out-of-school sport, efforts clearly need to be made to improve access to out-of-school sport for disabled children and young people.

## Data annexe

### Key messages

- Local and national datasets are publicly available on the prevalence of disability, including by background characteristics (such as age, gender and ethnicity). There are also datasets relating to the social and living circumstances of disabled children and their families. These datasets provide useful monitoring data that can be tracked over time, such as on the prevalence of disability.
- The disabled children's services national indicator (NI54) measures parental experiences of health, education and social services provided to disabled children.
- National indicator 110 – young people's participation in positive activities – gives a breakdown of children and young people's engagement in positive activities by their disability status for a limited number of these activities.

## 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, although the most comprehensive population estimate (from the 2001 Census) is now dated (ONS 2001). Data on the prevalence of disability by some of the demographic characteristics of children (such as age, gender and ethnicity) is also available, although 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 (ONS 2001) Census and the Family Resources Survey (DWP 2005). 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.



- 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

charts on the prevalence of disability, disabled children and young people's participation in positive activities and their access to services.

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 4.

## 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 (now the Department for Education); obtaining access to data published by the Office for National Statistics, the Department of Health and other government departments; obtaining 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* (2007) 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 Department for Children, Schools and Families (now the Department for Education). In addition to these two source documents, we have identified a number of other surveys (such as the Youth Cohort Study (DCSF 2008b), which also includes Wales), research studies and administrative datasets that include some indication of the prevalence of disability among children and young people.

Although there appears to be a number of sources of data about the apparent prevalence of disability among children and young people at both national and local levels, 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 is collected. While national cross-sectional surveys provide estimates of prevalence, no single administrative dataset collects data specifically on childhood disability.

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

- definitions derived from the *Disability Discrimination Act 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 and the Family Resources Survey, but are not used by the Department for Education (formerly the Department for Children, Schools and Families) for the collection of data on special educational needs and were not included in the 2001 Census
- definitions based on **limiting longstanding illness**, disability or infirmity, used in the 2001 Census but with no sub-classification data (by specific disability)
- definitions based on **longstanding illness**, disability or infirmity, 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 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.

**Department for Education (formerly the Department for Children, Schools and Families) 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 special educational needs variable. It is likely, therefore, that the Census underestimates the prevalence of disability.

**Local authorities' administrative data** on disability is collected as part of their statutory requirement under the *Children Act 1989* (GB. Statutes 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 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 Children in Need Census collection covered the period October 2008 to March 2009 while, from April 2009, the data collections cover the entire financial year.

**Cross-sectional surveys** (such as the Family Resources Survey) (DWP 2005) 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 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 (ONS 2005) and the Family Resources Survey are Disability Discrimination Act-related (and also use limiting longstanding illness and/or longstanding illness), the Health Survey for England (NHS 2010), the Survey of English Housing (DCLG 2009) and the General **LiFestyle survey (formerly known as the General household survey) (ONS 2010)** are not, primarily using variations of ‘limiting longstanding illness’ or ‘longstanding illness’ 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 Disability Discrimination Act-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) tends to be related to the codes from the International Classification of Diseases.

**‘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.

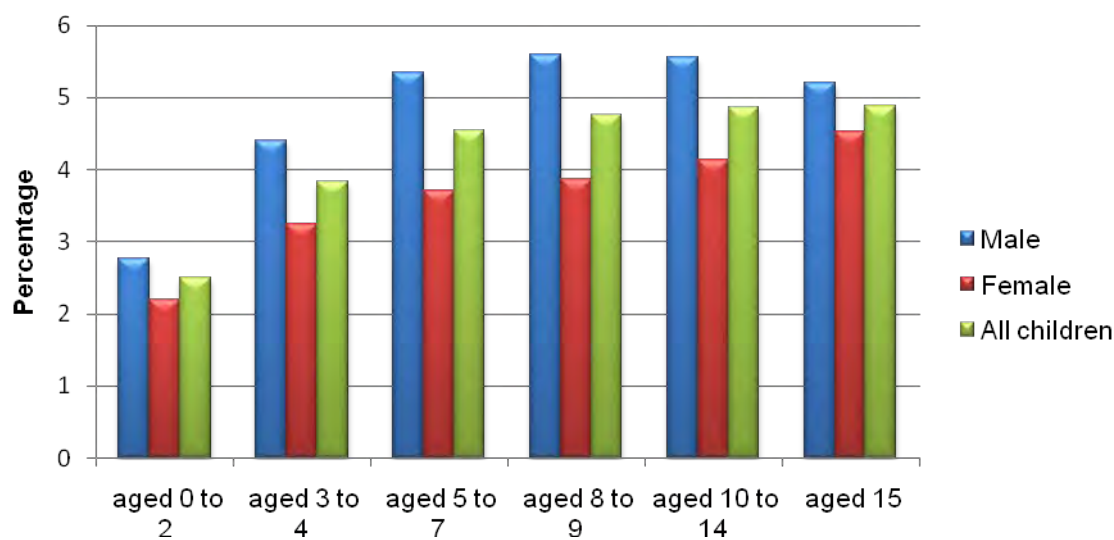
## Charts showing trends and regional data

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

Data from the 2001 Population Census (ONS 2001) 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 two, three to four, five to seven, eight to nine, 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 four, five to nine 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 an 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 LLSI was greater than the proportion of female children with such an illness/disability.

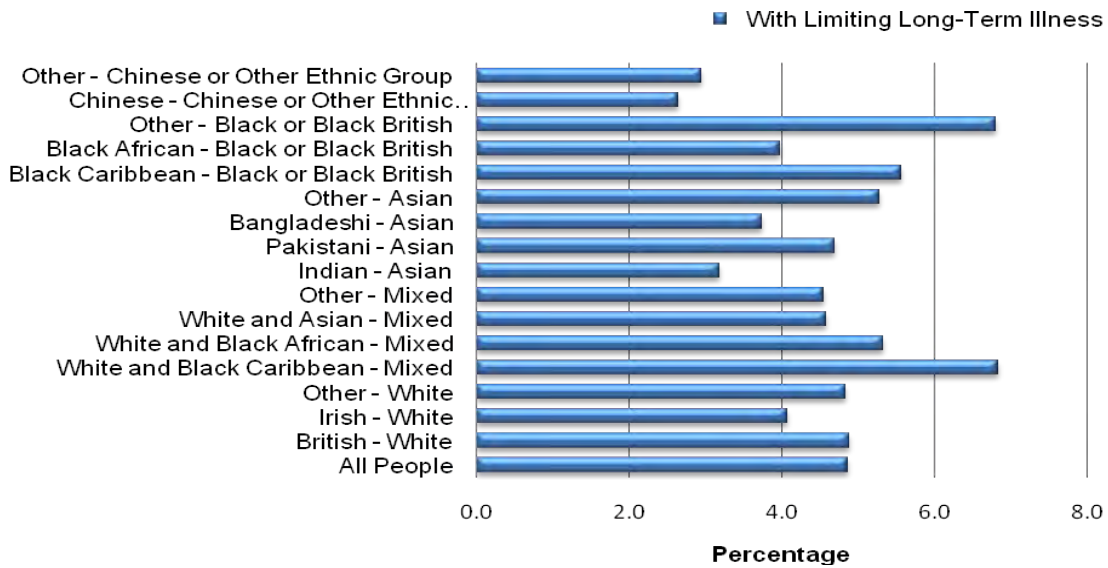
**Figure 1. All children with an LLSI: Population Census 2001: by sex**



Source: ONS 2001

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 an LLSI up to age 15: Population Census 2001: by ethnicity**

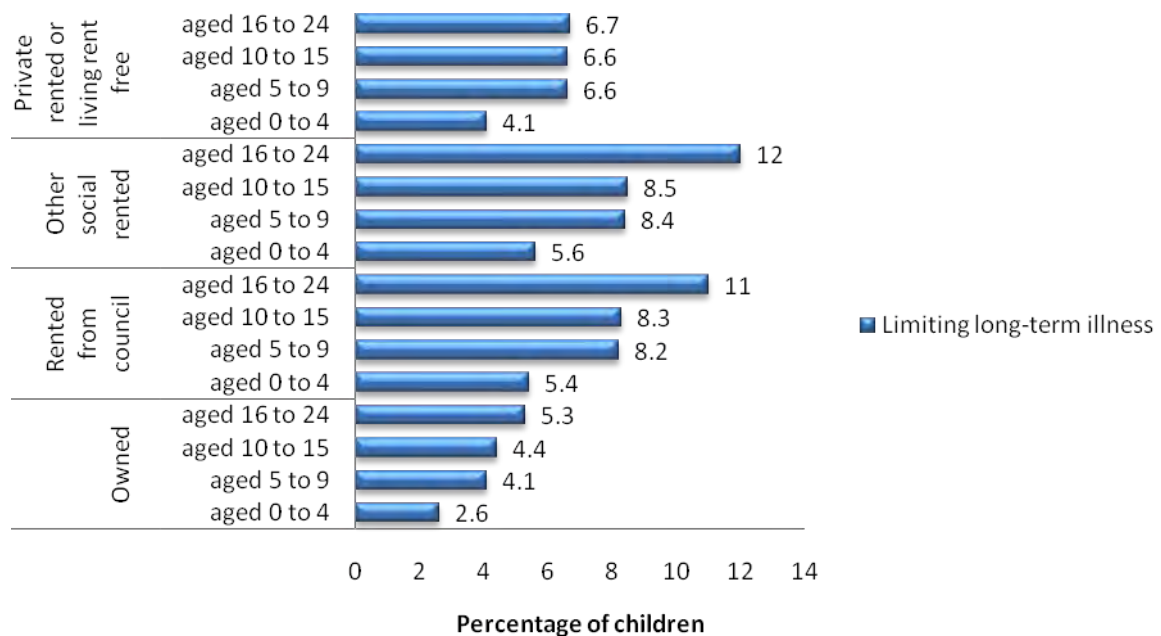


Source: ONS 2001

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 an LLSI up to age 24: Population Census 2001: by household tenure**

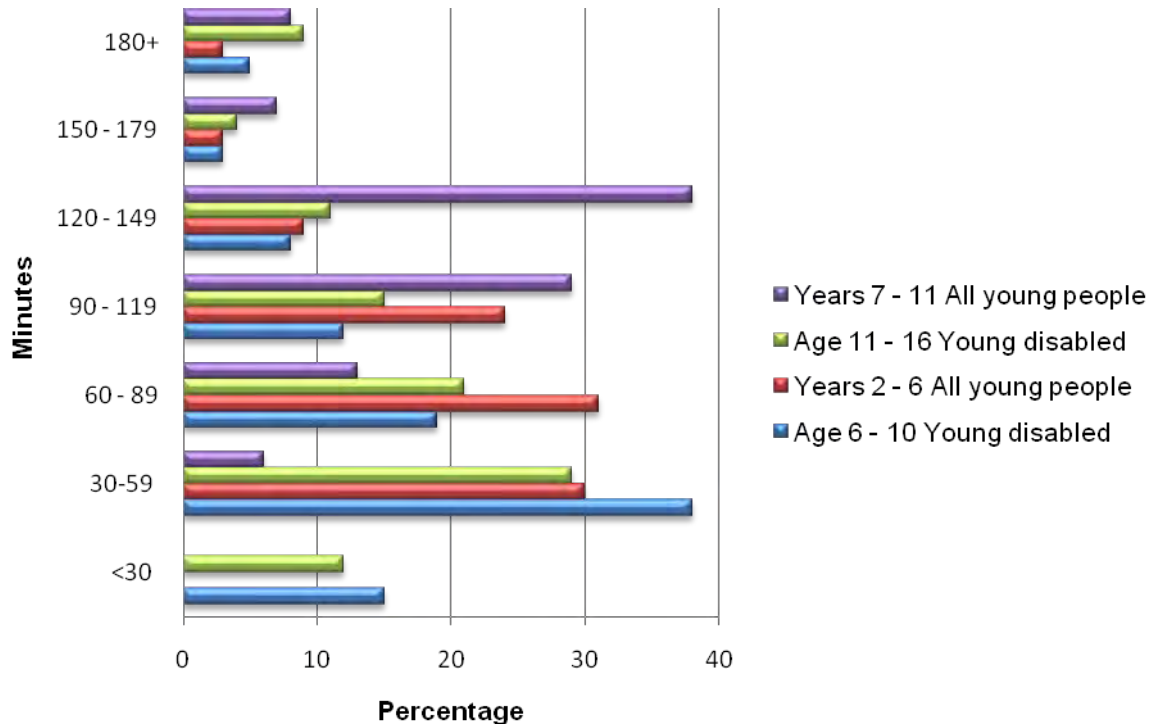


Source: ONS 2001

## Participation in positive activities

Data on disabled children and young people's participation in positive activities is currently sparse, 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' (Sport England 2001 p 46). Figure 4a 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 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) (Finch 2001) to participating in sporting activities outside of school.

**Figure 4a. Average time per week in physical education lessons: reported by young disabled in 2000 and by the overall population of young people in 1999: by primary and secondary age groups<sup>5</sup>**

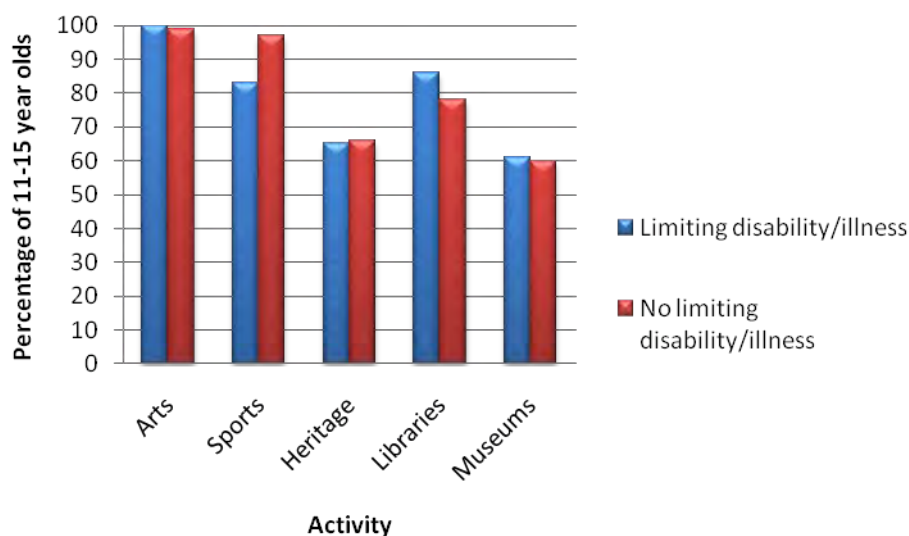


Source: Finch 2001

Data from the Taking Part survey (DCMS 2009) shows a similar story in terms of disabled children and young people’s participation in sport. Young people aged 11–15 with a limiting disability or illness were significantly less likely to have participated in sport in the last four weeks than young people of the same age without a limiting disability or illness (see Figure 4b). There was, however, no difference between them and their peers in the extent to which they took part in other cultural activities, such as visiting museums or libraries, in the past 12 months, suggesting that there might be more barriers for these disabled young people to taking part in sport than other positive activities. Further, data from the same survey showed that disabled and non-disabled children aged 5–10 participated in sport to the same degree, which may mean that there are more barriers or difficulties associated with taking part in sport for older children.

<sup>5</sup> 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 4b. Young people’s participation in sport (over the past four weeks) and in cultural activities (in the past 12 months) in 2008/09: comparison of those with and without a limiting disability or illness**

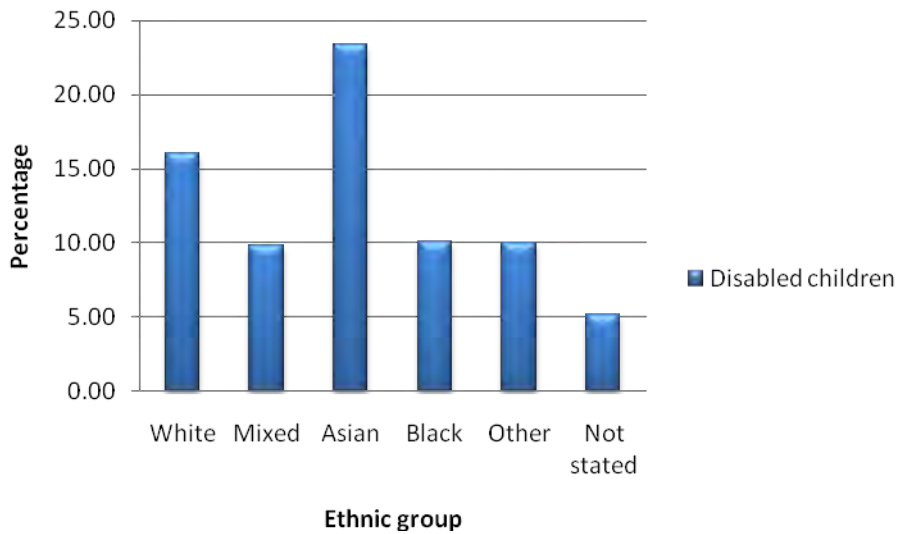


Source: DCMS 2009

## Access to services

The Children in Need Census 2005 (DfES 2006b) 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). The most recent Children in Need Census in 2009 records children’s access to services over a six month period rather than one week. Over this period in 2009, again, the majority (87 per cent) of those accessing services did not have a disability (DCSF 2009). The 2009 data, however, does not provide a breakdown of these children’s access to services by their ethnic background.

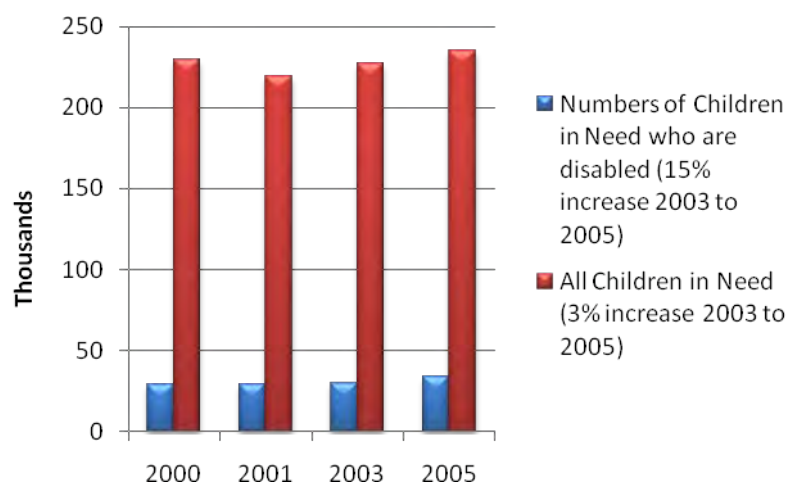
**Figure 5. Access to local authority social services' Children and Families Teams by disabled children in need: by ethnicity**



Source: DfES 2006b

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 3 per cent; the numbers of disabled children and families/carers accessing the service increased by 15 per cent over the same time period. Although recent data on the overall numbers of children in need is presented in the 2009 Children in Need Census (DCSF 2009), due to changes in the way the data is now being collected it is not directly comparable to previous years, meaning that trend data beyond 2005 is not currently available.

**Figure 6. Access to local authority social services' Children and Families Teams by children in need: 2000 to 2005**



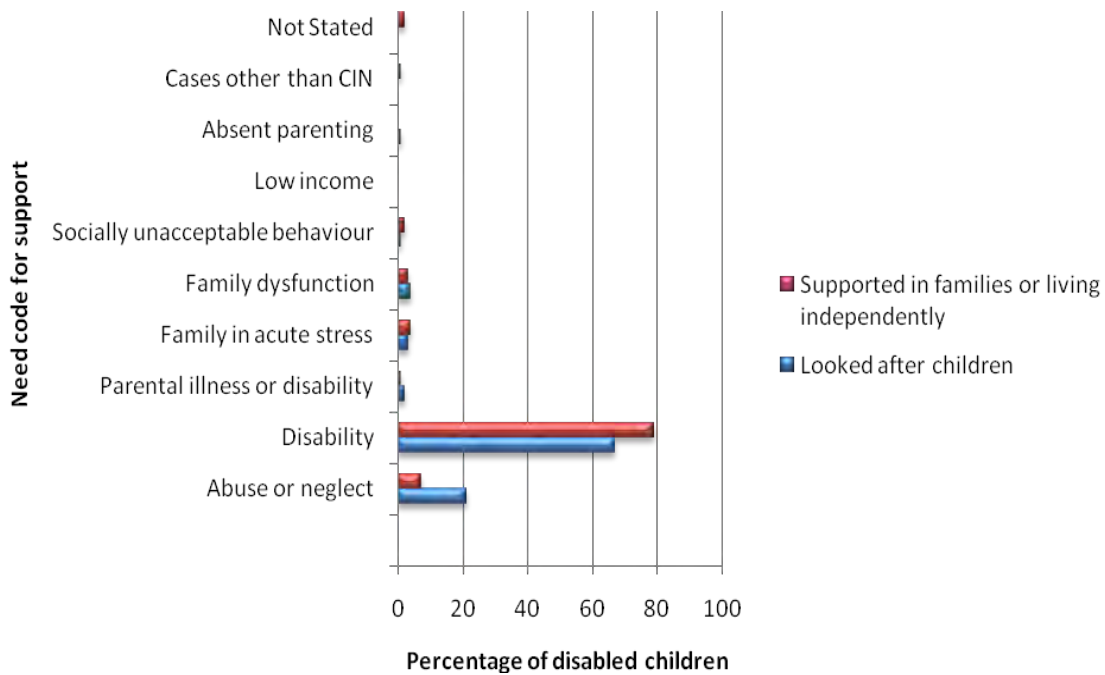
Source: DfES 2006b

In 2005<sup>6</sup>, 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).

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<sup>6</sup> The 2009 Census data (DCSF2009) does not currently break down reasons for access by whether children are looked after or living with families or independently, so 2005 data is presented here.

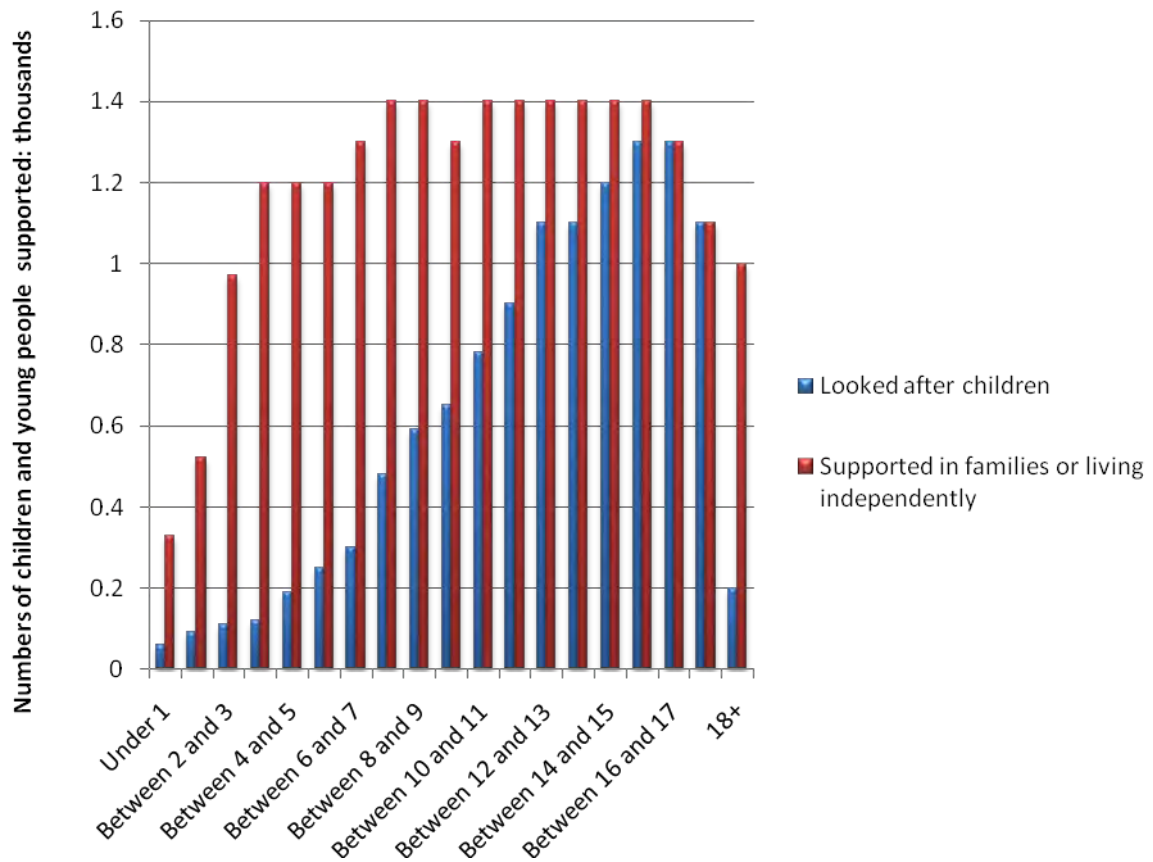
**Figure 7. Access to local authority social services' Children and Families Teams by children in need: by reason for access**



Source: DfES 2006b

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. Comparable data is not currently available in the 2009 Census.

**Figure 8. Access to local authority social services' Children and Families Teams by children in need: by age**



Source: DfES 2006b

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## Glossary

This glossary describes different types of study designs and defines some key concepts and terms that you will come across when reading research. It is arranged alphabetically.

### **Action research**

Action research is an iterative approach that normally takes place within a practice setting. Unlike models of research where data is collected, analysed and published when the project is complete, researchers in an action research model will interact with staff and users, feed back the results in stages and enable changes in direction, based on the findings, to be made while the project is still under way.

### **Bias**

The deviation from the truth or *reliability* of results due to the way(s) in which the study is conducted.

### **Blinding**

Refers to measures taken to disguise allocation to groups to avoid *bias*. In a *single-blind study*, participants are unaware of which group they have been assigned to, but the researcher does know (or *vice versa*). A *double-blind study* means that neither the researcher nor the participants are aware of the allocation to groups.

### **Case-control study**

Individuals with a particular problem are 'matched' with similar people (*control group*) without the problem. The exposure of the two groups to possible causes is then compared. This can be used to investigate risk factors.

### **Case study**

A case study refers to the in-depth investigation of a single subject or event. The most useful case studies highlight important issues that, while being from the perspective of only one person, can represent a commonly experienced problem.

### **Cohort study**

A cohort study collects information about the same individuals at regular intervals over a period of time, which may vary from months to decades.

### **Confidence interval (CI)**

A confidence interval is often used around percentages. For example, a newspaper might report that the average IQ of researchers is 99. If the 95 per cent confidence interval is 80–120, this means that 95 per cent of researchers have an IQ between 80 and 120.

### **Control group**

A control group is used in order to try to establish whether any effect found in the *intervention group* was due to the intervention or whether it would have occurred anyway. The control group is the comparison group that gets a different service/*intervention* (or no service/*intervention*) to the *intervention group*.

### **Critical appraisal**

A systematic way of assessing a research study, and considering it in terms of *validity*, *bias*, results and relevance to your own work.

### **Cross-sectional survey**

A representative *sample* of people is surveyed at one point in time. The survey may be repeated on a regular basis to establish trends. Unlike cohort studies, the same respondents are not re-sampled.

### **Effectiveness**

Describes the extent to which an *intervention* improves the *outcome(s)* (that is, changes that happen as a result of the *intervention*) for those receiving it and the extent to which these benefits outweigh the harm (if any) caused by the *intervention*.

### **Ethnography**

A *qualitative research* methodology that entails collecting and analysing data in a manner that considers the social and cultural settings of those involved.

### **Focus group**

The researcher facilitates and leads a group of individuals through a discussion around a specific topic. A focus group can be more or less structured and the researcher may choose to be directive or take on a more observing role, depending on the objective of the research. A key feature is that participants are able to interact with each other.

### **Homogeneity**

This term is used in a *systematic review* to describe the extent to which results were similar to each other. If many studies show similar results, we can be more confident about the findings. Studies are said to be 'homogeneous' if their results do not vary more than would be expected by chance. The opposite of homogeneity is *heterogeneity*, a measure of how study results differ.

### **Hypothesis**

A statement to be tested through investigation or research. A hypothesis should be stated in a way that renders it capable of being proved true or false by the investigation methods proposed.

### **Intervention**

A service, programme or policy intended to affect the welfare of individuals, families or communities.

### **Intervention group**

The group that receives an *intervention* (service, medicine, treatment). See also *case-control study* and *randomised controlled trial*.

### **Longitudinal study**

The same data is collected at different time points over a period of time. Longitudinal studies may be *cross-sectional* (different respondents) or *cohort* (same respondents). Used to measure long-term effects or changes.

### **Mean**

An average obtained by taking the sum of all values and dividing it by the number of values.

### **Meta-analysis**

A statistical technique that pools the results from several studies into one overall estimate of the effect of an *intervention*. (See also *Systematic review*.)

### **Narrative review**

In contrast to a *systematic review*, a narrative review tends to be less methodically executed, often focusing on easily accessible research, such as that published in major journals. A potential problem with this approach is that authors may consciously or unconsciously refer to those studies that reflect their own biases.

### **Outcome**

A change or effect that happens as a result of an *intervention*. An outcome may be for individuals, families, communities or organisations.

### **P-value (statistical significance)**

Broadly, this refers to the probability that the results found by a study have occurred by chance rather than as a result of the intervention. A p-value of 5 per cent (0.05) indicates that there is a 5 per cent probability that the results occurred by chance. A p-value of less than 5 per cent is generally regarded as *statistically significant*. This does not necessarily mean that the results of the study are important socially and clinically.

### **Participant observation**

A type of *qualitative research* in which the researchers participate in the social setting they are observing. *Observation* can be covert or non-covert. However, ethical issues arise with the use of covert *observation*.

### **Population survey**

A *sample* of the chosen population (or the whole population in the case of the decennial UK Census) is asked to provide responses to questions on the subject of interest. A population survey can be used to measure the prevalence of problems.

### **Power**

Sometimes referred to as 'statistical power'. The likelihood that a *sample* is large enough to detect a *statistically significant* difference between a *control group* and an *intervention group*, if such a difference actually exists. Power sampling can be used to calculate the required *sample* size.

### **'Pre-post' studies**

Sometimes referred to as 'before and after' studies, this type of research design involves taking measurements at the beginning and end of an *intervention* (and sometimes at 'follow-up'). The same measurements are taken at time 1 (pre) and time 2 (post), to see if any changes have occurred after the period of *intervention*. Typically, standardised *outcome* measures are used, such as a depression scale or a quality-of-life inventory. Pre-post studies do not contain *control groups*. Those with

*control groups* would be classified as *quasi-experimental studies* or experimental studies.

### **Purposeful (purposive) sampling**

Choosing specific participants with particular characteristics, rather than being based on random selection. Methodologically, the least robust form of sampling.

### **Qualitative research**

Concerned with the meanings that people give to their experiences and how they make sense of the world. It often studies people in their natural settings. A range of methods can be used, including *participant observation* and non-participant observation, talking with people (interviews, *focus groups*) and reading what they have written. It can be used to find out about social processes and what matters to people, how these vary in different circumstances, and why.

### **Quasi-experimental study**

This measures the difference between two groups, which are usually pre-existing populations, matched for similarity. One group receives a particular service; the other does not, or receives another type of service.

### **Randomised controlled trial**

An experiment in which individuals are randomly allocated either to receive an *intervention (intervention group)* or to receive no *intervention* or a different one, such as the standard service (*control group*). Both groups are measured at baseline and at the end of the *intervention* period and are often followed up later. The *outcomes* of the two groups are then compared to determine the *effectiveness* of the *intervention* under investigation.

### **Reliability**

Refers to the likelihood that the same results would be found if the study was repeated in the same way if carried out at different times by the same researcher or by two different researchers.

### **Replicability**

Researchers should provide sufficient information about a study so that it can be replicated by others. The notion of replicability implies that research should be transparent to its readers.

### **Sample**

A subset of cases selected from the population to be studied.

### **Sample size and power**

Sample size is a crucial determinant of whether a difference will be detected if it really exists. Sometimes the number of participants in a study is chosen because the number 'seems appropriate', or because that is how many participants the study can afford to test or interview. However, the appropriate size for a particular study depends on the likely size of the effect you are trying to detect – for example, the likely size of the *odds ratio*, or the magnitude of the difference between two *means*. Where the effect is likely to be small, then larger study numbers are required.

### **Semi-structured interview**

An interview where the researcher has a set of themes they want to discuss with a respondent, but they are not bound by these themes, and can investigate emerging issues arising during the course of the interview. (See also *Structured interview* and *Unstructured interview*.)

### **Standard deviation**

Measures how far results scatter or deviate from the *mean*. The smaller the standard deviation (in relation to the mean), the more similar the scores; the larger the standard deviation (in relation to the mean), the more spread out the scores.

### **Statistical significance (see also *P-value*)**

Significance levels show you how likely it is that a result is due to chance. The most common level is 0.05. This means that the finding has a chance of 5 per cent (0.05) or less of not being true.

### **Structured interview**

An interview in which the same predetermined questions are asked to each participant. (See also *Semi-structured interview* and *Unstructured interview*.)

### **Survey**

A survey gathers information via a questionnaire or *structured interview* at one time point to obtain responses from more than one person, which can then be quantified and subjected to statistical analysis.

### **Systematic review**

A systematic review is a critical assessment and evaluation of existing research that addresses a specific question. A systematic review is transparent and explicit about the search terms used and range of sources searched. It aims to be exhaustive and comprehensive in the range of sources searched. When a systematic review pools data across studies to provide an estimate of the overall treatment/ intervention effect, it is referred to as a *meta-analysis*.

### **Triangulation**

The use of more than one theory, method, data source or researcher in a research study to reinforce the trustworthiness of its findings.

### **Unstructured interview**

An interview in which a researcher asks participants very general questions, enabling them to shape the interview in whichever way they see fit, without a predetermined plan for the flow of the conversation. (See also *Semi-structured interview* and *Structured interview*.)

### **Validity**

Validity refers to the extent a study can be regarded as accurate and reliable. If the internal validity is high, the study has been designed and carried out in such a way as to avoid systematic *bias* – which means that it will give you a good estimate, for example, of the *effectiveness* of an *intervention*. External validity is also sometimes called transferability or generalisability, and refers to the extent to which you can

generalise the findings from one study and apply them to other populations, settings and arrangements.

**Variable**

A principal factor of experimental studies is that one element is manipulated on purpose by the researcher to see whether it has any impact on another measure. The element or factor that is being manipulated by the researcher is known as the independent variable, whereas the change (or *outcome*) resulting from the implementation of the independent variable is known as the dependent variable.



## Appendix 1: Research review methods

The 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 Theme Advisory Group.

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.

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 3.)

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

- the items of greatest relevance to the review questions
- the items that came closest to providing an ideal design to answer the review questions
- 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

The strengths of the review were:

- 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 limitations of the review were:

- 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 not being possible to adopt all of the processes expected of an extended systematic review
- it being limited to English-speaking countries only
- the inclusion, due to the lack of any other evidence, of quite weak evidence, typically from consultation exercises.

## Appendix 2: 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 3 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 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 Table 1. 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	Items selected for consideration	Items identified as relevant to the study
<b>Databases</b>			
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
<b>Internet databases/portals</b>			
British Education Internet Resource Catalogue (BEIRC)	81	2	N/A
CERUKplus	175	1	1
NHS EED	24	0	0
Research in Practice	6	0	0
Research Register for Social Care	105	4	1
Social Care Online	872	45	29
Theme Advisory Group recommendations (including texts and organisations)	87	87	65

**Note:** Where N/A is indicated, this is because these resources were browsed rather than searched.

## Search strategy

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

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

**Disabled children and young people set**

#17	disab*	#27	mental disorders
#18	disabilities	#28	mental retardation
#19	disabled children (ft)	#29	inclusion (ft)
#20	disabled students (ft)	#30	inclusive education (ft)
#21	disabled young people (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
#22	disabled adolescents (ft)	#32	#16 and #31
#23	intellectual impairment (ft)		
#24	learning disabilities		
#25	learning difficult* (ft)		
#26	learning disorders (ft)		

**Extended services set**

#33	extended services (ft)	#42	childrens centres (ft)
#34	extended schools (ft)	#43	childrens centers (ft)
#35	extended school day	#44	childcare pilot (ft)
#36	before school care (ft)	#45	childcare (ft)
#37	breakfast club* (ft)	#46	child care (ft)
#38	after school 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
#39	after school club* (ft)		
#40	out of school care (ft)		
#41	extracurricular activities		

**Youth work set**

#48	youth work (ft)	#53	youth services (ft)
#49	youth clubs	#54	youth opportunities
#50	youth groups (ft)	#55	#48 or #49 or #50 or #51 or #52 or #53 or #54
#51	youth programmes		
#52	youth service		

**Sports set**

#56	sports	#58	sports coach(ft)
#57	sport (ft)	#59	#56 or #57 or #58

**Play, leisure, recreation and short breaks set**

#60	play	#72	short break services (ft)
#61	play centres	#73	field trips
#62	play groups	#74	school visits
#63	play therapy	#75	vacations
#64	playgrounds	#76	holidays
#66	playground activities	#77	outdoor pursuits
#67	recreation	#78	adventure education
#68	recreational activities	#79	#60 or #61 or #62 or #63 or #64 or #65 or #66 or #67 or #68
#69	leisure (ft)		
#70	leisure activities (ft)		
#71	short breaks (ft)		
or #69 or #70 or #71 or #72 or #73 or #74 or #75 or #76 or #77 or #78			

#### Arts set

#80	arts	#86	cultural activities
#81	art	#87	#80 or #81 or #82 or #83 or #84 or #85 or #86
#82	dance	#88	#47 or #55 or #59 or #79 or #87
#83	drama	#89	#32 and #88
#84	music		
#85	art activities		

#### British Education Internet Resource Catalogue (BEIRC)

(searched 20/10/08)

The BEIRC 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)	#14	higher education students (ft)
#4	under eights	#15	adolescents
#5	children (+NT)	#16	young adults
#6	preschool children	#17	youth (ft)
#7	young children (ft)	#18	young people (ft)
#8	nursery school pupils (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
#9	kindergarten children		
#10	primary school pupils (ft)		
#11	primary school age		
#12	secondary school pupils (ft)		
#13	further education students (ft)		

**Disabled children and young people set**

#20	disab*	#27	learning difficulties
#21	disabled children (ft)	#28	learning disorders (ft)
#22	disabled students	#29	mental disorders
#23	disabled young people (ft)	#30	mental retardation (ft)
#24	disabled adolescents (ft)	#31	mental disability
#25	intellectual impairment (ft)	#32	physical disability
#26	learning disabilities (ft)	#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)	#49	childcare (ft)
#38	extended schools	#50	child care (ft)
#39	extended school day (ft)	#51	extended day
#40	before school care (ft)	#52	child care services
#41	breakfast club*	#53	day care
#42	after school care	#54	early childhood services
#43	after school club* (ft)	#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
#44	out of school care		
#45	extracurricular activities (ft)		
#46	childrens centres		
#47	childrens centers (ft)		
#48	childcare pilot (ft)		

**Sports set**

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

**Youth work set**

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

**Play, leisure, recreation and short breaks set**

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

**Arts set**

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

**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/](http://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	#16	extended school (ft) or extended school day (ft)
#2	young adult* (ft)	#17	before school care (ft) or after school care (ft)
#3	young people (ft)	#18	breakfast club* (ft) or after school club* (ft)
#4	young person (ft)	#19	extracurricular activit* (ft)
#5	infant	#20	children's cent* (ft)
#6	students	#21	youth work (ft) or youth club* (ft) or youth group* (ft) or youth program* (ft) or youth activit* (ft)
#7	youth (ft)	#22	cultural activit* (ft)
#8	#1 or #2 or #3 or #4 or #5 or #6 or #7	#23	exercise (+NT)
#9	disabled persons (+NT)	#24	leisure pursuits (+NT)
#10	mental disorders diagnosed in childhood (+NT)	#25	outdoor pursuits (ft)
#11	physical disab* (ft)	#26	art or drama or music
#12	early intervention (education)	#27	#16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26
#13	mental retardation (+NT)		
#14	hearing disorders or vision disorders		
#15	#9 or #10 or #11 or #12 or #13 or #14		

#28 #8 and #15 and #27

### **NHS EED**

(searched via CRD 21/10/08)

NHS EED contains over 7,000 abstracts of quality-assessed economic evaluations.

#1	disabled children (ft)	#4	disabled and leisure (ft)
#2	disabled young people (ft)	#5	disabled and extended services (ft)
#3	disabled and sport (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)	#13	extracurricular activit* (ft)
#2	adolescen* (ft)	#14	children's cent* (ft)
#3	young adult* (ft)	#15	youth work (ft) or youth club* (ft) or youth group* (ft) or youth program* (ft) or youth service* (ft)
#4	young person (ft)		
#5	young people (ft)		
#6	youth (ft)		
#7	#1 or #2 or #3 or #4 or #5 or #6	#16	cultural activit* (ft)
#8	disabilities (+NT)	#17	exercise (+NT)
#9	#7 and #8	#18	leisure pursuits (+NT)
#10	extended school (ft) or extended school day (ft)	#19	outdoor pursuits (ft)
#11	before school care (ft) or after school care (ft)	#20	art or drama or music
#12	breakfast club* (ft) or after school club* (ft)	#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)	#3	disabled youth (ft)
#2	disabled children (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)	#4	disabled students (ft)
#2	disabled children (ft)	#5	learning disabilities (kw) or physical disabilities (kw)
#3	disabled youth (ft) or disabled young people (ft) or disabled adolescents (ft)		

## 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)	#7	disab* (ft) and play (ft) not leisure (ft) not recreation (ft) not sport (ft)
#2	disab* (ft) and youth (ft)	#8	disab* (ft) and short breaks (ft)
#3	disab* (ft) and sport (ft)	#9	disab* (ft) and arts (ft)
#5	disab* (ft) and leisure (ft)	#10	disab* (ft) and transition (ft)
#6	disab* (ft) and recreation not leisure (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	<a href="http://www.4children.org.uk/">www.4children.org.uk/</a>	2
Aiming High for Disabled Children	<a href="http://www.everychildmatters.gov.uk/socialcare/ahdc/">www.everychildmatters.gov.uk/socialcare/ahdc/</a>	6
Barnardo's	<a href="http://www.barnardos.org.uk">www.barnardos.org.uk</a>	2
British Institute of Learning Disabilities	<a href="http://www.bild.org.uk/">www.bild.org.uk/</a>	0
Cabinet Office	<a href="http://www.cabinetoffice.gov.uk/">www.cabinetoffice.gov.uk/</a>	1
CanChild	<a href="http://www.canchild.ca">www.canchild.ca</a>	2

Cedar Foundation	<a href="http://www.cedar-foundation.org/">www.cedar-foundation.org/</a>	1
Children's Play Information Service (National Children's Bureau)	<a href="http://www.ncb.org.uk/Page.asp?originx6812in1832991054480z44q6370913124">www.ncb.org.uk/Page.asp?originx6812in1832991054480z44q6370913124</a>	4
Clubs for Young People	<a href="http://www.clubsforyoungpeople.org.uk">www.clubsforyoungpeople.org.uk</a>	1
Council for Disabled Children (CDC)	<a href="http://www.ncb.org.uk/Page.asp?sve=785">www.ncb.org.uk/Page.asp?sve=785</a>	4
Early Support Programme	<a href="http://www.direct.gov.uk/en/CaringForSomeone/CaringForADisabledChild/DG_10027494">www.direct.gov.uk/en/CaringForSomeone/CaringForADisabledChild/DG_10027494</a>	0
English Federation of Disability Sports (found via Sports England)	<a href="http://www.efds.co.uk/">www.efds.co.uk/</a>	2
Every Disabled Child Matters	<a href="http://www.edcm.org.uk">www.edcm.org.uk</a>	0
I CAN	<a href="http://www.ican.org.uk/">www.ican.org.uk/</a>	0
Joseph Rowntree Foundation	<a href="http://www.jrf.org.uk">www.jrf.org.uk</a>	8
KIDS	<a href="http://www.kids.org.uk/">www.kids.org.uk/</a>	5
National Deaf Children's Society	<a href="http://www.ndcs.org.uk">www.ndcs.org.uk</a>	0
Disability Archive UK	<a href="http://www.leeds.ac.uk/disability-studies/archiveuk">www.leeds.ac.uk/disability-studies/archiveuk</a>	0
National Youth Agency	<a href="http://www.nya.org.uk/">www.nya.org.uk/</a>	3
Norah Fry Research Centre (Bristol)	<a href="http://www.bristol.ac.uk/norahfry">www.bristol.ac.uk/norahfry</a>	4
Shared Care Network	<a href="http://www.sharedcarenetwork.org.uk/index.jsp">www.sharedcarenetwork.org.uk/index.jsp</a>	2
Sparcle Project (Newcastle University)	<a href="http://www.ncl.ac.uk/sparcle/">www.ncl.ac.uk/sparcle/</a>	1
Sport England	<a href="http://www.sportengland.org/">www.sportengland.org/</a>	0
Social Policy Research Unit (University of York)	<a href="http://www.york.ac.uk/inst/spru/">www.york.ac.uk/inst/spru/</a>	2
Strathclyde University (Kirsten Stalker)	<a href="http://www.strath.ac.uk/eps/staff/stalkerkirstenprof/">www.strath.ac.uk/eps/staff/stalkerkirstenprof/</a>	0
Thomas Coram Research Unit (Institute of Education)	<a href="http://ioewebserver.ioe.ac.uk/ioe/cms/get.asp?cid=470">http://ioewebserver.ioe.ac.uk/ioe/cms/get.asp?cid=470</a>	2
Together for Children	<a href="http://www.childrens-centres.org/default.aspx">www.childrens-centres.org/default.aspx</a>	0
Transition Information Network	<a href="http://www.transitioninfonetwork.org.uk">www.transitioninfonetwork.org.uk</a>	0
Youth Sport Trust	<a href="http://www.youthsporttrust.org/page/home-welcome/index.html">www.youthsporttrust.org/page/home-welcome/index.html</a>	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 parameters document (Appendix 3).

## Appendix 3: Parameters document

### 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)

Q1. What evidence is there of practice in children's centres/extended schools/youth services fully including disabled children and young people?

Q2. 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?

Q3. What support is needed for children and young people to access inclusive activities?

Q4. 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

UK only

Europe only

All countries (English language)

**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: final research report*, London: Office of the Deputy Prime Minister (available at [www.communities.gov.uk/documents/communities/pdf/158484.pdf](http://www.communities.gov.uk/documents/communities/pdf/158484.pdf), accessed 26 February 2010).
- Every Disabled Child Matters (2006) *Off the radar: how local authority plans fail disabled children*, London: EDCM (available at [www.ncb.org.uk/edcm/edcm\\_offtheradar\\_fullreport.pdf](http://www.ncb.org.uk/edcm/edcm_offtheradar_fullreport.pdf), accessed 26 February 2010).
- Every Disabled Child Matters (2008) *Between a rock and a hard place: campaign briefing*, London: Every Disabled Child Matters (available at [www.ncb.org.uk/edcm/edcm\\_briefing\\_rock.pdf](http://www.ncb.org.uk/edcm/edcm_briefing_rock.pdf), accessed 19 March 2010).
- Every Disabled Child Matters (2008) *Going places*, London: Every Disabled Child Matters (available at [www.ncb.org.uk/edcm/resources.aspx](http://www.ncb.org.uk/edcm/resources.aspx), accessed 19 March 2010).
- 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.ncb.org.uk/edcm/if\\_i\\_could\\_change\\_childrens.pdf](http://www.ncb.org.uk/edcm/if_i_could_change_childrens.pdf), accessed 19 March 2010).
- Finch, N. (2001) *Disability Survey 2000: young people with a disability and sport: headline findings*, London: Sport England (available at <http://php.york.ac.uk/inst/spru/research/summs/sport.php>, accessed 15 March 2010).
- 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.fieldsintrust.org/downloads/can\\_play\\_will\\_play.pdf](http://www.fieldsintrust.org/downloads/can_play_will_play.pdf), accessed 19 March 2010).
- 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](http://www.jrf.org.uk/bookshop/eBooks/1842630873.pdf), accessed 10 March 2010).
- NIACE report on the benefits of active play.
- Petrie, P., Knight, A., Zuurmond, M. and Potts, P. (2007) *On holiday! Policy and provision for disabled children and their families: final report*, London: Thomas Coram Research Unit, Institute of Education, University of London.
- Petrie, P., Storey, P. and Thompson, D. (2003) *Inclusive play: supporting provision for disabled children*, London: 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](http://www.cafamily.org.uk/pdfs/leisure.pdf), accessed 26 February 2010).

- 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 19 March 2010).

**DATABASES:** ASSIA; BEI; BEIRC; CERUKplus; ChildData; EED; 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 4: Relevant national indicators and data sources

Table: National indicators and data sources, by Every Child Matters outcome

National indicator (NI) number	NI detail	Data source (published information)	Scale	Frequency of data collection	Latest data collection	First data collection	Link to data source (and comments about trend data)
Demographics		Population Census (2001)	UK, regional and local authority	Every 10 years	2001	1801	<a href="http://www.nomisweb.co.uk/home/census2001.asp">www.nomisweb.co.uk/home/census2001.asp</a>  Trend data available
Demographics		People registered as blind/partially sighted, NHS, The Information Centre (2008)	National, regional and local authority Data available on children aged 0–4 and 5–17	Every three years (2009 data collection moved forward a year)	2008	1982	<a href="http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/people-registered-as-blind-and-partially-sighted-2008-england">www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/people-registered-as-blind-and-partially-sighted-2008-england</a>  Trend data available
Demographics		People registered as deaf or hard of hearing (March 2007), National Statistics/DH	National, regional and local authority Data based on 0- to 17-year-olds	Every three years	2007	1989	<a href="http://www.ic.nhs.uk/webfiles/publications/Registdeaf2007/2006-07%20Deaf.pdf">www.ic.nhs.uk/webfiles/publications/Registdeaf2007/2006-07%20Deaf.pdf</a>  Trend data available
Demographics		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,	Ad hoc (1995, 2002, 2007)	2007	1995	<a href="http://www.rnib.org.uk/aboutus/Research/reports/edemp/Pages/edemp.aspx">www.rnib.org.uk/aboutus/Research/reports/edemp/Pages/edemp.aspx</a>  Trend data not available

			24–35 months and 36–59 months				
Demographics		General Lifestyle Survey (GLF)	Great Britain only  Data available on children aged 0–4 and 5–17 years	Annual	2008	1971	<a href="http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=5756">www.statistics.gov.uk/StatBase/Product.asp?vlnk=5756</a> Trend data available (from General Household Survey)
Demographics		DWP: Family Resources Survey	Great Britain and Northern Ireland, and regional data	Annual	2007/08	1992	<a href="http://research.dwp.gov.uk/asd/frs/2007_08/frs_2007_08_report.pdf">http://research.dwp.gov.uk/asd/frs/2007_08/frs_2007_08_report.pdf</a>  Trend data available
<b>Be healthy</b>							
N154	Services for disabled children	DCSF Children in Need Census	National, regional and local authority Data based on children under 18, including unborn children	Annual from 2008/09 (and between 2000–05)	2008/09	February 2000	<a href="http://www.dcsf.gov.uk/rsgateway/DB/STR/d000892/index.shtml">www.dcsf.gov.uk/rsgateway/DB/STR/d000892/index.shtml</a>  Trend analysis may be possible for earlier years (2000–05). However, the data collection changed in 2008/09, so data is not comparable for all years

N154	Services for disabled children	BMRB Social Research Childcare and Early Years Providers Surveys: Children's Centres (2008)	National data only	Biannual 2001–05; annual 2006–08	2008	2001	<a href="http://www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RR164(R).pdf">www.dcsf.gov.uk/research/data/uploadfiles/DCSF-RR164(R).pdf</a> Trend data likely
N154	Services for disabled children	Health of Children and Young People	UK	N/A	N/A – derived from various data sources	N/A – derived from various data sources	<a href="http://www.statistics.gov.uk/cci/nugget.asp?id=795">www.statistics.gov.uk/cci/nugget.asp?id=795</a> <a href="http://www.statistics.gov.uk/Children/downloads/disability.pdf">www.statistics.gov.uk/Children/downloads/disability.pdf</a> Trend data available
N154	Services for disabled children	Health Survey for England	England only	Annual	2008	1991	<a href="http://www.ic.nhs.uk/statistics-and-data-collections/health-and-lifestyles-related-surveys/health-survey-for-england">www.ic.nhs.uk/statistics-and-data-collections/health-and-lifestyles-related-surveys/health-survey-for-england</a> Trend data available
<b>Stay safe</b>							
NI69	Children who experience bullying	Youth Cohort Study (YCS) and Longitudinal Study of Young People in England (LSYPE)	National	Annual	2008	2004 (for LYSPE) and 1985 for YCS	<a href="http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml</a> <a href="http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000850/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SBU/b000850/index.shtml</a> Trend data available
<b>Enjoy and achieve</b>							

NI72	Achievement of at least 78 points across the early years foundation stage with at least six in each of the scales in personal, social and emotional development (PSED) and communication , language and learning (CLL)	DCSF: Foundation Stage Profile	National, regional and local authority	Annual	2008/09	2003/4	<p><a href="http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000879/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SFR/s000879/index.shtml</a></p> <p>Secondary analysis required to explore attainment of students with special educational needs/a disability</p> <p>Trend analysis may be possible for some years. However, the data collection changed in 2006/07, so data is not comparable for all years</p>
NI92	Narrowing the gap between the lowest-achieving 20 per cent in the early years foundation stage profile and the rest	Foundation Stage Profile	National, regional and local authority	Annual	2008/09	2003/04	<p><a href="http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000879/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SFR/s000879/index.shtml</a></p> <p>Secondary analysis required to explore attainment of students with special educational needs/a disability</p> <p>Trend analysis may be possible for some years. However, the data collection changed in 2006/07, so data is not comparable for all years.</p>

Additional indicators – early years		DCSF: Early Years Foundation Stage Profile Attainment by Pupil Characteristics, in England 2008/09	National, regional and local authority	Annual	2008/09	2006/07	<a href="http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000911/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SFR/s000911/index.shtml</a>  Trend data available
NI104	The special educational needs/non-special educational needs gap – achieving key stage 2 English and maths threshold	DCSF: Key Stage 2 Attainment by Pupil Characteristics, in England 2008/09	National, regional and local authority	Annual	2008/09	2005/06	<a href="http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000889/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SFR/s000889/index.shtml</a>  Trend data available
NI105	The special educational needs/non-special educational needs gap – achieving 5 A*–C GCSEs including English and maths	DCSF: GCSE Attainment by Pupil Characteristics, in England 2008/09	National, regional and local authority	Annual	2008/09	2005/06	<a href="http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000900/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SFR/s000900/index.shtml</a>  Trend data available



Additional indicators – special educational needs		DCSF: Special Educational Needs in England: January 2009 Pupil Level Annual School Census (PLASC) and the SEN2 survey	National only	Annual	2009	1984/5	<a href="http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000852/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SFR/s000852/index.shtml</a>  Trend data available
<b>Positive contribution</b>							
NI110	Young people's participation in positive activities	Health of Children and Young People	UK	N/A	N/A – derived from various data sources	N/A – derived from various data sources	<a href="http://www.statistics.gov.uk/Children/downloads/disability.pdf">www.statistics.gov.uk/Children/downloads/disability.pdf</a> <a href="http://www.statistics.gov.uk/cci/nugget.asp?id=795">www.statistics.gov.uk/cci/nugget.asp?id=795</a>  Trend data available
NI110	Young people's participation in positive activities	Youth Cohort Study and Longitudinal Study of Young People in England	National	Annual	2008	2004	<a href="http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml</a>  <a href="http://www.dcsf.gov.uk/rsgateway/DB/SFR/s000760/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SFR/s000760/index.shtml</a>  <a href="http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000850/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SBU/b000850/index.shtml</a>  Trend data available
NI110	Young people's participation in positive activities	Taking Part: The National Survey of Culture, Leisure and Sport: Headline findings from the 2008/09 Taking	Sample survey, England only  2,622 interviews	Annual	2008/09	2005	<a href="http://www.culture.gov.uk/reference_library/publications/6409.aspx">www.culture.gov.uk/reference_library/publications/6409.aspx</a>  Trend data not available for 5- to 10-year-olds as first year of collection, but may be available for 11- to 15-year-olds

		Part child survey					
NI 110	Young people's participation in positive activities	PE and Sport Survey 2008/09	School census (99.8 per cent of all schools in England)	Annual	2008/09	2003/04	<a href="http://www.teachernet.gov.uk/doc/14380/DCSF-RR168.pdf">www.teachernet.gov.uk/doc/14380/DCSF-RR168.pdf</a>  Trend data available
NI 110	Young people's participation in positive activities	TellUs4	Sample survey: national and local authority	Annual	2009	2007	<a href="http://www.tellussurvey.org.uk/Default.aspx">www.tellussurvey.org.uk/Default.aspx</a>  Trend data not available
<b>Economic wellbeing</b>							
NI116	Proportion of children in poverty	DWP: Family Resources Survey	Great Britain and Northern Ireland, and regional data	Annual	2007/08	1979	<a href="http://research.dwp.gov.uk/asd/frs/2007_08/frs_2007_08_report.pdf">http://research.dwp.gov.uk/asd/frs/2007_08/frs_2007_08_report.pdf</a>  Trend data available
NI117	16- to 18-year-olds who are not in education, employment or training (NEET)	Youth Cohort Study and Longitudinal Study of Young People in England	National	Annual	2008	2004	<a href="http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SBU/b000795/index.shtml</a>  <a href="http://www.dcsf.gov.uk/rsgateway/DB/SBU/b000850/index.shtml">www.dcsf.gov.uk/rsgateway/DB/SBU/b000850/index.shtml</a>  Trend data may be available

## Appendix 5: Validated local practice process and assessment criteria

### What is validated local practice?

Validated local practice examples describe how local authorities and their partners have successfully tackled key challenges and improved outcomes for children and young people. Their success in achieving improved outcomes has been assessed as being sufficiently well evidenced to merit inclusion within the review.

### Collection methods

C4EO collected practice examples by sending invitations to local authorities and trusts to submit promising or proven practice examples to C4EO relevant to each theme after the knowledge workshops. A call for practice examples was also placed on the C4EO website and publicised through various publications. Members of the Theme Advisory Groups were also asked to use their own contacts and networks to publicise the call for practice examples. Respondents submitted examples in hard copy or via email.

### Validation process

Local authorities and their partners were asked to submit their practice examples in a form that was designed to encourage them to fully describe their practice and to provide evidence of how it had improved outcomes. The forms were then assessed by a validation panel made up of a small group of sector specialists, professionals drawn from across the children's sector who have an expertise and a track record of achievement in disability. Two sector specialists assessed each example against the following validation criteria:

**Adequacy of the information supplied.** Is there enough to apply the validation process? If not, and if the practice has potential, NFER will request more information; we will try to do this at screening stage.

**Strength of the rationale.** Was the intervention/practice fit for purpose and based on a clear and sound rationale? Was it based on prior and good-quality evidence of need and what works in similar contexts?

**Sufficiency of impact and outcome evidence.** Is there sufficient external and/or internal evaluation evidence that the practice/intervention has made a difference and led to improved outcomes? Are there good practitioner, service user and other stakeholder views? Do others implementing the same or similar practice or strategy changes or interventions report similar findings?

**Evidence of what has/has not worked and why.** Is there some good guidance here that will be useful to others? What are the golden threads for what works? What barriers and ways of overcoming these have been documented?

**Actual or potential for replication or transfer** to other contexts and settings. What evidence is there that the practice has already been successfully transferred to different settings, or is there the potential for replication? Which elements are especially transferable? What elements are non-negotiable, and which are open to adaptation to suit other contexts? What do people need to put in place to transfer the practice, without substantial loss of effect?

Validated practice has strong outcome evidence of impact on population groups, whereas promising practice has mainly qualitative outcome and output evidence, which refers to systems change.

Fourteen practices examples of relevancy to this review had been submitted at the time of writing, none of which were validated. This review therefore draws on five 'promising' practice examples.

All the practice examples featured within the review, and those submitted and validated since the review was written, are available on the [C4EO website](#).

## Appendix 6: Stakeholder data

### Parents and carers

Overall, out of the Parents and Carers Panel, 19 parents had a child with a disability. The panel was made up of four fathers and 15 mothers. Fifteen panel members responded to the early interventions and positive activities reviews and nine responded to the diverse needs review. They gave feedback on the reviews either by email or at meetings.

### Children and young people

A total of 10 young people took part in two focus groups carried out by Council for Disabled Children. Six disabled young people aged from 14 to 25 years were consulted by the National Children's Bureau via questionnaires and interview feedback. Two young people were from black and minority ethnic groups.

### Service providers

One hundred and seventy delegates attended the C4EO disabled children knowledge workshops (this figure excludes presenters, the C4EO and partners).

The breakdown is as follows:

<b>Category</b>	<b>Number of delegates</b>
Local authority children's services (excluding Sure Start)	122
Health	23
Third Sector	14
Councillors/lead members	0
Sure Start centres	0
Department for Children, Schools and Families (now Department for Education)/Government Offices	7
Miscellaneous	2
Parents and carers	2
<b>Total</b>	<b>170</b>

JUNE 2010

C4EODKR2

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

This knowledge review tells us what works in improving access to positive and inclusive activities for disabled children and young people. It is based on a rapid review of the research literature involving systematic searching, analysis of key data, promising local practice examples and views from service users and providers. It summarises the best available evidence that will help service providers to improve services and, ultimately, outcomes for children, young people and their families.

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