Services for Families with Disabled Children

A Scoping Study

Final Report
(Revision 1)

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September 2011
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Revision 1
The report has been updated to include policy and guideline changes set out by the UK Coalition government and where known, resultant changes to local policy implementation in Surrey.

The Report
This report presents the findings from a scoping study on the policy environment, service delivery and models of care for families with disabled children in Surrey.

The Scoping Study
The aim was to undertake a scoping study that would lead to the development of a research protocol for a comprehensive evaluation of the outcomes and costs of alternative models of care for disabled children.

The following tasks were undertaken:

- A review of current national and local policies for disabled children, governing the institutional arrangements for the delivery of services, funding mechanisms and cross agency working (i.e. links between health and social services) - carried out in Autumn 2009.
- Interviews were held with key informants (commissioners and providers of care) for information on current local policies, service commissioning and services that are available to parents – carried out between October 2009 and February 2010.
- A search of the literature and review of studies that reported evidence on the effectiveness and/or costs of alternative interventions for disabled children – carried out January - March 2010.
- A mapping exercise within Surrey was completed of the out-of-school services currently available for disabled children – carried out between November 2009 and March 2010.
- A research protocol was developed for two further research studies in Surrey, prepared March 2010.

The study has focused on policy and services for primary school age children (Age 4 -11 years).

Acknowledgements

The authors of the report would like to thank the following organisations for their help in preparing this report: Surrey County Council, Surrey District and Borough Councils, Surrey Community Action and local service providers.

The study was commissioned and funded by an anonymous donor through the support of Disability Challengers, a major provider of play schemes and short breaks for families with disabled children in Surrey. However, the views expressed in this report are those of the authors and not necessarily those of Disability Challengers.

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Executive Summary (Revision 1)

Key Findings

1. Services for families with disabled children have been delivered under the Every Child Matters (ECM) framework since 2003. The national policy environment is complex and fragmented and this leads to disjointed commissioning and service delivery.

2. Significant ring-fenced funding was made available by the previous UK Labour government, under the Aiming High for Disabled Children (AHDC) programme, to expand short break services in England. There was also a policy move towards more Personalised services, through Personal Budgets, and a drive for ‘seamless’ service delivery to families from local agencies.

3. The UK Coalition government has continued short break funding, as part of the non-ring-fenced Early Intervention Grant, and has expressed a continuing commitment to Personalised services, and a move to a ‘single assessment process’ for education, health and social care.

4. The move away from large Local Authority block contracts to ‘micro-commissioning’ by Personal Budget holders is making it difficult for service providers to plan and manage services.

5. Short break services are seen as key to help families cope with caring for a disabled child. There are a wide and varied range of day and overnight services and all providers aim to give children a positive experience on their break, as well as providing respite for carers.

6. Little is known about the pattern of usage of short break services, though older carers and families who have children with challenging behaviour or poor sleep patterns, use more residential services. Local Authorities have a preference for day services, particularly for children under 10, and residential providers have not benefited from recent short break funding initiatives. Some families use no services and it is not clear why.

7. Surrey is thought to have an above average provision of short break services. Many of these services are provided by charities, set up by parents and concerned professionals. These providers have worked with the statutory agencies to provide low-cost services across the County for many years and were able to expand services quickly under the AHDC programme.

8. The profile of families with disabled children in England is unclear due to the lack of adequate national datasets and statistics. Little is known about their out-of-school lives and the types of services that provide the best outcomes for different groups of families.

9. Studies have focused on service outcomes for the disabled child, and sometimes, mothers; however, outcomes for fathers and siblings are also important and research information for these groups is limited.

10. Families consider the way a service is delivered an important service outcome. It must have an appropriate environment, trained staff and varied activities. ECM Outcomes often do not apply, as disabled children may not follow a normative development pathway, and outcomes need to be individual to the child and their family.

11. There may be significant economic outcomes from short break services, such as, improved family income and health. However, it is difficult to attribute these directly to short break services, particularly long term outcomes, such as, reductions in family breakdowns and residential placements.

12. Play is important for children’s development and contributes to learning, social skills and language development. Lack of play can lead to negative behaviours and lack of brain growth.

13. Families value play services for their disabled children, as these allow the children to engage in normal childhood activities, as well as providing respite for carers. They may help increase disabled children’s physical activity and thus, help reduce obesity.

14. There is a policy push towards more inclusive services for families for disabled children. However, there is local professional and parental doubt that these are best for all children, and many parents of children with complex needs and Autistic Spectrum Disorders (ASD) have expressed a preference for segregated services for children with similar disabilities.
Policy

Traditionally, many services for disabled children in England have been delivered and funded by the third sector, with access and availability differing across the country. In the last 10 years, disabled children and their families have come to the fore of national government policy, along with a wider move to more personalized services. The former UK Labour government implemented a major programme, Aiming High for Disabled children (AHDC), to expand significantly short break services for these families, and to increase access to positive activities for disabled children. With the ending of AHDC programme in April 2011, and the proposed cuts by the UK Coalition government and Local Authorities (LAs), there is uncertainty surrounding the commissioning and availability of services. It is not known how LAs will use the funding provided in the new Early Intervention Grant for services for families with disabled children, as this funding is not ‘ring-fenced’ (£800m DoE, 2011).

The national policy has developed under separate policy initiatives by different government departments and the overall policy framework through which local services to disabled children are delivered is complex and disjointed. A play and leisure scheme can be considered a short break, out-of-school care (childcare), positive experience or an opportunity to participate in play and it can be commissioned by different local agencies and funded under several government programmes. This complex commissioning and funding environment makes it difficult for third sector service providers to build and deliver services and for families with disabled children to access them.

The recent Coalition government Green Paper (DoE, 2011) makes a clear commitment to extending the Personalisation agenda (DoE 2011), with a target date of 2014 for all eligible families to have the right to personalised funding. Although take-up has been low amongst families with disabled children, the positive outcomes reported by Individual Budget (IBs) holders (DCSF–RW067 2008) and the active government promotion of the scheme, are encouraging other families to switch to Personal Budgets (PBs). The latest figures from (TDC/LAIMP April 2010) show that the number of families with disabled children taking up Direct Payments has increased by 42% and those taking up Individual Budgets have increased significantly by 202%, from the previous year.

However, there is rising concern amongst service providers about the effects of policy changes on the service market, and on their funding and operating environment. In the new system, providers will lack the security of large, long-term, LA block contracts, and they will have to adjust to a more flexible market with ‘micro-commissioning’ by personal budget holders, which will impact on both short and long term planning (AVECO 2010).

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1 Short breaks usually provide opportunities for disabled children and young people to spend time away from their primary carers. These include day, evening, overnight or weekend activities and take place in the child’s own home, the home of an approved carer, or a residential or community setting. Short breaks can also be provided through a temporary carer relieving the primary carer of their caring responsibilities without their being separated from the disabled child or young person. Short break provision is therefore fairly widely defined, and ranges from supporting disabled children and young people to access universal leisure-time services, through to providing specialist services. It can also include other forms of support for families such as direct payments. DCSF definition used in Surrey Alliance, Surrey AHDC Funding Guidance

2 Positive activities are defined as leisure-time activities outside school hours and taking place in, or delivered by, children’s centres, extended services, youth services, school-based extra-curricular activities, play and leisure services, sport and recreation services, and the arts.

3 Personalisation (Baxter et al, 2011): to enable users to have direct influence on the choice and usage of their services instead of the current model where care managers arrange to choose and arrange support. Mechanisms to facilitate Personalisation include Personal Budgets (PBs) which are user-controlled budgets provided to service users for the purchase of social care support. It is an umbrella term that includes Direct Payments (DPs) and Individual Budgets (IBs). There is also potential for IBs to be expanded to include health and education funding.
Short Breaks

Short Breaks (respite) have long been recognised as essential to help families cope with caring for a severely disabled child and in the past, they have tended to be provided by specialist residential units or hospitals. With a shift in attitudes towards disability and equality, parents and professionals wanted more for these children and many charities were set up to provide child-centred units, where disabled children could enjoy themselves and have access to the same activities as non-disabled children.

There is a wide spectrum of disability and a varied range of day and residential short break services are required to meet the needs of all families with disabled children. These are provided at both specialist and mainstream centres, and there are also, more personal family-based services, that care for a child in their own or at a foster carer’s home and can provide one-to-one support for outings. AHDC funding has allowed short break services to expand and there are now more opportunities for children to enjoy out-of-school positive activities, such as play and leisure, away from their main carers (TDC, 2010).

Mapping of services in Surrey

Surrey is considered to have an above average provision of short break services and the mapping shows that the County has a good coverage of play and leisure schemes, as well as the more traditional residential respite services. The third sector provides most of the short break services in Surrey and a number of these charities have been established for many years. From their own fundraising and with additional support from Surrey County Council and local district and borough councils, they have been able to build specialist centres and offer out-of-school play and leisure services to many families with disabled children.

In the last 10 years, the main providers in Surrey have come together with the Local Authority (Play & Leisure Consortium) to develop services across the whole County, without the need for a referral process and where carers pay less than for mainstream leisure. This firm foundation allowed the funding from the AHDC programme to be ‘rolled out’ quickly and many providers were able to set-up and expand holiday and weekend schemes at short notice, within their existing service structure. However, local residential providers have not benefited to the same extent, as local AHDC funding was focused on day services and many providers had expanded their residential facilities in recent years, using their own charitable funds, and further building works were not feasible without guaranteed long term funding.

Before the AHDC programme, integrated services were already being expanded by specialist providers and also, mainstream providers were expanding support for children with low to moderate needs and making their services more inclusive4. This has continued within the AHDC programme, though some mainstream providers were unaware of these funding opportunities and had no spare staff capacity to investigate and apply for available funding, which could have helped more families with disabled children access their services.

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4 The meaning of inclusion is constantly evolving and the Council for Disabled Children (2008) have identified the following factors as being crucial: ‘being welcome; being part, not apart, going where you want to go; being actively involved, people expecting you; getting help when you need it’
Literature review

General findings

As part of the continuing development of national policy and effective practise, the previous Labour government commissioned a number of Disability Research Reviews which concluded that little is known about the profile of disabled children in England, due to the lack of adequate national datasets and statistics and there being no consistent definition of ‘disability’ across research studies. There is little knowledge about the out-of-school lives of disabled children and their families and their opportunities to take part in positive activities, though it is believed that these are limited and many disabled children are very isolated when not at school.

Although there is evidence for which types of services parents with disabled children most value, it is not known which services deliver the best outcomes for which group of families (who may have very differing needs), how long any benefits from these services last or if other types of services may be equally or more effective.

Research has concentrated on pre-school services and thus, services for children aged 5 to 8 years, adolescents and transition are poorly understood. Also, children with communication impairments or profound and multiple difficulties are seldom included in studies and when studies do focus on these groups, the children’s own views are often ignored.

Studies have tended to focus on outcomes for the disabled child only and few have looked at the wider family unit. Primary carer views are usually given by Mothers and the outcomes for Fathers and Siblings are rarely investigated but are important, as these affect the family dynamic and have indirect consequences for the disabled child.

Short Breaks – patterns of usage

Although short breaks have been shown to help carers cope with looking after a disabled child, there is limited knowledge about the pattern of usage of short break services and it is estimated that only 20% of families with disabled children access these services. Various factors may be involved but it is not clear why this figure is so low, though families still mention availability of any play and leisure scheme and transport to schemes as two of the main limiting factors in accessing play and leisure for their child. Carer surveys often seek the views of existing users of short break services and these surveys do not address why particular services are used or not used and why some families do not use any of these services. Carers surveyed have cited shortage of appropriate provision and transport, the child not wanting to go and their own feelings of failure as a carer as reasons for not using short break services. Also, few surveys seek the views of the children themselves on their preferences for short breaks.

Families tend to use short breaks they have used before, as they have built up confidence in the service and the child and staff are known to each other. Some families use multiple types of short break, though the actual pattern of usage and reasons are unknown. Local experience suggests it allows families to have increased access to services and different types of service may provide families with different types of support. The effects of this multi-usage of short break services on the availability of places for other families, is unknown.

There is some research on the type of short break preferred by carers and those with children who need constant supervision and support, have particularly challenging behaviours or poor sleep patterns, use more residential services, as do older parents. There has been a policy move away from residential services to day services, particularly for children who are under 10 years, and yet, some carers seem to value these services and consider them the only service that allows a complete break from caring.
Outcomes
The previous Labour government’s Every Child Matters programme provided the main framework for assessing the Outcomes for all children’s services in England. However, these Outcomes are difficult to interpret and often, are not applicable to disabled children who may not follow a normative developmental pathway. Outcomes need to be individual to the disabled child and their family, and are likely to be hierarchical. Disabled children’s primary needs, such as health, comfort and communication, must be met before they can engage in positive activities and for their families, they must have confidence that the service can meet the all the family’s needs. Wellbeing of children is included in many Outcome measures for services but this has proved difficult to measure and the Office of National Statistics has an on-going programme to define wellbeing and develop an effective measurement tool for children and adults.

Carers and disabled children consider ‘how the service’ is delivered an important outcome from any service. The criteria for a ‘good service’ include an appropriate, safe and friendly environment where the child has fun and where staff can fully meet the child’s needs and are able to cope in an emergency. Disabled children want a service to understand their impairments, help and listen to them and allow them to make choices. Families with disabled children found that these ‘good services’ tend to be provided by specialist providers though many mainstream providers have successfully made their services more inclusive to children with low and moderate needs.

There may be substantial economic benefits from short breaks, such as increased family income from allowing carers to work and to the state from improved carer health, fewer family breakdowns and a reduced number of disabled children placed in residential care, but it is difficult to quantify these benefits and attribute them directly to short break services.

Play, Playwork and Play Services
The outcomes of Play for disabled children have not been a national research priority and although it is widely recognised as beneficial in the educational setting for all children, more research is needed on the outcomes for disabled children from participating in unstructured and free play, and also, the role of play workers and support staff in play environments.

Like ‘disability’, there is no standard definition for ‘play’ but there is substantial evidence that play forms an important part in all children’s development. Play helps with children’s cognitive and social development and improves their mental and physical health. Long-term play deprivation (such as that once seen in Romanian orphanages) can cause negative behaviours and reduction in brain size, and some of these effects can be reversed, if children are subsequently introduced to play.

Play schemes are popular with families with disabled children and parents cite similar essential criteria for ‘good’ play schemes’ as for ‘good’ short break services, i.e. appropriate facilities, trained staff and varied activities. Parents do not consider play schemes as just providing respite for themselves, but see play as important for their disabled child’s social and personal development and want them to have an enjoyable experience at schemes and play like non-disabled children.

Disabled children are more prone to Obesity than other children and supported play activities may be one way of increasing their access to physical exercise. There are no specific guidelines for England, but the Scottish Government guidelines suggest they should have the opportunity to participate in exercise for at least one hour a day.

Inclusion and Inclusive Services
There is a policy drive towards more inclusive services for disabled children, as they are seen as a means to reduce social isolation for families with disabled children and help them feel more integrated within their communities. There is evidence that inclusive services can contribute to disabled children’s social development and understanding of their peer’s culture and this helps them...
cope with other inclusive and mainstream settings. Disabled children want to have the same opportunities as non-disabled children, particularly as they get older and for teenagers, access to mainstream facilities and activities is particularly important.

There are broad interpretations of ‘inclusion’ and successful services have planned how disabled children and their families can access the service fully and participate meaningfully when attending a scheme. Both short break and play research have identified some outcomes for a ‘good’ service from the carer’s and child’s perspective and it is these outcomes that seem to influence parental preferences for specialist services over mainstream services. The confidence carers have in specialist providers is often not present for mainstream providers and carers worry about lack of appropriate facilities and activities and whether their child will be bullied, not included in activities or left alone and untrained staff may not cope with an emergency. Many mainstream play schemes depend on low-paid and briefly trained staff to keep costs low for all families and feel unable to justify the additional costs for specialist training and additional specialist staff. Many are unaware that funding may be available from other sources to help, such as the AHDC programme. The more successful mainstream providers, such as local councils, have made direct efforts to find out about a child’s needs and decide on a case-by-case basis whether the service can cope and if not, if it is feasible to adapt facilities and provide one-to-one support. However, as the government imposes new legislation and policies, local councils are struggling to balance their legal obligations to not discriminate against families with disabled children with the pressures of providing low-cost play and holiday schemes for all families, on a reduced budget.

They may be many reasons why families with disabled children do not want to participate in inclusive activities and these can include the family’s predisposition to taking part in leisure activities and their perceptions on how suitable the activity is for their child. The child’s preferences and perceptions of their abilities are also a factor and they may not have the social skills to fully participate as they may have spent most of their lives in specialist settings (e.g. school) and not learned the nuances of children’s play behaviour needed to fully participate.

There is evidence that some disabled children benefit from specialist services for children with similar disabilities and parental surveys indicate a preference for specialist schemes for children with severe disabilities and those with autistic spectrum disorders. Their trained staff and specialist equipment are expensive and other specialist and mainstream providers can find it difficult to adapt their schemes and justify the additional costs.

The move towards providing more inclusive services has raised issues relating to funding. AHDC/short break funding can only fund services for disabled children and a provider’s own charitable funding may have similar restrictions. With specialist services oversubscribed, service commissioners and providers have concerns about allocating valuable spaces on these schemes to non-disabled children, or funding part of the service for all children, e.g. transport. Fees for integrated schemes set up by specialist providers, alongside their segregated schemes, are often subsidised by charity funding, and can cost the carer less than for an equivalent mainstream scheme. Similarly, mainstream schemes have limited public subsidy and often have higher charges, making specialist schemes more attractive to parents of disabled children on cost alone.

As inclusion becomes more widespread, funding and fees for play schemes where disabled children are well supported will become an issue for commissioners and service providers. If charity providers choose to set up more inclusive play schemes, they may find it difficult to persuade funders and trustees that their limited funds should be used to subsidise places for non-disabled children (including siblings), and they may have to revise their current funding model of low cost places for all families with disabled children, in addition to funding model changes for personal budgets.
Research Proposals

Carer Survey on Play and Leisure / Short Break Service Usage
One of the main issues identified during the study was the lack of knowledge surrounding the out-of-school lives of disabled children nationally. Some carer surveys have been undertaken by local authorities to advise on how AHDC funding should be directed but these surveys have focused on families who already use services and it is believed that there are many families who use no services. Little is known about the leisure time of these disabled children and whether they have access to any play and leisure outside school. Research indicates and local stakeholders believe that some disabled children are still very isolated when not in school. It is possible that families are not aware of the available schemes or their eligibility to use them and many schemes are still oversubscribed, so availability and transport to a scheme could still be factors.

The first research study seeks to provide more information on the out-of-school activities of disabled children and is a carer survey of all families with a disabled child in Surrey, distributed via specialist schools and mainstream schools with specialist provision. The aim is to access as many families with disabled children as feasible; especially those families who use no services, either by choice or through lack of formal assessment, information or other support services.

Investigative Study on Segregated and Inclusive Holiday Play Schemes
The scoping study identified a current policy and commissioning drive to expand inclusive services for families with disabled children. However, the way inclusion is delivered varies significantly between service providers and there is professional and carer doubt around whether these services are suitable for all disabled children or if some children’s needs are better met by segregated services with specialist support and appropriately trained staff. Carers of certain groups of children express a preference for segregated schemes and there are many popular schemes that cater for children with a single or similar disability. However, families do value access to mainstream provision and some would like siblings to access the same scheme, and disabled children want to participate in the same leisure services as non-disabled children. The second study will explore whether segregated and integrated services deliver different outcomes for different groups of disabled children, by investigating service provision in a range of integrated and segregated holiday play schemes.

Both studies should be completed in 2011.
Section 1: Study Overview

Policy Review

The initial phase of the project identified the main policies strands that govern service delivery for disabled children in England, using relevant reports from national government and non-government organisations, and through interviews with local service commissioners and providers.

The Aiming High for Disabled Children programme (AHDC, 2008-2011), initiated by the UK Labour government, was jointly delivered by local authorities and the NHS, with substantial government funding, with the aim of increasing the short break provision in England for families with disabled children.

Short Breaks services are wide and varied and further interviews with both service providers and commissioners identified a focus on increasing access to positive activities for disabled children, in particular, to schemes that offered out-of-school play and leisure opportunities. The AHDC funding was provided to expand provision for those families who were not eligible for social care funding and local service providers, who already provided play and leisure schemes for disabled children with limited local council grants, were able to use AHDC funding to increase open-access (non-referral) places to their play and leisure services.

Positive Activities, such as play and leisure, are now important parts of short break services and local stakeholders mentioned that play for disabled children had long been considered important locally in Surrey. A number of charities had provided these opportunities outside of a formal government policy, with help from the district and borough councils. Since 2003, a ‘Surrey Model’ of co-operation has developed where Surrey providers have worked with Surrey County Council (SCC) in the Play & Leisure consortium to extend the scope of services across the County and give all disabled children access to low-cost play and leisure, without a social-care referral. Recent national government Play policies recognised the need for play and the Play Strategy (2008) sought to improve play for children in England and as a result, SCC became involved in helping districts and boroughs improve playgrounds for all families, through the national Playbuilder programme.

Many of the local short breaks play and leisure schemes can also be considered as providing childcare for disabled children and SCC has an ‘including me’ project to help disabled children attend mainstream afterschool schemes. The national AHDC programme funded a new Disabled Children’s Access to Childcare (DCA TCH) initiative from April 2010, to be delivered by SCC Early Years teams, that aims to give families for disabled children access to the same childcare options as other families. In Surrey, SCC has focused on including disabled children in mainstream after-school clubs.

The policy review revealed a multi-department and complex policy framework for service delivery to disabled children and young people (See Figure 1). Within the time constraints of the study, it was only possible to focus on services for primary school children (Aged 4 – 11 years), as this age group are the main users of short break play services; it has not extended to preschool or adolescent disabled children or those in transition to adult services. Older children tend to prefer services such as befriending, ‘buddying’ and leisure trips instead of play services and the issues around each age group are different and complex; these children/young people would warrant a separate scoping study on adolescent specific policies and services.
Figure 1: Overview of National Policies and Funding Streams for Out-of-School (OSC) Services for Disabled Children, their links to local service delivery and the scoping area for the literature review and service mapping.

It illustrates the complexity of the national policy and local programmes for service commissioning and provision that govern out-of-school services for disabled children.

Notes:
1. It is not known how much funding of NHS funding is being provided for new short break services or the type of services that will be funded. The AHDC programme will end in April 2011.
2. The new UK Coalition government has continued funding for short breaks via the Early Intervention Grant to LAs; however, this funding has not been ‘ring fenced’ (£800m DoE, 2011).

Literature review and local service mapping

The second phase of the study involved a literature review and local service mapping based on the three strands of policy and services identified in the first phase: short breaks, play and leisure and out-of-school childcare. The policy review revealed the importance of outcomes in the delivery of services, a focus on how short breaks could improve disabled children’s wellbeing and the promotion of more inclusive services. The literature review was expanded to include a review of these three concepts, outcomes, wellbeing and inclusion.

The initial literature review found many recent and comprehensive reviews on the lives of families with disabled children. The reviews concluded that there was a general lack of knowledge about these families and the lives of disabled children outside school, and that many families with disabled children are not accessing any services. Additionally, it was unclear how effective current services
were, what outcomes they delivered for different groups of families and how cost effective they were. The reviews also found that there were few rigorous evaluations of taking part in positive activities, whether segregated or integrated, and there is parental and professional doubt surrounding inclusive services, in the way they are delivered and if they deliver the best outcomes for some groups of disabled children.

**Short Break Development**

The term ‘short break’ is relatively new in terms of services for disabled children, and traditionally, the term ‘respite’ was frequently used. Short breaks cover a widely defined set of services and they refer to time disabled children spend away from their primary carer and where they can participate in play and leisure.

A more detailed definition of Short Breaks was needed and the different types of residential and day short break services was compiled and these were used to generate the local service mapping and scope the literature review.

**Local service mapping**

The study generated a service mapping for Surrey. The policy review had identified three types of services: short breaks, play and leisure service and out-of-school care (OSC). Although short breaks were specifically designed for disabled children, play and leisure services and OSC services are provided for all children and in recent years, many of these mainstream services have become more inclusive. The range and categorisation of services made it difficult to find all the services for disabled children in Surrey. The process of generating the mapping identified the continuing problems of providing information to parents at a central source.

A new web-based service developed by Surrey Information on Disability (SIB) and funded by the AHDC programme, was launched in March 2011.

**Research protocol**

One of the main gaps in evidence is the lack of information on the out-of-schools lives of disabled children and their opportunities to participate in play and leisure. Also, there is a policy move towards providing more inclusive services for disabled children and to widen access to mainstream provision. However, it is uncertain whether inclusion is best for all disabled children, particularly those children with complex needs or Autistic Spectrum Disorders.

To address these gaps in knowledge, the research protocol proposes two studies, both using Surrey as a case study: one study aims to provide more information on what disabled children do outside school and pattern of usage of short break and play and leisure services by families, and an additional study will investigate whether segregated or integrated play services deliver different outcomes for different groups of families with disabled children.
Section 2: National Policy Review

The Policy review was undertaken before the new UK Coalition Government took power in May 2010 and the policies listed here are those of the previous Labour Government. Separate policies and funding streams to Local Authorities (e.g. AHDC, Playbuilder) have been replaced by a ‘non-ring fenced’ Early Intervention Grant (£800m).

The Coalition DfE has published a Green Paper: A new approach to SEN & Disability, Mar 2011 which proposes to simplifying the bureaucratic education and care system and improve choice in services for families with disabled children, with the aim of improving life outcomes for disabled children.

They include the following proposals:

- Introducing a single assessment process which will provide a complete ‘Education, Health & Care Plan’ for each child (by 2014)
- providing a ‘local offer’ of easy-to-understand information on all services so carers can choose appropriate services
- the option of a personal budget (by 2014) for those with EHC Plan with Key workers trained to advise and help families access services
- a clearer system, so professionals and the third sector can work together
- better commissioning which is ‘integrated & collaborative’ and includes:
  - LA (education & social care)
  - Health & wellbeing boards, GP consortia
  - Voluntary, Community & Faith Sector

In separate guidance (Short Breaks for Carers: Advice for LA, DoE, Mar 2011), carers needs must be considered, as well as the child’s needs, when assessing eligibility for Short Break services.

Key Messages

1. The Every Child Matters (2003) programme and its subsequent update by the Children Plan (2008) is the main framework under which all services for disabled children are delivered in England. It required all local authorities to have a Director of Children’s Services and a lead council member for children, together with a Children’s Trust.

2. The Children’s Trust is a partnership between all local agencies involved in service delivery for disabled children with the aim to integrate services and encourage joint working and accountability (known as ‘Surrey Alliance’ locally to avoid confusion with the existing charity - The Children’s Trust, Tadworth). Families with disabled children should have a seamless service and not become involved in inter-agency disputes concerning provision and funding.

3. The NHS Child Health Strategy identified continuing problems with joint working such as conflicting targets and priorities, different organisational structures and under-developed and differing methods in commissioning and funding.

4. Play and leisure services for disabled children are provided under three main government funding programmes:
   b. Play: Play Strategy delivered through the Playbuilder programme by local authorities with support from districts and boroughs, from 2009.
5. Play England has commissioned a joint play and short break pathfinder group to advise local authorities on how to link the AHDC and Playbuilder programmes.

6. Local Authorities now have statutory obligations to deliver the same services to disabled children and their families as other families. Also, Equality legislation means that mainstream facilities and service providers must make reasonable adjustments to their buildings, facilities and services to allow disabled people to use their services.

7. Families with disabled children have the right to be provided with Individual Budgets for their child so as they can choose and pay for services themselves. This change impacts on the way services are commissioned by local authorities and the NHS and also, on their relationship with service providers.

Section 2.1: Overview

The main policy through which all children’s services are delivered in the UK is the Every Child Matters (ECM, 2003) programme which sets out an ambitious set of goals to improve the lives of all children in the UK. The programme saw the integration of services as key to improving children’s lives and established local Children’s Trusts to facilitate joint working between agencies. In 2005, the Prime Minister’s Policy Unit set out a vision for what needs to happen in the next 20 years to improve the services provided to help families with disabled children live an ‘ordinary’ life and this resulted in the Aiming High for Disabled Children (AHDC) programme. Within the ECM framework, the AHDC programme has provided significant funding (£340m over 2008-2011) to increase the provision of short break services to disabled children and their families. The Coalition government has included £800m, as part of the new Early Intervention Grant to Local Authorities, for services for families with disabled children (DoE, 2011), though it is not ‘ring fenced’, and with significant budgets cuts in other areas, LAs are unlikely to maintain current funding levels for these services.

Government involvement in play and leisure services for disabled children is recent as these were seen as ‘optional’ services and not government’s responsibility. It was left to national and local charities to provide play and leisure opportunities, sometimes with limited support from their local councils. Disabled children were often not considered in terms of mainstream play but recent equality legislation requires all service commissioners and funders to take reasonable steps to include disabled children in their services. Expansion of play services started with the Dobson Review (2004) and National Lottery funding was used to deliver a play programme through Play England. The recent Play Strategy (2008) aimed to improve play for all children and for disabled children to have the same access to play provision as other children. This policy overlaps with AHDC’s aim to increase access to positive activities on short breaks and the government have set an additional programme in place to help local authorities bring the AHDC and Playbuilder programmes together and pool funding.

A new childcare policy, Disabled Children’s Access to Childcare (DCATCH, funded from April 2010) aims to help families with disabled children gain access to the same after-school childcare as other families. There could be a policy and funding overlap with AHDC and Playbuilder, if the short break service providers become involved in childcare for disabled children. However, in Surrey, DCATCH is delivered by SCC Early Years teams and is focused on expanding access to mainstream after-school clubs for disabled children, rather than on specialist provision.

When a disabled child spends a few hours away from their primary carer and is enjoying play or leisure activities, it can be considered a short break for them and their carer, childcare for the carer and a play opportunity for the child. Although the same service is being provided, there are at least
three separate policy and funding streams covering these types of play and leisure services. This means separate programmes (such as Together for Children’s AHDC/Playbuilder programme) must be initiated and separately funded to bring overlapping programmes together and advise local authorities on the best way to do this. Also, programmes such as AHDC require the NHS and LA to work together to provide a single set of services to meet the needs of families with disabled children and there is professional concern that this will be achieved. Joint service deliver generates an additional level of complexity to service commissioning, as organisations have different institutional structures, commissioning services and funding models.

The introduction of Individual Budgets (IBs), where families with disabled children will be able to pay for services directly, provides challenges to both the local authorities and service providers; carers can choose to use social care funding to pay for play and leisure services directly and access a portfolio of both mainstream and specialist schemes that suit their current family situation, preferences and needs. No longer will the local authority funding be concentrated on the service providers that traditionally have provided short break services and many existing block contracts will end. Service providers will need to attract parents to their services and provide disabled children with positive experiences they enjoy and want to come back to and the provider will be dependent on a more fragmented funding model. While large providers may already have the resources and infrastructure to deal with this new business model, some small providers may lose their existing stable and continuing source of funding from local authorities and find it difficult to survive on less predictable funding streams. There is concern within the sector as to how IBs will be implemented and the way they may affect current services and it is acknowledged within the local authority and voluntary sector that service providers and families will need considerable help to adjust to this new funding model.

Section 2.2: Method
An initial search of government department websites for relevant policies and legislation led to the policy review focusing on four key government departments: the Treasury, Department for Children, Schools and Families (DCSF), Department of Health (DH) and Department for Culture, Media and Sport (DCMS). These initial searches elicited the Aiming High for Disabled Children (AHDC) Short Breaks programme and the Play Strategy as the main policy streams governing play and leisure for disabled children.

This was followed by lateral searches for key documents on ‘Short Breaks’ and ‘Play and Leisure’ for disabled children from UK government departments, universities, charities and other non-government organisations (NGOs). See Appendix 3.

With devolved governments in Scotland, Wales and Northern Ireland, each country has developed their own local policies and there is no longer a joint UK implementation of policy and strategy affecting disabled children. Some searches have been done on the Scottish and Northern Ireland government research websites for Short Break studies.

The main documents used for this report are listed at Appendix 1.

Section 2.3: National policies and Legislation
The following key national strategies, policies and legislation are driving current government policy in the play and leisure area for disabled children:

Policies

• National Service Framework (NSF) for Children, Young People and Maternity Services (2004). This set out standards for health and social care for disabled children to meet the ECM outcomes. It includes improving access to play and leisure opportunities and short break services under Standard 8. The recent Child Health Strategy, Healthy minds, brighter futures (2009) brings together, the NSF, Children’s Plan and NHS Next Stage Review (2008) and sets out how the NHS will work with Local Authorities to deliver short breaks for disabled children.

• Aiming High for Disabled Children (2007): short break programme. This is a government programme to fund and deliver more ‘flexible breaks’ for carers of disabled children. This report was the culmination of the Disabled Children’s Review, one of a series of reviews in the Comprehensive Spending Review (2007) which set each department’s spending plans and priorities. It built on recommendations already set out in the Prime Minister’s Strategy Unit ‘Improving the life chances of disabled children’ report and the NSF.

• Play Strategy (2008). This is a recent strategy to deliver high quality play opportunities to all children in the England. In 2009, Play England (the government’s national delivery partner for the strategy) formed a joint play and short break pathfinder group with KIDS, Skills Active and Together for Disabled Children. This group has reported on 4 pathfinder local authorities that have linked short break and play funding to improve services.

• Disabled Children’s Access to Childcare (DCATCH) (AHDC, 2007). A policy being funded by AHDC programme from April 2010 that aims to give disabled children and their families the same access to the childcare options that are open to other families that became a duty on local authorities in the Childcare Act (2006).

Legislation

• Children’s Act (2004) is the legislation for ECM policy and requires Local Authorities (LAs) to set up a Children’s Trust partnership with other local agency (e.g. NHS) to ensure the seamless delivery of health, social and education services by resolving issues, such as who is responsible for the provision and funding of local services. (statutory requirements relating to Children’s Trusts being revised by Coalition government)

• Disability Equality Duty (2005) requires LAs to be proactive and ensure the needs of disabled children are met when developing policy.

• Childcare Act (2006) requires LAs to assess and meet the childcare needs families with disabled children up to 18 years.

• NHS Act (2006) allows NHS and Local Authorities to enter into joint funding and commissioning arrangements.

• Education Act (2006).

• Carers and Disabled Children’s Act (2000): Section 6 of the 2000 Act requires local authorities to carry out an assessment (i) where the carers are providing a substantial amount of care on a regular basis; (ii) they request such an assessment; and (iii) where the local authority is satisfied that the child and family are persons for whom it may provide services under section 17 of the 1989 Act (DoE, 2011 Short Breaks for Carers of Disabled Children, Advice for local authorities)
Figure 2.3: Framework of National Policies and Legislation that have impacted Out-of-School Services for Disabled children in England, since 2003.

The picture illustrates the complexity and defragmentation of the policies around the issue. Over time, new policies and legislation have been added to try and fix problems with actual implementation. The result is a legislative ‘jungle’ which is ineffective, costly and difficult to navigate for third sector providers.

Recent policies on Carers services and changes introduced by the Childcare Act (2006) are not included here, but these will also influence service provision and contribute to the complexity of the framework.
Section 2.4: Overview of the key national policy documents:


The policies outlined in the Every Child Matter (ECM) green paper, presented by the Treasury in 2003 and enshrined in The Children Act in 2004, provide the main framework for all current children’s services in England, including those for disabled children. It set out five outcomes, along with national targets and indicators, to achieve the report’s primary goals detailed in the ECM Outcomes framework (2005 & 2008). The aims under some of these goals have implications for the play and leisure opportunities for disabled children and are:

BE HEALTHY – aims include that Children and Young People ‘are physically healthy’, ‘are mentally and emotionally healthy’ and ‘live healthy lifestyles’. In this area, the inspectorates make judgements on whether carers receive support to keep their children healthy, healthy lifestyles are promoted and the health needs of disabled children are addressed. The inspectorates look for evidence that all children are enabled and encouraged to take regular exercise.

BE SAFE – aims include that Children and Young People and their carers are informed about key risks and about how to deal with them. They should have a safe environment and be helped to stay safe. The inspectorates focus mainly on child protection aspects of this aim.

ENJOY & ACHIEVE – aims include that Children and Young People ‘achieve personal and social development and enjoy recreation’. In this area, the inspectorates make judgements on whether carers receive support in helping their children to enjoy and achieve, all children can access a range of recreational activities (including play provision) and disabled children and young people are helped to enjoy and achieve. The inspectorates look for evidence that there are safe and accessible places where children and young people can play and socialise.

MAKE A POSITIVE CONTRIBUTION – aims include that Children and Young People ‘develop self-confidence and successfully deal with significant life changes and challenges’. In this area, the inspectorates make judgements on whether all children are supported in developing socially and emotionally and for evidence that extended day-care and respite care is available to disabled children.

ACHIEVE ECONOMIC WELL-BEING – aims include that childcare is available for parents to work and disabled children and young people are helped to achieve economic well-being. In this area, the inspectorates make judgements on whether initiatives are targeted at the most needy and address family needs in an integrated way.


As part of delivering on the ECM outcomes, the NHS developed a ten year strategy (2004-2014) to improve the health and well-being of all children in UK by introducing 11 national standards for children’s health and social care – the Children’s National Service Framework. As part of the local Children’s Trust, the PCT would contribute to the strategic planning and joint commissioning of local services and expand multi-agency working. Families were to have a single point of contact for services, a Key Worker, to provide them with information and help them build a comprehensive care package that meets the family’s needs.

Standard 8: ‘Disabled children and Young People and those with Complex Health Needs’ seeks to promote social inclusion for disabled children and their families so they can lead ordinary lives and participate in childhood, family and community activities. To reduce isolation and loneliness, there should be services that allow children to have fun, build new friendships with other children and encourage more independence.
Improving the life chances of disabled children (Prime Minister’s Strategy Unit) (2005)

This report set out the government’s vision for improving life chances of disabled people and achieving full opportunities and choices to improve their quality of life and be respected and included as equal members of society by 2025. Part of this vision was the recognition that disabled children needed ordinary life experiences, such as interacting with other children through play. There was a commitment to implement the report’s recommendations in England and where possible, throughout the UK.

Budget (2006)

The Budget (2006) announced that the 2007 Comprehensive Spending Review would be informed by a series of policy reviews, one of which was a review of policies for children and young people. This review consisted of sub-reviews, setting out the action the Government would take to:

- raise the life chances of all children and young people, preventing problems by building resilience to the risks of poor outcomes and supporting children and young people as soon as possible when problems emerge
- support those families with the poorest outcomes
- support families with disabled children to improve their outcomes
(Disabled Children Review)

Aiming High for Disabled Children (AHDC) (2007) : better support for families

In 2007, the Treasury and Department for Education and Skills (now DCSF) published the outcomes of the Disabled Children Review and this transformation programme is driving change in local services for disabled children. It included a package of policies, with £340 million funding, to boost the provision of vital services support disabled children and their families. It introduced Individual Budgets for disabled children to increase parental choice and control over the support services they use and allow them to set up tailored arrangements to suit their individual needs. The new UK Coalition government has proposed to redirect £20m of Child Trust Fund monies annually to provide more respite for families with severely disabled children.

The review recognised that improved services for disabled children were dependent on a coordinated approach by the key services of health, social services and education. It focused on three priority areas, access and empowerment, response services and timely support, and improving quality and capacity of services. To achieve these improvements, a set of national expectations for local service delivery, the core offer, for all disabled children and their families was set out:

- Information: able to access information at every stage of child’s life.
- Transparency: levels of support determined on a fair, understandable & transparent basis and the eligibility criteria defined according to need and published.
- Participation: fully involved in service planning, commissioning and delivery, increasing choice and control (including access to support forums)
- Assessment: integrated process (Common Assessment Framework-CAF) at all levels
- Feedback: clear & published complaints procedure.

It is under the AHDC programme that Short Break provision should be substantially increased and transformed. It is managed nationally by the DCSF and DH and locally, by the Local Authority and NHS through the Children’s Trust.

In 2008, the DCSF and DH published implementation guidance to transform short break services provided by PCTs and Local Authorities (LAs). They made available £269m ‘ring fenced’ funding over the 2008-2011 period for LAs, with PCTs due to get additional funding (Sep 2008). The government aims to have LA short break service on a statutory footing from April 2011 and there are 21 Pathfinder LAs piloting Short Break commissioning since 2008 (Surrey is not a Pathfinder Authority).

The guidance defines short breaks for disabled children as ‘enjoyable experiences away from their primary carer, thereby contributing to their personal and social development and reducing social isolation’. They include day, evening and weekend activities in a community setting that last more than a few hours. They must be reliable and meet the needs of the child and family. It recognises that disabled children want more fun things to do and the central role of play schemes in providing these enjoyable activities, especially during school holidays where they are likely to reduce demand on costly overnight services.

The expectations for a Short breaks service are set out in the Full Service Offer and they include:

- being based on a needs assessment of the local disabled child, taking into account children and families views
- offering significantly increased provision against 2007-08 provision
- using fair, understandable and transparent eligibility criteria
- offering wider range of reliable local short breaks
- promoting positive experiences by promoting friendships, new experiences and supportive relationships with carers
- being culturally appropriate provision
- being available on a planned and regular basis – including weekend and holiday provision
- providing fit for purpose and age appropriate provision
- utilising the most appropriate service provider, based on quality, skills, experience and cost

The report details how Short Breaks services will be judged by service commissioners, within the Every Child Matters Outcomes framework. The following are a subset of the ECM Outcomes that are relevant to play and leisure short breaks for children with low to moderate needs:

**BE HEALTHY** – the short break environment is appropriately adapted and the necessary equipment in place.

**BE SAFE** (having security, stability and appropriate care) - the children do not have a multiplicity of carers but are cared for by the same members of staff or carers who develop an understanding of the child’s unique way of communicating.

**ENJOY & ACHIEVE** – whilst in their short break service, the children are happy and have fun, have access to activities etc. ..., can develop social networks and friendships and have appropriate systems to communication, and their parents have a real break. 

**MAKE A POSITIVE CONTRIBUTION** – the children are enabled and supported to communicate their views about the service and are able to develop positive relationships and their self-confidence.

**ACHIEVE ECONOMIC WELL-BEING** – the childcare aspects of this ECM aim is covered by the DCATCH programme – see below.
Disabled Children’s Access to Childcare (DCATCH) (Childcare Act, 2006 & ADHC, 2007)

In 2005, Sure Start recommended that disabled children and their families should have access to the same range of childcare options that are open to other families and this became a duty on local authorities in the Childcare Act (2006). The AHDC programme provided funding of £35 million to support development of giving families with disabled children better access to childcare and chose 10 pilot areas to work on this DCATCH initiative. A report published by DCSF (Dec 2009) contains information on the ‘lessons learned’ from the pilot and funding was released in April 2010 (£12.5 million) to roll out DCATCH across England, with non-pilot authorities (including Surrey) received at least £59,000 and up to £119,000, depending on size and characteristics, like social deprivation. It recommends ‘Parent Champions’ who have experience of using childcare for their disabled child and who can promote the new services to other carers and give them greater confidence in using services and provide someone with whom they discuss their concerns. Local Authorities can use funds as would most benefit their area by creating Parent Champions, provide specialist training for childminders and staff so as they can care for disabled children and providing better information to parents. The DCSF is also running an evaluation of DCATCH that will report in 2011.

The Children’s Plan (DCSF, 2007)

This builds on the ECM programme and is the government’s ‘vision’ for children in 2020; it incorporates a ten-year plan with a number of Strategic Objectives, including those for short breaks and play. Under the ‘Secure the well-being and health of children and young people’ objective, the actions included:

- Over 3 years, to provide Short Breaks for disabled children to help with enhancing children’s wellbeing and specifically by encouraging participation in positive activities to develop personal and social skills (£90 million capital made available).
- To produce a Child and Young People’s Health Strategy (published by DH in 2009) and specifically, to reduce obesity in children.
- To produce a Play Strategy (published by DCSF & DCMS in 2008) and also, to build or refurbish playgrounds and make them accessible for disabled children (£225 million was made available).

Play Strategy (DCSF & DCMS, 2008)

In 2004, the DCMS and DfES commissioned the Dobson review on Children and Play and the DCMS implemented the recommendations through the Big Lottery Fund - making £155 million funding available (the Children’s Play Initiative) to improve open-access play provision in areas of greatest need in England. The Children’s Play Council (part of the National Children’s Bureau) was awarded a grant to deliver a regional support and development infrastructure for England, known as the Play England project. The changes in play facilities through Play England were mainly delivered through local districts and boroughs applying directly for grants.

In 2007, the DCSF and DCMS took dual responsibility (‘dual key’) for children’s play policy. The DCSF launched the Children’s Plan with children’s play as one of its main elements and £225 million funding to Local Authorities to improve play facilities across England. In 2008, DCSF & DCMS held a consultation on the national play strategy (‘Fair Play’) that resulted in the national Play Strategy and a further £10 million investment, bringing the total to £235 million. Each LA should have received £1 million capital funding by April 2009 (‘Playbuilder’ capital). During the consultation phase, 12% of the responses were from disabled children, and this has reinforced the need for accessible play areas for these children.

The Play Strategy sets out short, medium and long-term objectives for Play until 2020. It has contracted Play England as its national delivery partner and to provide LAs with the expertise, advice
and guidance to deliver on the Strategy. The main focus is to have outside spaces and recreational facilities, some with supervised play, available locally to all communities. All these play spaces should be exciting and accessible to disabled children.

The Play Strategy is managed nationally by the DCSF and DCMS and locally, by the Local Authority and districts through the Children’s Trust. The government has also commissioned Together for Disabled Children, who are already engaged on helping LAs implement the AHDC goals, to advise further on bringing together the AHDC and Playbuilder programmes and increase play opportunities for disabled children.

_The Coalition government cut the Playbuilder funding by 28% nationally and also removed the ring-fencing around the grant (included in the Early Intervention Grant 2011)_


This recent children’s health strategy seeks to build on the goals from the ECM programme and to set out plans for the NHS to meet the ‘vision’ outlined in the Children’s Plan, not only of improved health for children by 2020 but also, improved wellbeing. The NHS is to receive £340 million funding over three years (2008-2011) for new services for disabled children, including short breaks and particularly, those that offer innovative approaches to service provision. This strategy details the Public Service Agreements (PSA 12) that the government will use to measure the progress by Local Authorities and PCTs and states that the strategy should be delivered locally through the Children’s Trusts.

The Children’s Plan (2007) set out plans to make the Children’s Trust statutory and this should strengthen the partnership and encourage increased joint working and accountability at the strategic level between the NHS and local authorities. However, the Child Health Strategy identified problems that remain within some Children’s Trusts, such as conflicting targets and priorities, engaging the PCT fully and under-developed commissioning. Many of the problems result from differing methods of commissioning and funding and organisational structures that will take time to resolve._ (statutory requirements relating to Children’s Trusts being revised by Coalition government)_
Section 3: Local Policy Review

The Local Policy review was undertaken before the new UK Coalition Government took power in May 2010 and the local policies and institutional structures listed here, are likely change.

Key Messages

1. The Surrey Strategic Partnership Leadership Group is run by Surrey County Council (SCC) and it brings together all the local agencies to decide local priorities and produce a Sustainable Community Strategy. This forms the basis for a three-year Local Area Agreement (LAA) with National Government and sets government funding for Surrey. The current LAA has a number of indicators that measure delivery of services to disabled children and their families.

2. The Children’s Trust in Surrey (Surrey Alliance) is one of the main contributors to the Sustainable Community Strategy.

3. The Voluntary, Community and Faith sector (VCSF) have elected representatives from 2010 (by the Surrey Assembly) on the Surrey Strategic Partnership Leadership Group, its delivery Management Group and Thematic Partnerships (e.g. children and young people) and this will allow the sector to be more formally involved on local policy and decisions.

4. The Surrey Children’s and Young People Plan (2009/10) makes the Director of Children’s Services (SCC) and Director of Strategy and Service delivery (NHS Surrey) accountable for the delivery of Short Breaks from July 2009 and aims to increase these from April 2010. For policies that require joint working between agencies, agreements should be in place around joint teams and budgets e.g. SCC and NHS should have a joint agreement on AHDC short break programme

5. SCC has ring-fenced funding until 2011 to delivery its part of the AHDC programme and it is now in its second year. This programme has expanded play and leisure services in the County, specifically in East Surrey and for children with complex medical needs.

6. NHS Surrey is to provide ADHC matched funding with SCC for short breaks but this funding is not ring-fenced. PCTs were to publish their short break plans in Autumn 2009.

7. Play in Surrey has been delivered through the districts and boroughs in Surrey and most produced play strategies and audits (2007-2010) to access ‘Big Lottery’ funding through Play England. Play for disabled children has been mainly delivered by funding local specialist providers to provide play at specialist centres or funding limited additional support at council-run play schemes.

8. The recent Playbuilder programme in Surrey is run by SCC but will still be delivered through the districts and boroughs. SCC has concentrated on upgrading playgrounds in 2009/10 but in 2010/11, they are looking to use community facilities to make mainstream play services more inclusive for disabled children.

As a result of the Coalition government cuts to the Playbuilder funding by 28% nationally and also removed the ring-fencing around the grant, Surrey’s contribution for 2010/2011 was £379,931, as opposed to the £607,890 that SCC was expecting.

9. The DCATCH programme is new to Surrey in April 2010 and should expand access to out-of-school childcare for disabled children and their families. A number of existing short break services can be considered as providing childcare after school and in school holidays and some are using existing AHDC funds. DCATCH in Surrey has focused on increasing access to mainstream after school clubs for families with disabled children.

10. The introduction of Individual Budgets (IB) will allow families to use the service provider of their choice and so this will affect the funding model of service commissioning and provision. There are challenges for service providers to change their business practises to accommodate this new service commissioning model.
11. Local Authorities may have to provide ‘vetting’ and ‘brokerage’ services to facilitate the introduction of Individual Budgets to safeguard recipients and help them commission their own services. Surrey Independent living Council (SILC) helps families with disabled children move to Direct Payments, and although a voluntary sector organisation, it works closely with and is funded by SCC.

12. Local carers cite similar problems with services as those found nationally, e.g. lack of provision, transport and information and suitability of schemes as the main issues around short break usage. There is also confusion around eligibility for services, the assessment process and accessing and using Individual Budgets.

13. Charities have provided short breaks and play and leisure services for disabled children in Surrey for a number of years and they continue to work together and with the Local Authority in the ‘Play and Leisure Consortium’ to provide ‘non-referral’ low-cost services across the County. ADHC funding allowed providers to expand day services in the last 2 years; however, residential services have found accessing AHDC funds more difficult, as their services are limited by building capacity.

14. The AHDC programme in Surrey has expanded mainly segregated service provision but some funds have allowed mainstream providers to increase support for disabled children and make their schemes more inclusive. Local and national surveys indicate a parental preference for segregated schemes for children with severe Autistic Spectrum Disorders (ASDs) and children with profound and multiple complex needs (PMLD).

15. The local AHDC team identified a need for a central information service for families with disabled children to find local play and leisure activities, suitable for their child. Surrey information on Disability (SID) launched a web-based service in March 2011.

**Section 3.1: Overview**

The AHDC programme is delivered jointly by Surrey County Council (SCC) and NHS Surrey and the local Children’s Trust (Surrey Alliance) is responsible for ensuring joint working between the two agencies. However, where SCC’s AHDC funding has been ring-fenced by national government until 2011, NHS Surrey’s AHDC funding is part of a wider programme from the Department of Health and is not ring fenced. Funding has allowed an expansion of non-residential play and leisure short break services from mainly specialist service providers and allowed some mainstream providers to make their services more inclusive.

A condition of ADHC funding is that it is only used for new services and this has made it difficult for residential short break providers to access this funding as most cannot easily expand their buildings and facilities and many have concerns about continued funding past 2011. Some providers have expanded play and leisure opportunities using their existing specialist facilities and some additional community buildings. However, successful and popular schemes that are already at maximum capacity have not been able to access this funding.

The service mapping for Surrey (Appendix 5) shows the breath and variety of short break services across the County that are available to families with disabled children. In the past, these service providers have received some funding from the borough and district councils who were responsible for play services in Surrey and from the local authority social care budget to provide short breaks. However, the charities relied mainly on benefactors and fundraising to build and run purpose-built, specialist centres and to keep costs low for families not eligible for social care funding. Even with the existing AHDC and possible future Playbuilder funding, there is still a need for considerable charitable funding to keep these services running.

SCC AHDC’s team surveyed parents who use short break services and found that there is still confusion amongst carers about which services they are entitled to and the social care procedures they need to follow to access them. This includes how Personal Budgets (including, Individual
Budgets and Direct Payments) can help families manage the support they need and what is involved in accessing, managing and using the payments. Surrey Independent Living Council (SILC) is funded and works in partnership with SCC to provide a free advice and support for families who want to consider personal budgets and decide to receive Direct Payments.

**Section 3.2: Method**

Local government policies and procedures within Surrey were obtained from Surrey County Council’s website and published documents. Information was also obtained from interviews with SCC Commissioning manager for AHDC, the Playbuilder scheme manager, Chairman of the Surrey Chief Leisure Officers Group, CEO of the Voluntary, Community and Faith Sector (Surrey Community Action) and from visits to a number of local service providers.

**Section 3.3: Local Government Structure and Multi-agency Working**

Local services in Surrey for disabled children are delivered by Surrey County Council (SCC), NHS Surrey and the Borough and District Councils. These separate bodies meet together with the Police and other local partners at the Surrey Strategic Partnership Leadership Group (SSPLG). This forum decides on the priorities for local services in Surrey and together with the national priorities and standards, these form the basis for the Local Area Agreement (LAA). The local priorities contained in the LAA are based on the Surrey’s Sustainable Community Strategy (for 2020) and the local Children’s Trust (Surrey Alliance) is one of the main contributors to this strategy.

An overview of where the Children’s Trust in Surrey is located with the main local government structures and organisations in Surrey is given at Figure 3.3.1, along with its policy and legislative environment at Figure 3.3.2.
Figure 3.3.1 Schema of Local Government Structures in Surrey, illustrating the large number of agencies and complex hierarchy involved in local decision making and service commissioning.

Figure 3.3.2 The Surrey Children’s Trust (Surrey Alliance) within the extensive policy & legislation environment that governs service delivery to disabled children.
Local Area Agreement (LAA) and National Indicators

The three-year LAA is agreed with Central Government and forms the basis for improving services and quality of life in Surrey. There is a legal duty on the SCC to prepare an LAA and on other public services to cooperate with councils in negotiating and fulfilling the LAA. The aim is to encourage joint working between local agencies to provide a seamless service to the user. The Audit Commission has just reported (October 2009) on the problems facing LAs and the NHS in implementing joint working and sets out a number of recommendations for the DH, NHS and local councils to carry forward. For services with both a health and social service component, there should be agreements between SCC and NHS Surrey around joint teams and budgets (e.g. AHDC short break programme). However, where the Local Authorities have been addressing Short Breaks since 2008, the local PCTs are continuing to prepare short break service plans for their Autumn Statements in 2009. These differences in programme timescales and also, government funding mechanism are often the main reason different agencies find it difficult deliver joint services.

In Surrey, the current LAA contains 28 indicators, selected from the Government’s National Indicators set of targets, which reflect the priorities in Surrey. The LAA contains the service level agreements, i.e. the expectations on what to deliver and its measurement and monitoring; one of the PSA delivery agreements (no. 12) details 5 indicators that central government will use to monitor developments that impact on children’s health and also, the quality of support for disabled children with mental health needs (2 are relevant):

**PSA 12: Indicator 4**: emotional health & wellbeing, and child and mental health services (CAMHS); measured through the annual ‘Tell US’ survey from 2008. For CAMHS, improvements will be measured by the percentage of PCTs & LAs who together provide a comprehensive service for their area. From 2009, a new Outcome based indicator on children’s psychological health will exist, to enable CAMHS to measure success of its work.

**PSA 12: Indicator 5**: Parents’ experiences of services for disabled children (as defined by DDA, 1995) and the ‘core offer’ (part of the AHDC agenda and a NHS Vital Sign Local Priority Tier 3):
- clear information
- transparency in how families can access services
- integrated assessment
- participation in sharing local services
- effective feedback

This measure will cover families of all disabled children and ask about all services provided by LA and PCT. By 2011, disabled young people and their parents should be able to report a more favourable experience of these services.

The Surrey Children’s Trust – ‘Surrey Alliance’

The ECM programme (2003) and the Children’s Act (2004) required local authorities to have one person in charge of Children’s services (Director of Children’s Services) and a lead council member for children should be appointed (Surrey’s Cabinet Member for Children & Learning). These two statutory roles are responsible for the local education and social services provided to all children in Surrey. There is also a responsibility on the local authority to establish a Children’s Trust with the aim of integrating key services such as education, social services and some health services and who will report back to elected members of the council. The ECM green paper saw the integration of education and social services as key to improving the life chance of disabled children. In Surrey, the Children’s Trust is known as the **Surrey Alliance for Children, Young People and Families**.
Children’s and Young People Plan (CYPP)

The Surrey Alliance is responsible for the local Children’s and Young People Plan (CYPP) (not just the Local Authority) and it should detail how the PCT and LA will meet jointly the needs of disabled children in their local area. The current Surrey CYP Plan (2009/2010) is an interim one year plan to allow more integrated joint working arrangements to be developed. One of its Outcomes (B.3) makes the Head of Children’s Services (SCC) and the Director of Strategy and Service Delivery (NHS Surrey) accountable for delivery of Short Breaks from July 2009 and aims to increase these services from April 2010.

Voluntary, Community & Faith Sector (VCSF) in Surrey

Many of the services for disabled children are provided by charities in Surrey and the faith sector is one on the largest providers of youth services in the County. In 2008, SCC commissioned the National Association for Voluntary and Community Action (NAVCA) to work with the voluntary, community and faith sector (VCFS) in Surrey and formulate proposals to formalise the relationship between these groups and the Surrey Strategic Partnership. NAVCA identified many forums, networks and partnerships both within the VCFS and with the statutory bodies in Surrey and that engagement with the statutory bodies was patchy across the County. In 2010, the engagement of the VCFS was formalised in Surrey by elections within the sector, by a newly formed Surrey Assembly (VCFS only), to choose representatives on Surrey’s Strategic Leadership Group, its Delivery Management Group and Thematic Partnerships (e.g. Children and Young People). These representatives will now act as communication conduits between the statutory organisations and the VCFS to allow the sector to become more formally involved in local policy and decisions.

Section 3.4: Children and Young People’s Play in Surrey

Most play and leisure services in Surrey are provided and funded either by the district and borough authorities or by the voluntary and community sector, including charities.

The boroughs and districts manage most of the parks and open spaces with play equipment, although in some parts of the county, they are managed by parish councils, housing associations or community groups. They also run, commission or grant aid play schemes and work with voluntary sports clubs. Most of the Surrey district authorities (10/11) have undertaken play audits and completed play strategies under the ECM (2003) programme and some have used it to bid for lottery funding from the Big Lottery Fund’s “Children’s Play Programme”. As one of its Play priorities for 2007-2010, Guildford Borough Council is dealing with inequality and exclusion for disabled children through their partnership work with Disability Challengers.

Surrey Chief Leisure Officers’ Group (SCLOG) enable the individual districts to liaise and coordinate on Play in Surrey and also report to the Surrey Strategic Partnership Leadership Group. Surrey County Council (SCC) has a responsibility to ensure play is included within the strategic decision-making of the county council, but this is a fairly new responsibility that has come with the national Play Strategy and acceptance of the Playbuilder grant. The County Council will be building on the local play audits to create a play strategy for Surrey that links into the Surrey Alliance for Children, Young People and Families. The Surrey Sports Partnership has also done a lot of work over the years on ensuring that disabled children have access to leisure activities.

Currently, SCC are considering options in terms of the AHDC and Playbuilder funding. The majority of the Playbuilder funding will be distributed as it is now, in equal amounts for each district or borough, but there may be some remaining money which can be combined for projects that have
been funded by Playbuilder but might be improved with the addition of more inclusive elements, as these things often emerge in the light of experience on a particular site. SCC is encouraging the boroughs and districts to consider whether they have any major sites that could be used by disabled children and their families if given improved facilities and possibly funded through AHDC.

The Coalition government cut the Playbuilder funding by 28% nationally and also removed the ring-fencing around the grant and Surrey’s contribution for 2010/2011 was £379,931, as opposed to the £607,890 that was originally planned.

SCC has decided to continue to fund the projects in Surrey, albeit with a reduced capital sum, in proportion to the government's Play Builder grant, so there are now 14 more sites in Surrey. A number of these have been subsidised by local fundraising and borough/district funds and all, with the exception of the scheme at Redhill YMCA, have been installed and are being maintained by the borough/district council. (Sites are given at Appendix 5 Mapping of Local Services in Surrey)

After-school childcare for disabled children in Surrey
Surrey was not a pathfinder authority for the Disabled Children’s Access to Childcare (DCATCH) initiative and only will receive funding in April 2010 to facilitate increased access to childcare in Surrey for disabled children. This programme should recruit local ‘parent champions’ who already use local schemes to provide information and support to new carers and build their confidence in using childcare for their disabled child. Surrey’s AHDC programme has already provided funds to expand after school-clubs and school holiday play schemes. Third sector service providers have also provided after-school clubs for many years and some use their own transport from special schools to the scheme’s premises and for some children on the social care register, SCC also provides after-school transport. SCC has an existing limited out-of-school care programme, called ‘including me’, for 5-11 year old disabled children who attend special schools or units and which looks at ways to help children attend a local mainstream after-school club one night a week.

Families may also apply for Working Tax credits, if they use childcare schemes that are registered with OFSTED. This includes OFSTED registered childminders or personal assistants who they employ to care for their disabled child and include those paid for by Personal Budgets.

AHDC programme in Surrey
The AHDC programme is delivered jointly by Surrey County Council (SCC) and NHS Surrey and with the Surrey Alliance responsible for ensuring joint working between the two agencies. SCC was provided with ring fenced three year funding from 2008 to 2011 and NHS Surrey has matched non-ring fenced funding as part of a wider programme from the Department of Health. SCC is in its final year of the programme and it is unclear what funds will be available past 2011.

Surrey AHDC team and Surrey Alliance (2008) carried out a survey of local parents who currently use short breaks and found that:

- carers wanted more short breaks so they could have a break from caring and spend time with other children.
- carers wanted a range of services, including emergency support, a regular sitting service (for younger children) and a trained carer for whole-family short holidays (e.g. weddings). Buddying services and overnight activity breaks were popular for older children.
- carers wanted breaks with trained and experienced staff (with 1:1 support, if need) and a wide range of activities that the child enjoyed.
• carers valued play and leisure schemes but there was still a problem with a shortage of places and parents wanted local schemes with longer hours and more schemes in the school holidays. Access to transport to and from schemes was also an issue.
• lack of information and difficulty accessing it were still problems for carers and they wanted a single ‘Information Point’. Carers get information from professionals, other parents, schools and the internet but SCC own websites were not often cited.
• there is still confusion amongst carers around the services they are entitled to and the social care procedures to be followed; this includes how Individual Budgets (Direct Payments) can help families and what is involved in accessing, managing and using the payments.
• Families with children on the Autistic Spectrum and or with high medical needs said they would prefer specialist schemes but carers also mentioned they wanted more inclusive schemes, like Cubs or Brownies and so as siblings could attend.
• Carers of young children were keen for their child to attend an after-school club, preferably near home so local friendships could develop but if this was at a mainstream school, there was concern about their child being vulnerable in a non-specialist setting and the lack of trained staff. Again, transport was an issue, particularly the lack of flexibility of SCC transport on pick-up and drop-off times (school transport often involves long journeys by taxi at relatively high costs and may not be the best option for after-school schemes).

The above responses mirror national responses in carer surveys and show that families with disabled children in Surrey have the same problems accessing and using short breaks as most families with disabled children in the UK.

Residential providers have been less likely to access this funding, as the government made it a condition that only new services can funded by AHDC money. Service providers who cannot easily expand buildings and facilities, such as residential services, have not been able to take full advantage of this new funding and so, continue to rely on charitable funding and the main social care budget.

In Surrey, the AHDC funding has allowed group base provision in specialist centres to be expanded, in particular, out-of-school clubs. Service providers are using existing specialist facilities and some community buildings to expand after-school clubs, Saturday schemes and holiday clubs, and this has increase opportunities for disabled children to enjoy local play and leisure opportunities. Service commissioners have used the funding to fill gaps in provision for children with complex needs and in areas of the County where no provision existed and some local providers have become involved in advising and training staff for mainstream providers (e.g. local councils) on how to run an out-of-school club for disabled children. Most new schemes have evolved from established service provision at specialist centres and due to pressure on places and the characteristics of the children who attend, many are for disabled children only (e.g. The Children’s Trust and National Autistic Society). Parental surveys (e.g. by Surrey Alliance) also show a preference for services that provide specific support to children with PMLD and ASD. Some service providers have managed to provide integrated schemes for all children, either by increasing one-to-one support in their mainstream schemes (e.g. Guildford FISH and YMCA) or by specifically setting up an integrated play-scheme (e.g. Disability Challengers).

Surrey Independent Living Council (SILC)

SILC is a voluntary sector organisation run by and for disabled people. It is funded by SCC to help families with disabled children decide if Direct Payments are right for their family and if so, helps them organise, purchase and manage the support they need for their child.
Surrey Play and Leisure Consortium

In the last 10 years, a ‘Surrey Model’ of co-operation has developed between the main service providers in Surrey and the Local Authority (SCC) to provide services across the County, where disabled children can enjoy play and leisure, without the need for a referral process and where they pay less than for mainstream leisure. This firm foundation allowed the AHDC programme to create more opportunities where ‘gaps in provision’ remained and to extend existing services. More providers have joined this ‘Play and Leisure Partnership’ which meets regularly with SCC and is committed to providing a minimum level of service in every borough and district in Surrey, and allows providers to share best practise in service provision (e.g. playwork, inclusion, staff training).

Social Information on Disability (SID)

With so many different types of service providers in Surrey and also, different commissioning organisations, there has been no central source of play and leisure services for carers and this issue was raised in a local carer survey by the SCC AHDC team. Carers want a central information point like a ‘one-stop shop’ to help them find the most appropriate service(s) for their child. In early 2011, to address this concern, SCC AHDC team commissioned Social Information on Disability (SID) to develop a web-based Information resource on short breaks and activities for families with disabled children in Surrey.
Section 4: Short Breaks Development

Key Messages

1. Currently, there is a wide variety of residential and non-residential short break provision and each type exists to meet the differing needs of disabled children and their families. All providers seek to give the child a positive experience on their short break by providing play and leisure activities.

2. In Surrey, most of the short break services are provided by charitable trusts, a number of which have existed for over 25 years. Their facilities and services have evolved from families’ needs and preferences rather than from government policy.

3. As part of the AHDC programme, local authorities are required to develop a range of short break services to meet the needs of families with disabled children. It recommends a move away from more costly residential breaks for children even though some families value these types of breaks as they allow them a complete break from caring.

4. Recently, local commissioners have sought to expand these services with AHDC funding and many existing providers have been able to quickly expand services. Specialist play and leisure schemes in the school holidays, weekends and after-school have expanded across the Surrey.

5. The latest surveys from the Aiming High for Disabled children (AHDC) National indicator reports by PCTs and Local Authorities (DCSF &DH, 2010) show a significant number of families are not accessing short break provision.

Section 4.1: Overview
Traditional short breaks were seen as providing respite for carers, were only available to children with severe disabilities and were often taken in a hospital-based environment. Gradually, there was a move to providing breaks in specialist residential units and these were run by the NHS and by local authorities. Parents and professionals saw the need for a more ‘homely’ environment and for the child to enjoy the break and charitable trusts started to set-up and run separate short break schemes that were affordable to all parents. These residential services are popular with parents with children with severe disabilities and who have life-limiting conditions. There was also a move to provide home-sitting services in the child’s or a foster family’s home which were more suitable for younger children as the child was in a known environment and it proved to be less costly than residential short breaks. A shortage of carers meant that local authorities moved to having paid foster carers so that these services could be expanded and some residential short break providers use staff to provide a similar outreach domiciliary service.

Parents also wanted their disabled child to have access to play and leisure activities and as these services were not provided by local authorities, charities set up play schemes and built specialist premises to meet this growing need. With a change in policy, disabled children now have a right to these services and to have them as part of their care packages. Also, AHDC funding can be used to expand these services and the disabled child does not have to meet the social care threshold to access them. Many specialist providers have been able to expand their out-of-school play schemes significantly by introducing after-school schemes and more holiday play schemes. Also, mainstream providers have been able to access AHDC funding to supply 1:1 support in their play schemes and adapt facilities and buildings so as more disabled children can attend.

There are still issues around the provision of inclusive schemes for children. Some specialist providers have tried to set up schemes for all children, but as there is still a shortage of provision for disabled children in Surrey, it meant the provider was using a valuable place for a non-disabled child. Also, there is a funding issue with inclusive schemes, as both AHDC funds and often the charity’s...
own funds are intended to be used solely for disabled children and it would not be possible for the non-disabled children to be subsidised at the scheme and this makes inclusive scheme funding models more complicated for providers and parents. A number of charities have been set up to provide services for a single disability and again, there are issues around running play schemes for children with other disabilities and non-disabled children.

Section 4.2: Residential (Overnight) short breaks

Residential short breaks were provided traditionally by hospital and specialist residential units and funded and run by the NHS or Local Authority. Although, some of these units still exist and Surrey County Council has recently opened a new unit at Tadworth, the AHDC short break guidance implies that local authorities should consider the ‘value for money’ of these breaks against less costly non-residential short breaks and also, that residential short breaks should not be the only service offered to parents.

Charities have also provided residential short break services that are popular with parents, as they allow them to have a ‘real break’ and go on holiday with other children. A study in N. Ireland (McConkey & Adam, 2000) found although professionals perceived home-based breaks as more beneficial to families than hospital-setting breaks and residential breaks were less popular by the families surveyed, some carers (14%) found residential breaks valuable. Local residential service providers in Surrey find parents of older children use residential services for up to 2 weeks for a complete break, to have a holiday themselves or when they need to be away from home for family emergencies.

There are different types of overnight short break services available to families, some at their own home and some in specialist centres and foster carer homes:

- **Family based short breaks** (e.g. [White Lodge Family Link scheme]): the short break takes place in another family’s home and tends to be on weekends, as the foster carer may have other own work commitments. Typically, foster carers will be linked to only one or two children. These have been more successful with younger children and those with less complex needs; they are less successful with teenagers, particularly those with moving or handling needs and boys with Autism where the foster relationship breaks down more often (Barson, 1998 cited in Gray et al, 2006).

- **Contract-carer (mainly provided by local authorities or social enterprises)** these have expanded recently to offer family-based breaks to children with more complex needs (e.g. those who need specialist equipment) and for children with ASD who in the past would have taken residential short breaks. As the foster carers are paid and are full-time, they can provide regular breaks to more children and the specialist equipment can be concentrated in fewer homes.

- **Overnight sitting services** (e.g. [The Children's Trust Outreach programme]): these services have been limited and have tended to be provided to children with PMLD or have palliative care needs by health providers linked to specialist units. These have the benefit that the house is already adapted and the short break is suitable for very young children and for children that find new environments difficult (e.g. those with ASD).

- **Residential (specialist unit)** (e.g. the Chase Hospice & The Children’s Trust): More short break services are being provided by hospices (palliative care) and in specialist units for those with complex moving and handling needs and challenging behaviour.

- **Residential (non-specialist)** (e.g. Cherry Trees): Some overnight short breaks have been provided through the charity sector, traditionally to give parents respite, though they have
also sought to give the children ‘home-from-home’ and ‘sleepover’ experiences. Often, these breaks are taken at weekends and in the school holidays, as the child has to attend school during the week. However, some schemes provide transport to and from special schools, either in their own min-buses or via the local authority. In Surrey, some of these providers have expanded into day short breaks, such as after-school clubs, using their existing facilities for residential breaks.

Section 4.3: Day (Non-residential) short breaks

These breaks are needed for families who do not want an overnight service or who want both day and overnight provision. In general, the local authority can provided day short breaks at a lower cost than residential short breaks. Again, there are differing types of short break services provided for families:

- **Home-based day care (sitter service)** (e.g. The Children’s Trust Outreach programme): these services have been used where children cannot access services outside the home and by outreach services from specialist units. This has the benefit of using existing trained staff but may require additional staff to provide the required capacity. Sitters may take children out into the community. They have been preferred by ethnic minorities families and should be used only when it is a family preferred service or as part of a package.
- **Befriending services (buddying)** (e.g Halow Trust): these offer one-to-one relationships and allow the child to access activities in the community. They often depend on volunteers and the services had been declining nationally (though expanding in Surrey). This service suits older children by allowing peer befriending and those young people with low incidence needs (Gray et al, 2006).
- **Group based specialist provision in specialist centre** (e.g. Treetops at White Lodge, National Autistic Society & Disability Challengers): traditionally, these breaks were held at specialist centres with the appropriate facilities and trained staff. To receive funding, children had to be on the social care register and thus, these short breaks were for children who had high support needs and/or require a high staffing ratio and specifically trained support staff. The AHDC funding has allowed these service providers to introduce play and leisure breaks for all disabled children and those providers who solely provided play and leisure services can now receive funding to provide short breaks specifically.

The AHDC Short Break implementation guidance has not addressed specifically different types of activities that are provided on short break. All service providers try and provide a good experience for the children but for some, the main focus is providing ‘respite’ for carers or therapeutic help and behaviour management for the children, while other providers set out to provide an overall positive experience for the child with an emphasis on play and leisure. This seems to be determined by the history of the service provider; some charities were set up to provide play opportunities or home-from-home experiences for children while those with health orientated centres also try and provide medical, therapeutic and educational components in their short break services; therapeutic components seem particular important for children with complex health needs while also promoting independence (Thurgate, 2005).
Section 5: Surrey Service Provision Mapping

Key Messages

1. There are many different types of service that can offer disabled children an opportunity to participate in play and leisure. All of these specialist and mainstream services can be considered to offer ‘short breaks’ to families with disabled children.

2. With so many groups and organisations involved in these services, it is difficult to find information on all the services in Surrey. There was central source of information and this gap in information services is being addressed by a web-based service developed by Surrey Information on Disability (SID) and funded by the AHDC programme.

3. Surrey has a wide range of services that offer play and leisure opportunities to families with disabled children. They are available across the County and AHDC funds are expanding services and introducing new services for children with complex needs and autistic spectrum disorders.

4. Some specialist providers offer inclusive services and more mainstream schemes are providing support for children with low to moderate needs.

Section 5.1: Overview

The short break categories detailed in Section 4 were used to guide the mapping process and the focus was maintained on Short Breaks, Play and Leisure and OSC services. Although short breaks were specifically designed for disabled children, play and leisure services and OSC services are provided for all children and in recent years, many of these mainstream services have become more inclusive. All short breaks providers (including traditional ‘respite’ providers) now seek to provide a positive experience for the child, and play and leisure form part of the normal set of activities and opportunities on any short break and so there is no clear distinction between different types of scheme. The wide range and categorisation of services makes it difficult to find all the services for disabled children in Surrey. The process of generating the mapping identified the continuing problems of providing information to parents at a central source.

Local commissioners and providers believe Surrey has an above average short break and play and leisure service provision for families with disabled children. Many service providers are charities founded by local professionals and parents to give disabled children access to the same play and leisure activities as other children and have developed over many years into popular and well-funded organisations. Many of these services have been helped by the AHDC programme to expand their services in the past 2 years and information on new services, planned for Easter and summer 2010, was not yet available.

Some specialist providers are providing inclusive schemes either just for siblings or for all disabled children. However, there is still a number of specialist schemes for one or similar disabilities, e.g. Epilepsy, Down’s syndrome and Autistic Spectrum Disorders. Many holiday play schemes are provided by local councils and more of these schemes are providing support to enable disabled children with low to moderate needs to attend, with some using AHDC funds to achieve this.
Figure 5.1 Overview of the types of services and providers (with examples) in Surrey, showing the different dimensions that can determine the groups of families who may use a play scheme, and the provider’s access to funding streams.

The information on local services for disabled children is not held in a central area in Surrey. SCC completed a ‘needs analyse’ for children with complex needs in March 2008 and this was the starting point for the mapping exercise. Although all short break services are known to the local authority social care teams, play and leisure schemes tend to be run locally by the districts and boroughs in Surrey and often by individual leisure centres, so there is no central knowledge source for all these schemes and nor is it easy to find out what support there is for disabled children. OSC is run by the SCC Early Years and Childcare Service and regulated by OFSTED and again, as many of these schemes take all children, it is difficult to find out what they can offer disabled children.

There are many of mainstream providers in Surrey and these were considered outside the scope of the review and have only been included in the mapping where they were found on the information sites for families with disabled children or from information from local stakeholders.

Social Information on Disability (SID) has launched a website called FAB – Family Activities & Breaks (www.asksid.org.uk/fab Mar 2011) to help families with disabled children or young people find out about a wide range of leisure activities and short breaks across Surrey.

SID was awarded funding from Surrey County Council’s Aiming High fund to design the website in response that showed that parents had great difficulty finding out about short breaks for disabled children because there is no central point for information.

The FAB website has up-to-date information on specialist leisure activities, sports, social clubs, play schemes, childcare and short breaks for disabled children and young people in Surrey.

Press release (SID, 25 March 2011)
Section 5.2: Method

Information on available services was gathered during interviews with local stakeholders and visits to service providers. This information formed the basis of the mapping.

Additionally, web-based searches were carried out between January and March 2010 on:

- Surrey County Council and District and Borough Websites
- Surrey-based information sites (e.g. SID) for relevant schemes
- National information websites (e.g. Shared Care network)
- Local and National charity websites

*The information sources and mapping is included at Appendix 5.*
Section 6: Literature Review

Key Messages:

1. Research has tended to focus separately on the three areas of interest: Short Breaks, Play and Out-of-School Childcare.

2. The previous UK Labour Government commissioned a number of Disability Research Reviews that found there was:
   a. a lack of useful national statistics on families with disabled children;
   b. no consistent definition of disability in research studies and a tendency to treat disabled children as one homogenous group;
   c. little knowledge about the out-of-school lives of disabled children
   d. few studies on the effectiveness of current services and which services work best for which groups of families with disabled children
   e. poor understanding of adolescent and transition services, and services for children aged 5-8 years and those with severe and multiple disabilities and communication needs
   f. a focus on primary carers (usually mothers) and little research on the outcomes for fathers and siblings

3. Short break research has shown the respite benefits of these services for carers but there are few studies on the outcomes for disabled children themselves. Little is known about the pattern of usage of these services and which short breaks services are needed by which groups of families.

4. The definition and measurement of Service Outcomes have proved difficult to define and measure for families with disabled children as they are often individual to the family and are more likely to relate to ‘how a service is deliver’ rather than be a specific measureable outcome.

5. The evidence for the Economic benefits of Short Breaks is mixed and it has proved difficult to attribute benefits directly to short break services, such as allowing carers to work, better family health, and fewer family breakdowns and residential placements.

6. Play research has focused on the benefits of Play in development and learning for all children and there is a lack of research on the specific benefits for disabled children. There are problems with the definition of Playwork and the methodologies used in play research.

7. Play may help disabled children engage in physical exercise and reduce obesity.

Key Messages for the relevant research areas are given at the start of the following sections:

- Section 6.3 Short Break Services - Patterns of Usage
- Section 6.4 Outcomes (including wellbeing and economic outcomes)
- Section 6.5 Play and Playwork
- Section 6.6 Play Schemes for Disabled Children
- Section 6.7 Inclusive Services
- Section 6.8 Gaps in Research Evidence
Section 6.1: Overview

The starting point for the literature review was the three types of services for disabled children identified in the policy review: short breaks (respite), play and out-of-school childcare. Similarly to national policy areas, research had tended to focus on one of these types of services, even though they often involved similar service delivery.

The government and other non-government organisations have commissioned a number of significant reviews on disabled children and their families in recent years and these reviews found substantial gaps in the evidence base relating to families with disabled children and their out-of-school lives. A significant problem is the lack of a consistent definition of ‘disability’ and a tendency to treat disabled children as one homogenous group. This problem renders the national data sets and surveys less than useful for service commissioning.

Short Breaks (respite) services has been considered essential to help carers look after their disabled child and a number of studies have shown this is the one of the most valued aspects of these services. However, there are conflicting national figures on how many families are using these services, and some reports have found it to be as low as 20% of families. Little is known about how families access and use these services and why some families use no services, though families do tend to use services they have used before. There is some evidence that residential services are valued by older carers and those who have children with challenging behaviour or who disrupt their carer’s sleep.

Although there are many services, there is little evidence on what works in terms of outcomes and which services are best for which groups of disabled children and their families. The definition of outcomes and their applicability to disabled children is also problematic. Adolescent and transition services are particularly poorly understood, as research has concentrated on pre-school services. Also, children age 5-8, those with communication impairments or profound and multiple difficulties are often not included in studies.

Research has tended to focus on the disabled child and not on the wider family unit. Though views of Mothers have been sought (as the usual primary carer), the views and service outcomes for Fathers and Siblings are also important, as these affect the family dynamic and have indirect consequences for the disabled child.

Older Short Break (respite) research focused mainly on the outcomes for carers and only more recently, have studies started to investigate the outcomes for the children themselves. There is a considerable body of play research for all children, particularly on its beneficial effects on development and learning, but limited research on its benefits for disabled children. Out-of-school care research has looked at the outcomes for all families and not specifically for families with disabled children. Only a few studies have investigated directly the outcomes for play and leisure short breaks services for disabled children and their families.

More research is needed into the economic benefits of short breaks and out-of-school care as the evidence is mixed on the direct and indirect benefits to the child, the wider family and the state. They can allow parents to work and thus, help to increase the family’s financial basis. However, indirect benefits such as less carer stress, preventing family break-up and fewer residential placements, are harder to identify and quantify.

Play has not been a research priority and although it is widely recognised as beneficial in the educational setting, there is little research on the outcomes for disabled children of participating in ‘play focused’ short breaks. Playwork is a recent profession and its definition is ambiguous, so it has been difficult to assess the evidence for the benefits to children of playworkers. Also, play was often investigated using tradition research methodologies and it is now recognised that play research is more suited to a mixed-methodology approach.
Obesity is a rising concern to policy makers and health professionals, and access to play through play schemes may be one way of increasing physical exercise for disabled children, who have been shown to be more prone to obesity than their non-disabled peers.

As a result of the government’s policy of giving families with disabled children better access to mainstream services, there has been an increased focus on inclusive services. It is believed that this will help reduce the isolation felt by these families and disabled children want to participate in the same activities as other children. However, parents are concerned that mainstream services cannot deliver the quality of care they have come to expect from specialist providers, and are sometimes reluctant to try out inclusive services. Key workers or ‘bridge workers’ can help build up confidence in services and increase the number of families using inclusive services.

Some carers still value segregated services, particularly those with children who have severe disabilities or Autistics Spectrum Disorders, as they consider that a specialist environment, with appropriate medical or behavioural support, is essential to meet their child’s basic needs. There is some evidence that segregated services

Section 6.2: Method

The national policy review identified three types of models of care for disabled children – short breaks (respite), play and leisure services and childcare. Discussions with local informants also identified these types of services as the main services that families with disabled children use to help them cope with caring and also, allow their child to access the same activities as non-disabled children. The literature review sought research evidence on the outcomes of positive activities (including wellbeing) for disabled children, with a particularly focus on short-break and out-of-school play and leisure services. The national policy review showed a general move towards more inclusion for disabled children and locally, service commissioners and providers are trying to increase inclusion in play and leisure activities for disabled children. Thus, the review looked for studies on social inclusion and studies where integrated/segregated play and leisure schemes had been evaluated.

The literature review was not a comprehensive review of the research literature, as the scoping study covered broad areas of academic research. Instead, the review sought to identify the main areas of research and find gaps in the evidence base, so as to generate a research proposal for future work. As short breaks and positive activities for disabled children are high on the political agenda, Government departments (mainly the DCSF and DH) and other national organisations, such as charities and research institutes, have commissioned recent comprehensive research reviews by UK universities in these areas. These comprehensive reviews have used professional information specialists to carry out systematic and detailed searches of research databases. Within the time and cost constraints of this scoping study, it was not possible to carry out such detailed searches and these documents were considered as reliable sources for this review. Thus, this literature review is mainly a ‘review of reviews’, using recent reports from other UK Universities and their literature reviews.

This was followed by some short systematic searches:

- There have been limited searches of academic online databases (EBSCO &EMBASE) for papers on the categories of Disabled Children, Short Breaks (Respite), Play and Leisure, Inclusion, Integration and Segregation, Outcomes and Wellbeing. These searches can have more focus once the area of research interest is confirmed.

- As ‘short break’ research has been carried out in other regions of the UK, searches were done on the Scottish Government and The Office of the First Minister and Deputy First Minister in Northern Ireland databases; these databases list the research done in their respective Universities (though often only the Abstract was available). This was not looked at for Wales.
• Some seminal researchers who are actively working in this area were identified in the course of the literature review: Beresford (SPRU, University of York), Petrie (Thomas Coram Institute, University of London) and McConkey (Institute of Nursing Research, University of Ulster). Specific searches for these authors were done on EBSCO and their Institutes’ websites.

Additional Points:

• More research is now published directly by research institutes for national government, health boards, charities and other NGOs. These do not always appear in the main research databases. Intute.ac.uk produced some government policies and other relevant documents but it is unknown how complete the research databases are.

• Terms: ‘Short Break’s is a recent term and some older and international studies have used ‘respite’ instead. International studies tend to use ‘recreation’ instead of leisure. Some research is disability specific e.g. cerebral palsy and is not always key-worded as ‘disabled children’ or similar; learning difficulties has a wide definition and it is difficult to know the characteristics of children involved in studies.

• The University of Lancaster (CeDR) is due to publish an International Literature review on Short Breaks for Department of Health in April 2010: Robertson, Hatton, Emerson, Well, Collins, Langer, Welch (2009) The impacts of short break provision on disabled children and their families: An international literature review.

• DCSF have commissioned a study in March 2010 to provide an evaluation of the impact of short break provision in promoting severely disabled children’s well-being and of the financial costs and benefits of short break provision for disabled children. This is due to be published in April 2011.

• There is a body of evidence that taking part in sporting activities has direct benefits on physical wellbeing and there are many opportunities for disabled children to take part in sport. Although, sport does offer short break leisure activities, this area was considered outside the scope of this review and studies investigating disabled children and sport have not been covered as part of the literature review.

Research Institutes – recent literature reviews

The Centre for Excellence and Outcomes in Children and Young People’s Services (C4EO) is funded by DCSF and has commissioned three recent reviews on disability (2009). It has a Theme Advisory Group (TAG) who guide and shape their work on Disability, and is made up of experts from the voluntary sector, policy makers and service providers. C4EO also provides information to Directors of Children’s Services and Children’s Trusts to help improve outcomes for families with disabled children.

In addition to producing one of the Disability reviews for C4EO, the Social Policy Research Unit (SPRU), Children and Families Research Team at the University of York, carries out research on the needs of disabled or chronically ill children and their families, both for Department of Health and C4EO. SPRU has conducted extensive research on services and interventions for disabled children and their families. They focus on including the views of children about their needs and experiences and the support they receive from services. A number of their recent literature reviews, research studies and conference reports have been to inform this literature review.

Two additional literature reviews were used in this report: a review of evidence for the benefits of Play and Play Work (Manwaring and Taylor, 2007) and an assessment of the costs and benefits of out-of-school care by the Scottish Executive (2003).
**Defining Disability**

Defining ‘disabled children’ and ‘disability’ has been problematic, as there is no agreed national or international definition that is in common usage - this report uses the definitions given in UK legislation (see Appendix 2).

**Disability Statistics**

Also, there are no accurate national or local statistics on the number of disabled children or their disabilities; these can only be estimated from Census data and the UK Family Resources Survey – a nationally representative cross-sectional survey. A recent analysis of the 2004/5 survey estimated that 7% of UK children are disabled, as defined by Disability Discrimination Act (DDA) 1995, with a higher rate amongst boys and with disabled children more likely to live in poverty. In addition, 22% of parents with disabled children cited ‘facilities nearby where their child can play’ as a need they couldn’t afford (Blackburn et al, 2010).

The usefulness of statistics on disability is reduced by inadequate and non-uniform definitions of disability.
Section 6.3: Short Breaks – Patterns of Usage

Key Messages

1. Parental surveys indicate that parents and carers believe short breaks help them cope with looking after a disabled child.
2. Recent surveys indicate only 20% of families with disabled children are accessing short break services. Shortage of appropriate provision and lack of choice are often cited by parents, and worries about staff not being able to cope, their child not enjoying the break and issues around admissions of failure as a carer are also reasons for low usage.
3. Surveys often only seek the views of carers already using short breaks and many carers are never given an opportunity to give their views on what services they need to cope and why they are not using existing services. Also, few studies have sought the views of disabled children themselves.
4. There is evidence that families use more than one type of short break but little research on their pattern of usage of short break or if this multi-usage reduces access for other families.
5. Families tend to use services they have used before, possibly because they have built up confidence in the service.
6. Research indicates that carers with children who needed constant supervision and support and had behaviours, such as poor sleep, screaming, and aggression were more likely to use short breaks. Also, older parents use more residential breaks, possibly due to other caring commitments, higher risk pregnancies or their own failing health.

One of the main services that parents mentioned in surveys that would help them cope with looking after a disabled child are short break services. These allow them to take a break from caring and the lack of them was the single biggest cause of unhappiness (AHDC: Short Break Implementation Guidance, 2008). Recent reports suggest that short break provision is still inadequate, with a low percentage of families accessing short break provision: NEF (2009) estimate that only 21% of families with disabled children, that could benefit from short breaks, are receiving them and this figure is reflected locally, with approximately only 1000 families accessing short breaks in Surrey but with 5000 families estimated to have a disabled child (Surrey AHDC figures, 2009). National and local surveys often seek only the views of carers already using short breaks (e.g. Surrey Alliance Parent and Carer Survey) and this means that many carers are never given an opportunity to give their views on what services they need to cope. Also, few studies have sought the views of disabled children themselves.

It is not clear why families do not use short break provision and it is necessary to fully understand why families are not accessing short break services so as suitable services can be developed and offered to all families (Thurgate, 2005). Some surveys have found a shortage of provision for those with low incidence needs, complex needs and ASD (e.g. Marchant et al, 2007, Gray et al, 2006, Cramer & Carlin, 2008) and parents also cite lack of choice as an ongoing problem (Thurgate, 2005).

Marchant et al (2007) found some parents considered it an admission of failure as a carer and those who had children with complex needs, were worried that staff may not be able to meet their child’s medical needs and the child may find the break difficult to deal with. A study of holiday breaks for adults with learning difficulties found it was often the families who most need a break who did not avail themselves of it (McConkey et al, 2006), even when they were encouraged to do so and the service was free. Carers worried their relative would not fit in or receive appropriate care and the perceived risks outweigh the benefits; they thought their relative did not want to be away from home and often the person with learning difficulties could not advocate for themselves. However, carers views were more positive once they had used the service and were often successful in winning over other carers to use the short break service. Families who have never used short break
services need help to develop confidence in them and appreciate the benefits to the whole family, so as they can make an informed choice. They need to be aware of the hidden costs of not taking a break in terms of their physical and mental health and also, the mental health and challenging behaviour of their relative (McGrother et al, 2001 cited in McConkey et al, 2006).

One of the few UK studies that looked at short break usage in detail was a 1996-7 survey of 476 parents (McConkey and Adams, 2000). This was 32% of the disabled children being looked after by a Health and Social Care Board in N. Ireland and who were in receipt of some social service during the year the survey took place. The results showed that 45% of children took part in some form of leisure break, 25% used domiciliary services, 22% had residential breaks, 22% had hospital breaks, 17.5% had residential holidays and 10% had a break in another family’s home. In all 3% had 4 different types of break, 9% had three services, 26% had two services and 61% had one service. Informal breaks (with friends and relatives) were reported by 37% of families and the discriminating factor here was family income; those with one income were more likely (68%) to have friends or relatives to help than those with two incomes (15%) or on benefits (19%). There is also an effect of ‘past usage’; parents prefer services they have used before, particularly residential services.

In a later study (McConkey et al 2004), parents rated three residential services, 2 voluntary small services (3-4 beds) and a bigger NHS unit (12 beds) based in a hospital grounds. The NHS unit was rated lowly in terms of environment and on ‘if the child looked forward to going’ to the provider; however, some parents did rate this service highly and it showed that there was no one type of service for all families.

Thurgate (2005) reviewed the literature on respite with children with complex health needs and identified 5 themes relating to accessing respite: choice, utilisation, more care, availability and staff. Choice was affected by availability and suitability of provision and was dependent on location and needs of the family. Whereas, McConkey found 39% of children had accessed more than one service, Thurgate found only around 20% of the children with complex needs accessed more than one type of short break and there was no recent research on the effects of multi respite usage for the child or the family or if it caused other children to receive less respite. Also, social workers and parents differ on the perceived need for respite with social workers underestimating this need. Like McConkey et al (2005), Thurgate found parents needed more information about appropriate respite, particularly about staff qualifications so they can trust their service provider to care for their child for long periods.

Thurgate also reviewed the research for characteristics of children and parents who access short breaks:

- children with poor sleep, screaming, aggression to others and who took medication, and also those who needed help with everyday activities and constant supervision.
- parents over 40 years of age but it was not clear why. They may be better able to demand it, have additional demands (like older parents to care for) or have more high risk pregnancies.
- most parents were married and in social class III (skilled manual & non-manual).

McConkey and Adams (2000) investigated distinguishing characteristics of children who use each type of break, with children with no awareness of common dangers, long standing emotional problems and difficult to manage behaviours being more likely to use overnight breaks. When parents were asked how valuable each type of short breaks was to them, Extra Activities (playgroups, after-school clubs, outings to the cinema, leisure centre etc.) were most valued, particularly to children under 10 years of age, with only parents with children who were ‘unaware of danger’ or ‘highly dependent’ preferring residential units.
Section 6.4: Outcomes

Key Messages

1. National policies, such as ECM and AHDC, have ‘defined outcomes’ for service delivery and service providers must monitor outcomes to receive public funding.
2. ECM Outcomes for disabled children are different from those for non-disabled children, as the normal developmental outcomes may not apply. Outcomes around maintaining quality of life, achieving change and service delivery are important to families.
3. ECM Outcomes focus on the child rather than the wider family unit and do not recognise that carer stress has a direct impact on the child and can lead to residential placements. Mothers, fathers and siblings of disabled children may have different needs and want other outcomes from short break services. There is little research on the outcomes of services for Father and Siblings.
4. The core criteria for any service mentioned by young people and their parents are the training, behaviour and interactions of service staff.
5. There is some evidence that taking part in positive activities contributes to the ECM Outcomes, as it can improve health, provide enjoyment and friendship, help develop life skills and promote a sense of belonging in the community. There is evidence that segregated schemes can be better for some social outcomes e.g. friendship.
6. Short breaks can create social outcomes not only the disabled child but also for their families (including siblings) and communities; they can increase social inclusion by allowing the family to take part in local activities.
7. Few studies exist on the outcomes for a disabled child participating in short breaks, such as the benefits of having a break from their primary carer, and taking part in positive activities with other children, such as sleepovers. Also, some disabled children experience the same negative feelings as non-disabled children when away from their primary carer, such as distress and homesickness.
8. Short breaks can create economic benefits such as, increasing family income by allowing parents to work longer hours, creating local employment and decreasing poverty. Employers have a wider pool of employees and it can reduce staff turnover, training and absences. It is estimated that current provision savings are £36.5m and full short break provision savings could be as high as £173.9m (NEF 2009).
9. Wellbeing of children is included in many Outcome measures for services, but it is difficult to define and measure.

As part of any service funded by the local authority, the service provider must measure Outcomes for the child and the family. For disabled children, measuring outcomes is problematic, as they may have communication impairments and the development milestones for children often do not apply. The Every Child Matters (ECM) Outcome measures are not sufficient and are difficult to apply directly to disabled children, who can need a hierarchy of outcomes; fundamental outcomes, such as health, comfort and communication must be met before the higher ECM outcome of ‘enjoying and achieving’ can occur. Services need to meet the needs of the wider family unit and the ECM framework concentrates on the child’s outcomes only.

Carers are concerned with outcomes based around a ‘good’ service, such as, trained staff, appropriate environment and somewhere that gives them peace of mind when their child is attending. Disabled children want the staff to understand their disability, help and listen to them and allow them to make choices. For them, maintaining their existing quality of life can be an outcome in itself, along with help to improve other factors, such as confidence and self-esteem. The way the service is delivered is important, in that, disabled children want to feel valued, respected and in control. Direct outcome measurement from a service can be very difficult, as social outcomes...
such as self-esteem and confidence are affected by many factors and isolating the benefit of attending a single service can prove impossible.

Short break research has tended to focus on the respite aspect of the service and there is substantial evidence that a break from caring help carers cope with the stresses of caring for a disabled child and gives them time to rest and sleep, as well as enabling them to participate in activities away from caring, such as work, socialising with partners, friends and family and spending time with their non-disabled children. Only recently, have studies considered the child’s experience on the break but researchers tend to concentrate on asking parents and staff about the child’s experience with little research involving the children themselves.

There is an increasing research focus on the economic benefits of short breaks and these could be substantial if the carer can work and the family’s finances improve leading to less poverty and improved health. Employers also benefit from more potential employees who are less stressed and more focused and are less likely to have unplanned absences. However, like social outcomes, it is difficult to isolate the direct economic benefits of short breaks.

Wellbeing of children is included in many Outcome measures for services but such a multi-faceted and complex concept is difficult to measure and to show improvements to wellbeing are directly related to specific interventions. There are a number of ongoing government and NGO projects investigating how to measure wellbeing in children. Children’s wellbeing is heavily dependent on their family and environment, and services directed only at the child are unlikely to succeed.

**Section 6.4.1: Defining Outcomes**

The SPRU (University of York) has an extensive Outcomes research programme and has produced a number of research reports over the last 10 years, including a report for the Department of Health (DH2147) on disabled children, young people and parent’s perceptions on outcomes from support services (Beresford et al, 2007). After consulting users in 2001, the programme produced a framework for understanding outcomes (Qureshi, 2001b, cited in Beresford et al, 2007):

- **Maintenance Outcomes** – e.g. maintaining acceptable levels of comfort, social contact.
- **Change Outcomes** – e.g. improving confidence, improving accessibility of the environment and ability to get about, reducing risk of harm, regaining self-care skills.
- **Process Outcomes** – e.g. the way services are provided, whether people feel valued and respected, have a ‘say’ over provision and the ‘fit’ of the service to family / culture.

The framework expands the concept of outcomes: it considers that services may not always be about improved Outcomes, but for some people, it may be about maintaining quality of life. How the service is delivered and its effects on the service users are as important as the service delivery itself, as this can undermine or enhance quality of life. For disabled children, the framework has benefits, as there is evidence that maintenance of physical comfort and social comfort is important for children with progressive needs to maintain the well-being of the whole family.
Parents and young people identified the core outcome criteria for any service and many of these are focused on process delivery, especially their interactions with staff:

<table>
<thead>
<tr>
<th>Core Criteria for any Service</th>
<th>Young People</th>
<th>Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>staff understand about my illness or disability</td>
<td>meeting the child and whole families’ needs</td>
</tr>
<tr>
<td></td>
<td>staff know how to help me and look after me</td>
<td>listening to both the child and their family</td>
</tr>
<tr>
<td></td>
<td>staff listen to me</td>
<td>treating the child and all family members with respect</td>
</tr>
<tr>
<td></td>
<td>staff ask me for ideas and take notice of what I say</td>
<td>staff knowledge and training</td>
</tr>
<tr>
<td></td>
<td>I can ask staff questions and they explain things to me</td>
<td>welcoming and helpful staff</td>
</tr>
<tr>
<td></td>
<td>staff allow me to make choices</td>
<td>service respects each family’s culture</td>
</tr>
</tbody>
</table>

Table 6.4.1: Summary of the core criteria, cited by Disabled Children and their Parents, as part of an Outcomes framework for services.

In Northern Ireland (McConkey et al, 2004), parents provided views on the things they liked best about the services they used. Staffing, environment and peace of mind were the top recurring themes. Parents like qualified and friendly staff with a good child-staff ratio in a homely environment, especially if they could build up a good relationship with the staff and there was consistency on care workers (e.g. key workers) when the child attended. Local service providers in Surrey also cited continuity of staff as an important factor in services, for both parents and children.

Section 6.4.2: ECM Outcomes and Disabled Children

Beresford et al (2007) found there had been little research on disabled children and their parent’s aspirations for service outcomes or on the views of staff who work in services, so it was difficult to assess the effectiveness of services. To address this gap, they piloted tools to facilitate discussion about Outcomes and record and monitor Outcomes and plans for achieving them. (90 mothers and 18 fathers, 29 children and 18 teenagers with ASD took part). The main findings were:

- It is not clear how ECM outcomes can be interpreted for disabled children – normative developmental models do not apply and meaning of Outcomes may differ from non-disabled children.
- ECM Outcomes focus on the child’s rather than parent’s outcomes (that help to support their caring role), when these have a direct impact on the child’s outcomes e.g. parents are vulnerable to stress and that impinges on children’s development and can result in residential placements. Also there is a low involvement of fathers and siblings in research.
- Disabled children need a hierarchy of Outcomes – fundamental ones (physical health and comfort, emotional well-being, being safe, having means to communication (not in ECM outcomes) and being understood. These need to be met before ‘higher level’ Outcomes can be achieved.
- Outcomes need to change over time and be individual to the child and family.
- New research methods needed to allow disabled children to participation in studies (e.g. children with ASD).
- Need interviews to explore children’s and parent’s views of desired outcomes (they differ)
- Disabled Young People have low self-expectations and this leads to low aspirations (Beresford, 2004 cited in Bereford et al, 2007).
• Need longitudinal research (to deal with change in aspirations), more qualitative research and research on a broader range of disabilities.

Although there are problems with the ECM Outcomes, DRR5 (Beresford & Clarke, 2009) found some evidence that positive activities contribute to the ECM Outcomes:

• Being Healthy - sport and physical exercise has positive effect on physical health; the scheme setting and type of sport affects the outcomes
• Enjoyment & friendship - help meet social needs but there is evidence that segregated schemes can be better for some social outcomes e.g. friendship
• Achieving – helps developing life skills
• Participating – promotes sense of belonging and being part of the community

However, there is little evidence for ‘what works’ in terms of Outcomes from positive activities.

Section 6.4.3: Outcomes for Short Breaks & OSC

The AHDC: Short Break Implementation Guidance and the DCSF/PriceWaterhouseCooper (2006) cite evidence that short breaks provide beneficial outcomes to both the state and parents as they can reduce long-term intervention costs and the number of long-term residential places and also, prevent family breakdown. Parents are able to do things together as a whole family and dedicate time to other children (siblings). A recent telephone survey by NEF (2009) of five pathfinder local authorities, found that short breaks provided families with a mechanism to cope with the pressures of caring for a disabled child, reducing stress and worry, allowing time for siblings and a general increase in a sense of well-being for the whole family.

McConkey et al (2004) surveyed parents in Northern Ireland on perceived benefits of short breaks to carers and children and the results were subsequently used by the Health and Social Service Board in Northern Ireland in service commissioning. A break from caring, being able to spend time with other family members, relaxation/rest/uninterrupted sleep and the family being able to do other things were the top four mentioned benefits to the carer. Social interaction, change of environment and enjoying it were the top three benefits to the child mentioned and break of routine, getting used to being away from home, activities /outings and teaching independence were mentioned by nearly 10% of carers.

Historically, the view of short breaks in the UK focused on respite for carers and the belief that breaks from caring made their lives easier. More recently, focus has shifted to the disabled child’s experience and helping them to live a normal as possible life. Cotterill et al (1997) argued that short breaks should provide disabled children with the opportunity for increased independence, a widened range of activities, improved quality of life and social integration into the community.

Marchant et al (2007) found few studies have looked at the outcomes for the child for having a break from their primary carer(s) and more research is needed on the children’s views and preferences. It is thought that time out from home at a positive activity, such as, holiday play scheme, family link or ‘buddying’ scheme offers the child opportunities to participate in the community, have fun, make friends and develop independence and in one study nurses thought the children needed a break as much as the parents (Case-Smith, 2004 & Mausner et al, 1995, cited by Marchant et al).

It is believed that most children enjoy their short breaks but in research studies, data is often collected by teachers and others, who may have a different perception of need, and not directly from the child, who may not be able to express their views effectively. McConkey et al (2004) found that even when parents rated a service highly, some children did not look forward to attending, as they did not like leaving the family home. For some children, there can be negative outcomes from
short breaks, such as homesickness and distress when away from carers (McConkey & Adams, 2000), but most studies report positive outcomes for the child.

Section 6.4.4: Economic Outcomes for Short Breaks & OSC

The Scottish Executive (2003) carried out a literature review on the benefits and costs of out-of-school care (OSC), including weekend and holiday schemes, for all children to carers, children, communities and employers. There were gaps in existing literature but the report found families with disabled children gain some of the same economic benefits from OSC as other families, such as increased income from parents being able to work. This economic benefit of increased income and tax receipts is often cited in reports that look at the cost/benefits of providing short breaks to disabled children (e.g. NEF, 2009). The report identified the need to conduct further research into the precise benefits and costs of OSC.

There were a number of potential benefits for which substantial evidence could not be found and only assumed, for example, economic benefits to a child through increased parental earnings, better engagement of a child with the school, the benefits of integrating children with additional needs and especially, wider and longer term benefits to employers and the community. Additionally, not all impacts were considered positive. For example, a career in OSC is most often associated with low pay and low status. Overall, the review did show that OSC brings about both economic and social benefits, particularly to the most disadvantaged areas and households.

While not being able to isolate the short breaks from other AHDC provision, NEF (2009) estimates the financials saving from current level of provision as £36.5 millions and could be as high as £173.9 million, if there was full coverage of short break provision.

Costs of Service Provision

The Scottish Executive found that the actual detailed and specific costings of OSC were difficult to calculate due to the wide range of variables which affect the cost of developing and sustaining OSC provision. Costs can be broken down into two main categories, capital and revenue, and typically include costs for purchase or upgrade of premises, costs of equipment, staff recruitment (all capital), rent, staff wages and training, utility charges, insurance and management systems (all revenue). These costs however are not consistent or static across OSC facilities or over time. The key variables which can impact on costs are: location of premises, model of provision, management model, hours of operation, staff ratios, type of premises, space per child, specific requirements, e.g. for children with additional needs, local infrastructure and support, and the policy context the service operates in.
### Table 6.4.4: Overview of Social and Economic Outcomes from Short Breaks and OSC

<table>
<thead>
<tr>
<th>Social Outcomes</th>
<th>Financial Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Children</strong></td>
<td></td>
</tr>
<tr>
<td>Ability to lead more ordinary lives,</td>
<td>Assumed economic benefits from parents’ access to earnings</td>
</tr>
<tr>
<td>Improvements to their life and social skills.</td>
<td></td>
</tr>
<tr>
<td>Safe, secure and change of environment</td>
<td></td>
</tr>
<tr>
<td>Social interaction with children of different ages, ethnic backgrounds and</td>
<td></td>
</tr>
<tr>
<td>with additional needs.</td>
<td></td>
</tr>
<tr>
<td>Increased emotional health (enjoyment,</td>
<td></td>
</tr>
<tr>
<td>independence, confidence, self-esteem and motivation)</td>
<td></td>
</tr>
<tr>
<td>Broadening of experiences and skills</td>
<td></td>
</tr>
<tr>
<td>Health benefits through healthy eating</td>
<td></td>
</tr>
<tr>
<td>and physical activity</td>
<td></td>
</tr>
<tr>
<td>Help prevent family breakdown</td>
<td></td>
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<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Parents</strong></td>
<td></td>
</tr>
<tr>
<td>Support and advice from services and other parents</td>
<td>Access to employment, education and training</td>
</tr>
<tr>
<td>Respite and ‘time off’, sleep &amp; rest</td>
<td>Increased or stable earnings</td>
</tr>
<tr>
<td>Assists the physical and mental health of families through stress reduction</td>
<td>Decreased dependency on benefits</td>
</tr>
<tr>
<td>Social interaction through participation in work, education or training</td>
<td>Increase in working hours</td>
</tr>
<tr>
<td>Allowing time for siblings and other family</td>
<td>Movement from part-time to full-time working</td>
</tr>
<tr>
<td>Help prevent family breakdown</td>
<td>Increased ability to do a job and increased job satisfaction</td>
</tr>
<tr>
<td></td>
<td>Fewer unplanned absences</td>
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<tr>
<td></td>
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<tr>
<td><strong>Communities</strong></td>
<td></td>
</tr>
<tr>
<td>Participation: promotes sense of belonging and being part of community</td>
<td>Contributes to tackling poverty, disadvantage and regeneration</td>
</tr>
<tr>
<td>Development of citizenship in children</td>
<td>Creation of a positive environment for children</td>
</tr>
<tr>
<td>Social inclusion of families, especially from disadvantaged areas</td>
<td>Employment creation and job opportunities in OSC services</td>
</tr>
<tr>
<td>Linkages of families and schools to the community</td>
<td></td>
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<td></td>
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<tr>
<td><strong>Employers</strong></td>
<td></td>
</tr>
<tr>
<td>Less stressed employees</td>
<td>Better staff retention rates and associated reduction in recruitment costs</td>
</tr>
<tr>
<td></td>
<td>Investment in training and staff development programmes recouped</td>
</tr>
<tr>
<td></td>
<td>Reduction in unplanned absences</td>
</tr>
<tr>
<td></td>
<td>Wider pool of potential recruits for jobs</td>
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<td></td>
<td>Employment creation in services</td>
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<tr>
<td><strong>State</strong></td>
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<tr>
<td>Help prevent family breakdown</td>
<td>Can reduce long term intervention costs</td>
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<td></td>
<td>Less long-term residential placements</td>
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<tr>
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<td>reduced health costs</td>
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<tr>
<td></td>
<td>Increased tax receipts from less parental stress</td>
</tr>
<tr>
<td></td>
<td>Decreased welfare benefits from parental illness and inability to work</td>
</tr>
<tr>
<td></td>
<td>Fewer problems in sibling schooling</td>
</tr>
</tbody>
</table>
Section 6.4.5: Wellbeing

Wellbeing of children is included in many Outcome measures for service delivery but there is little national data available on children’s wellbeing, particularly for younger children (under 11yrs).

The Office of National Statistics (2009) produced a working paper on the challenges of measuring children’s wellbeing and is currently undertaking an analysis of current measurement tools and their feasibility. The points they identified from research included:

- Ambiguity in definition of wellbeing and thus, it is hard to measure.
- Wellbeing for adults, young people and children differ:
- Blurred boundary between young people and adults.
- Children’s well-being is highly dependent on a nurturing family.
- Young People are highly influenced by peers and fitting in.
- National level data on subjective wellbeing will become available from the OFSTED ‘Tell Us’ surveys.
- There is a lack of data on wellbeing for ethnic minority, disabled, looked after & refugee children.
- More data on younger children is needed, as children aged 11-15 years are often used in surveys.
- There has been a focus on negative measures and needs to change to more positive measures, as this encourages Local Authorities to focus on the strengths of services.

The New Philanthropy Capital has been developing a questionnaire for charities to measure children’s wellbeing since 2008 (Heady and Oliveira, 2008) and hopes to publish it in 2010.

Action for Children and New Economics Foundation (2009) have investigated the economic benefits of investing in children’s well-being and has produced a guide to measuring children’s well-being as part of its Backing the Future project. They draw a number of conclusions from case study evidence on what services need to offer to improve psychological and social well-being in children. A child’s wellbeing cannot be improved in isolation - it is heavily dependent on the child’s family, social and community environment. Taking this into account, services should:

- build relationships based on trust and stability and link children into the wider community.
- help improve the wellbeing of the whole family
- promote positive emotions and experiences
- encourage children to use their strengths to participate in the delivery of services and activities
- promote play, enjoyment and fun to help boost happiness and stimulate creativity and learning
- recognise external factors influencing wellbeing, such as poverty

Disability Research Review 5 (Beresford & Clarke, 2009) reviewed the evidence base on improving the wellbeing of children through improving access to positive and inclusive activities and they found some major gaps in the evidence base (see section 6.8.4). However, they did find evidence for the way inclusive services should be resourced, structured and delivered (see section 6.7, Inclusive Services).

Disability Research Review 4 (Newman et al, 2009) found mothers, as often the primary carers, have been the primary participants in research, (this is also seen in recent national and local surveys and
participation forums). There is a need for research that differentiates between outcomes for fathers and mothers and whether they are the primary carer. Dutch research on the impact on perceived changes in wellbeing of placing their child in a therapeutic toddler group for 10 months, found mothers reported greater gains in wellbeing than fathers while fathers gained more insight into the child’s abilities. Mothers had a greater perceived need for support while fathers had a greater need for understanding (Hendricks at al, 2000, cited in DRR4). There is also evidence that reducing stress on the primary carer reduces the stress on the whole family and has benefit to the wider family unit.

Section 6.5: Play & Playwork

Key Messages

1. Play research has tended to focus on all children and there is limited direct research on its benefits for disabled children.
2. Research indicates that Play is essential to children’s development. It enhances learning, social skills and language development. It also improves wellbeing by improving confidence and self-esteem.
3. There is no standard definition of Play and Playwork, and as neither have been a research priority, there is a need for more research and different research methodologies.
4. Play deprivation can result in anti-social behaviours, depression and lack of brain growth.
5. Play services can have direct economic benefits by creating small businesses and local employment and indirectly, by allowing parents to train and work.
6. Disabled children are more prone to obesity through taking less exercise and eating fattier and sugary foods. Play activities provide an enjoyable way for them to engage in exercise. It is recommended that they participate in at least one hour of exercise a day.

Play research has focused on the benefits and necessity of Play for all children and disabled children have tended to be included as a separate group (similarly to socially disadvantaged children or teenagers) within these wider studies. Psychology research into play as a positive activity for social and educational development has a long history and the need for children’s play in schools and communities has been recognised for many years. As well as the health benefits from the active exercise in play, children learn through play and can use it to work out social norms and build friendships with other children. When the political situation in Eastern Europe changed, researchers were able to study children in orphanages who had been deprived of play and found their neurological development negatively affected, and the children showed increased aggression and depression. More positively, these effects were reversed when the children were introduced to play activities.

Section 6.5.1: The benefits of Play and Playwork (Manwaring and Taylor 2007)

Manwaring and Taylor carried out a review of the research literature (2001 – 2006) on the benefits of Play and Playwork and the effects of the absence of play on all children and young people. The review built on another major review published in 2001 (Cole-Hamilton et al 2001), and undertook a literature review, contacted key government departments and research institutes, including the Thomas Coram Research Institute at the University of London, where extensive studies have been completed on children and play.

As play had not been a research priority, the evidence base has significant gaps, and the review concluded that there was a need for more research and new research methodologies. The review’s first problem was defining Play, Playwork and Play Settings (see Appendix 2, Definitions), the relationship between them and the research traditions within which research has been carried out. The review found evidence for the benefits of play and playwork on children’s education and
learning and their health and wellbeing, and also found economic benefits from creating play businesses and employment.

**Research Methodologies:**

Traditionally, play has been investigated using a scientific approach but more recently, the nature of play has allowed a more social constructionist approach to be taken, alongside applied investigation:

**Scientific Approach:** as seen in the development psychology world (from work by Piaget and Vygotsky). Play is seen as an innate, instinctive and driven form of behaviour that is essential to life, evolution, growth and development. Research within this method tends towards the observation and experimentation approach, with quantitative methodologies and evidence.

**Social Constructionist Approach:** this newer approach recognises that the nature and value attached to play has changed over time and varies within and between cultures. This approach uses quantitative methodologies, with observation, ethnography (field studies) and discourse analysis and deconstruction.

**Applied approach:** lies between academic investigation and the child-centred and reflective practice of playwork.

The review concludes that a multi-disciplinary and pragmatic approach is taken for future research work and whatever works in practice guides the methodology chosen; however the social constructionist and applied approaches would enhance the understanding of the benefits of play and playwork.

The review found evidence for the following benefits of play:

- play is recognised for the important contribution it makes to education and life-long learning, with outcomes enhanced when play is ‘properly directed’ by adults. Play allows children to take risks, explore and experiment, try new things and push boundaries.
- play can enhance problem solving skills (from animal studies).
- play gives opportunities to learn social skills (teamwork, communication, listening, turn-taking and co-operation) and language development through social interaction.
- play contributes to emotional well-being and learning by requiring communication and negotiating with others (playground), responsibility for others (e.g. younger siblings) and story-telling.
- parents can learn about their children’s play through observation and by playing alongside them; this encourages parents to engage in their children’s learning, through play in non-institutional settings
- play improves health and well-being and mitigates negative factors such as poverty, social isolation and a lack of strong relationships. Play builds confidence, self-esteem and resilience in the longer term. Physical exercise combats obesity and direction from trained staff increases activity in play settings.
- Play opportunities can provide direct economic benefits through the creation of new small business and local employment. Indirect benefits, such as out-of-school clubs, allow parents to work or train. See Section 6.4.4 Economic Outcomes.

and evidence for the following negative results from play deprivation:

- child is likely to become more aggressive, violent and anti-social.
- increased risk of obesity.
- chronically play deprived children suffer symptoms from depression to a gradual loss of electrical activity in the brain.
the ages 0-7 are seen as a developmentally ‘sensitive’ period for neurological growth and play deprivation in this period is considered particularly damaging.

- studies have shown play is essential for brain growth which implies that play deprivation will adversely affect brain growth. A US study reported devastating effects of play deprivation on Romanian orphans, linking it to a reduction in brain size (Tobin 1997, cited in review). When play was introduced to Romanian children through a British Charity, the children changed dramatically. Their social interaction, motor skills and understanding of their world improved and they began to play in highly creative ways (Brown and Webb, 2005 cited in review).
- When animals are deprived of play, they show highly aggressive and bizarre behaviour and completely lose touch with social norms and accepted behaviour protocols.

**Section 6.5.2: Physical Activity and Obesity**

*Latest UK Physical Guidelines from Department of Health (July 2011) are detailed at:*  

However, there are no specific guidelines for disabled children, other than a reference to the Scottish Executive report: let’s make Scotland more active: A Strategy for Physical Activity (2003):

All children and young people, including those with disabilities, should have the opportunity to be physically active through their home, school, college or university and community. This should include:

- having the opportunity and being encouraged to take part in physical activity **for at least one hour a day**; and
- having access to a range of physical activities including play, sports, dance, exercise, outdoor activities, active travel, such as walking and cycling, and being encouraged to be active in daily tasks in and around school, college or university.

([http://www.scotland.gov.uk/Publications/2003/02/16324/17924](http://www.scotland.gov.uk/Publications/2003/02/16324/17924))

A number of studies show that children and young people with a disability and those from Ethnic minority groups are, overall, less active than other young people. This puts them at higher risk of the diseases associated with inactivity earlier in their adult life. Also, they are less likely to have developed the necessary foundations for activity in later life.

Play activities allow disabled children to increase their physical activity and help to reduce obesity. They tend to spend more time in cars than non-disabled children and often need support from others with their mobility and this means they are less likely to participate in exercise. Disabled children are more prone to obesity than non-disabled children and therefore, more prone to health problems (e.g. heart disease and diabetes) in adulthood and low self-esteem and isolation, through being bullied and stigmatised.

In a recent study in Northern Ireland for the Education, Health and Social Care Boards (Slevin et al, 2008), 460 pupils (24% from special schools) filled in a questionnaire about food intake, eating patterns and physical activity, with help from adults for children with more severe needs. Physical measurements were taken (weight, height, waist size, body fat and BMI calculated) and it was found that while 24% of non-disabled children were overweight, 33% of the disabled children were overweight, and also, they were also more likely to eat fatty and sugary foods (30% v. 25%) and spend fewer hours on moderate activities and significantly less time on high level activities. It
suggests that this group of children need targeted health strategies to prevent over-weight and obesity.

Sit et al (2007) found that children from five special schools in Hong Kong with physical disability, mild intellectual disability, hearing impairments and visual impairments accrued little moderate-to-vigorous activity during PE and breaks at school. Activity varied across disability types with physically disabled children being the least active.

Section 6.6: Play Schemes for Disabled Children

Key Messages

1. Play schemes are popular with families with disabled children, as they are seen to allow disabled children to take part in normal childhood activities, as well as providing respite for carers.
2. Parents liked schemes that had good indoor and outdoor facilities and with trained staff who communicated well with parents. This overlaps with the ‘good’ outcomes cited for short breaks.
3. Children liked the companionship and meeting peers, being with adults who helped them have fun and taking part in activities they choose and were not boring.
4. Playschemes with untrained staff found it harder to cope with disabled children and their behaviour, particularly on outings from the main centres.
5. Schemes should be long-term as children get disappointed when a scheme ends and can become more isolated than before. For sustained outcomes, such as friendships, increased social skills and reduced isolation, schemes need to be regular and continuous. Family-link and buddying schemes may have better outcomes, than short-term holiday schemes, because of the strong relationship formed between disabled child and carer.

Play schemes are often cited as the service of choice by families with disabled children and as for short breaks services, as they give disabled children the opportunity to experience out-of-school play and leisure activities, either in a specialist or mainstream centre. Surveys of disabled children and young people indicate that like all children, they want to spend time with their friends and participate in leisure and community activities with family and peers (e.g. Marchant et al, 2007). Carers want good play services with appropriate facilities, trained staff and varied activities. These key criteria are seen as essential for carers to have confidence that their child will be happy and looked after when attending the play scheme.

Section 6.6.1: Study of Summer Playschemes (Petrie, 2000)

One of the most extensive studies on play services for children (including disabled children) was a sociological study carried out in the late 1990s and funded by the Department of Health, that resulted in the book, ‘Out-of-School lives, Out-of-School children (Petrie et al, 2000). The researchers looked at the perspectives, organisation and practise of 6 service providers of out-of-school play services in a large city in SE England (3 Integrated and 3 Segregated schemes) in terms of access to services, resourcing, & staffing, practice in integrated services, play & risk, how staff worked with challenging behaviour, communication between staff & between parents and staff, and difficulties that outings to places of interest presented for staff. Researchers paid 5-7 visits lasting between 1.5 to 8 hours in length at each provider. Most children were referred by social services and thus children with more severe disabilities were over-represented. The findings are covered in detail below, as they are relevant directly to the proposed research study on inclusion of disabled children in holiday play schemes, and many of the parent’s views collected in the study are still reflected in more recent national parental surveys.
Parents / Carers

**Satisfactions**
- Availability was paramount.
- Respite: although this was delivered by other services, mothers expressed high satisfaction with play schemes and distinguished the benefits from this everyday normal childhood activity.
- Children could be ‘ordinary’, play and be happy – child centred activity.
- Greater freedom for child – self-realisation, move around, not restricted, choice & control.
- Companionship – less social isolation.
- Varied activities.
- Security – in scheme and from bullying.
- Sometimes, educational.
- Good communication between parents and staff and school e.g. having agreed on methods of controlling behaviour, staff being informed about children and staff reported back to parents.
- Premises – good indoor and outdoor facilities, quiet rooms, safe environment.

**Dissatisfactions**
- mirror images of ‘satisfactions’: not safe, stimulated or cared for, not informed, items stolen, bad hygiene, bad premises.
- Lack of feedback on what child did at scheme.
- Organisational problems: rationing of places, lack of information, social service referral only, transport issues.

Children / Young People

- companionship and opportunities to meet others
- being with adults who are supportive, caring and fun but not those who sought to control them, shouted at them or exhibited a superior social status because they were adults, or being unfair and not listening.
- choice of activities

Did not like being bored e.g. with over-familiar activities

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**Table 6.6: Summary of Satisfactions and Dissatisfactions of Holiday Play Schemes in SE England (mid 1990s) cited by Parents (mainly mothers) and Children and Young People.**

The study found that all play services observed fulfilled many of the intentions of the service providers. All schemes were oversubscribed and rationed their spaces for disabled children - one of the integrated schemes had to limit non-disabled children, so as to have a 2:1 ratio in favour of disabled children (though they had wanted equal numbers). All schemes allowed children to play, be physically active, and to interact with their peers, and thus, empower them. Segregated providers were aware they provided ‘respite’, but considered their main aim was to provide play for the child. Services designed specifically for children had features and equipment for disabled children (e.g. large tricycles, footballs with bells, large scale toys, soft play, waterbed). About half of the services fell short of ensuring children’s wellbeing, safety and comfort by having inadequate resources, untrained staff & limited methods for working with all children. All received Local Authority (LA) funding, were registered and were seen to meet LA standards. The researchers found problems with some of the schemes (see dissatisfactions above) that would now be part of government inspections. Holiday schemes run for limited time periods and staff are often recruited late, so these issues can be difficult to identify for inspectors. Government inspections, premises and staff checks have improved since the study was undertaken in the late 1990s, and these issues may no longer be applicable to most schemes.
The study identified the following key factors for differentiating the play schemes and there is overlap with outcomes for short break and inclusive services on staff and communication:

**Staff:** Resources (particularly 1:1 key workers) were essential to let the more impaired disabled children attend schemes. Trained staff could balance risk and reflect on what they had allowed to happen. Untrained staff expended more energy than trained staff and were exposed to more difficulties, such as managing behaviour. Staff needed a professional understanding as to what behaviour to allow and what to ‘punish’, i.e. when to treat a disabled child the same as non-disabled child or when to allow for differences and understanding. Staffing and training was variable, depending on resources and the scheme, but better generally, in segregated and Local Authority schemes.

**Challenging Behaviour:** The staff used different responses to challenging behaviour: Democratic where the rights of users and staff were acknowledged and guided what was ‘acceptable behaviour’, laissez-faire where there was little or no interference from staff and punitive were staff hurt or threatened the child; staff sometimes used a mixture of these, depending on the child.

**Communication:** Some providers had clear procedures on communication between staff and between staff and parents: diet, medication and current problems were recorded in writing; staff spoke to parents or if children came by LA transport, they phoned to inform them of progress or difficulties. However, best practise was not always followed.

**Outings:** some schemes had common activities for disabled and non-disabled children and some used these activities to relieve cramped facilities. Outings cause problems for untrained staff in coping with disabled children and also, disabled children faced rejection from public and non-disabled children in public settings.

**Section 6.6.2: Other Research on Playschemes**

Kilpatrick and McClinton (2004) surveyed teachers, parents and scheme staff at the end of a 10 week 10-week pilot Saturday play scheme in Belfast in 1998, attended by 11 children, aged 8-12 years, with moderate learning difficulties. The main conclusions of the study were that the project was highly successful: the children enjoyed it and were able to engage in different activities, though teachers thought some children benefited more than others. Parents valued the respite on a Saturday morning and were confident of their child’s whereabouts, that they were being cared for and receiving stimulating play. The scheme was time-limited and dependent on the good-will of those involved. The project leader identified the lack of training opportunities and the various statutory agencies found that finding trained personnel was very difficult. Children’s aspirations were raised and they found it difficult to understand when the scheme ended. At a review session five years later in 2003, seven parents said that their child’s experiences of play and leisure since the scheme, were worse and they were now more isolated than ever. This corresponds with McConkey and McCullough’s (2006) findings that there was no evidence that taking part in a holiday short break improved friendship or leisure pursuits for adults with learning difficulties.

For long-term outcomes, taking part in positive activities may need to be regular and continuous, to establish the participation and allow friendships to develop. This is still difficult where access to schemes is often rationed and children are only able to attend on irregular basis. It may also explain the popularity of family-link and buddying schemes where the scheme is based on developing strong relationships between the disabled child and the short-break carer.
Section 6.7: Inclusive Services

Key Messages

1. A policy of integrating disabled children into mainstream schools and other services has allowed families with disabled children to access more mainstream services and environments.

2. Short Breaks are seen as a key way of reducing social isolation for disabled children and their families, though many families are still socially isolated.

3. There is no standard definition or interpretation of ‘Inclusion’ in policy or service delivery. It can range from allowing a disabled child to attend a scheme with no additional support (pseudo inclusion) to schemes that have been specifically set up to be inclusive, with additional staff and activities to promote interaction (active inclusion).

4. The characteristics of a fully inclusive service include skilled staff, appropriate facilities and activities to promote inclusion. Parents need enough information to be confident the service can cope with their child and deal with emergencies and the child may need to build their own confidence in the staff and activities.

5. Research indicates that some families need a ‘bridge worker’ to provide information and deal with the practicalities of using a scheme and who can give them confidence to use different schemes.

6. Transport is still a major issue for many families and is especially important for older children seeking more independence.

7. There are complex reasons why some families with disabled children do not want to take part in inclusive activities, such as, parental and child perceptions on play and leisure and whether they consider that short break service are not suitable for the family’s needs.

8. It is likely that both integrated and segregated schemes are needed, along with more inclusion in mainstream services. Parents and children want choice as mainstream and specialist services fulfil different functions.

The everyday lives of disabled children have changed in the last 20 years with more children being educated in mainstream playgroups and schools. Also, legislation and a policy of more inclusion has helped to make mainstream service providers consider disabled children when building or adapting facilities and providing services. This integration of disabled children and inclusion in more mainstream activities means that the boundaries around services for disabled children are becoming blurred. Many leisure centres now have disabled children in open public sessions with the help of specialist equipment and dedicated support staff. Also, mainstream play and leisure schemes are finding ways to include disabled children in their activities and where this is successful, the need for specialist schemes becomes less.

However, for some children, integrated services may not be appropriate, and the diversity of disabilities needs to be appreciated. Children with Autistic Spectrum Disorders (ASD) can find integrated schemes too chaotic, unstructured and noisy, those with complex medical needs may need specialist medical facilities and staff and those with very challenging behaviour may need a safe and secure environment. Carers of these children indicate they prefer segregated schemes.

Section 6.7.1: Disability Research Review 5 (Beresford & Clarke 2009)

Disability Research Review 5 (DRR5) found that the factors associated with disabled children participating in inclusive activities are multiple and complex, and not restricted to the service itself. These factors include the family’s predisposition to taking part in leisure activities and their perceptions on how suitable the activity is for their child, especially a child with more complex
needs. The child’s preferences and perceptions of their abilities are also a factor and they may not have the social skills to fully participate, as they may have spent most of their lives in specialist settings (e.g. school) and not learned the nuances of children’s play behaviour, for them to fully participate.

There is a problem with ambiguous definitions and variability of ‘inclusive services’. DRRS found that inclusion in services is interpreted in a number of ways:

- **pseudo**: disabled children allowed to use service at the same time as non-disabled children but staff do not actively help them to participate.
- **active inclusion**: disabled children are actively included and the scheme is designed and resourced to enable disabled and non-disabled children to participate together in activities or experiences.
- **opportunity inclusion**: services specifically designed for disabled children with similar levels of ability.

The review concluded that future research should focus and evaluate the ways in which ‘inclusion’ is being interpreted and implemented by service providers and it set out what are the ‘hallmarks of inclusive services’ from the evidence:

- Skilled staff must actively support inclusion through activities and interactions between all the children.
- Service settings must support inclusion with the appropriate facilities, not just physically accessible and safe, e.g. places to be quiet for children with challenging behaviour.
- Families need support to find and participate in services and clubs, especially where the child has complex needs, needs medical interventions or 1:1 support. Carers want to be confident the service can cope with their child and any emergencies. The service may also need information and advice from the carers and other professionals to be fully able to take a child. Children often need a period of time to get used to a new activity and may need extra support during this phase.
- Transport is still a major barrier to participation and without door-to-door transport, some children cannot participate in any activity. This was a major problem for the older children in Knight et al (2009) study on promoting social inclusion.

**Section 6.7.2: Other Research**

Disabled children can be actively involved in inclusion themselves and initiate change in the play environment. An observational study of play in six primary school playgrounds in Yorkshire found disabled children were involved in many types of play and their inclusion was often facilitated by themselves, by other children or by staff and sometimes included the adaptation of play (Woolby et al, 2006, cited in Manwaring and Taylor).

In a recent study (Knight, Petrie et al, 2009), of disabled children and young people (7-19 years), their parents and service staff were interviewed about out-of-school activities and holiday clubs and other leisure opportunities. These services were seen as a partial solution to the isolation felt by the disabled children and also, helped in promoting inclusion with non-disabled children. Being with other people and making friends were the main reasons for young people liking holiday schemes. However, although they liked mainstream experiences, they thought providers needed a better understanding of their situation and the help they needed to participate. Lack of transport was also an issue, due to the cost and also, the length of time on the bus with an extreme case of a child spending 2.5 hrs in the bus to get to a Saturday scheme. The main message on ‘inclusion’ from this study was that families need a ‘bridge worker’ to help with information and advice, and sort out the
practicalities of using a scheme, such as liaising with the school and getting equipment. This ‘project co-ordinator’ role was also found to be key in arranging holiday breaks for adults with learning difficulties (McConkey & McCullough, 2006). (The government DCATCH childcare initiative has recommended ‘parent champions’ are recruited with previous experience of schemes to help new parents build confidence in schemes).

There can also be negative attitudes from the non-disabled population to inclusion. Petrie et al (2000) found that the children provoked negative reactions from families with non-disabled children when the play scheme took the disabled children to a park. Research from Germany on physically disabled adult’s views on an outdoor public space, found they felt stigmatised by the green space in a park specifically designed for them, and the non-disabled users, particularly those with higher income and better education, were reluctant to concede the entire park’s design and infrastructure to accommodate disabled visitors. (Seeland & Nicolè, 2006).

In one study focusing on the differing outcomes and parental views on inclusion (Petrie, 2000), parents appeared not to have considered segregation or integration as a factor when using play schemes and only found it relevant in terms of schooling. This may have been because in the mid 1990s, getting access to any scheme was parents’ top priority; parental awareness of inclusion may be higher now as it has come up the lobbying and political agenda. Disability Research Review 5 (Beresford & Clarke, 2009) found segregated activities may be better for developing social skills and social mixing, as well as developing peer relationships. Parents wanted a choice of both inclusive and segregated activities because they fulfil different functions and children may need access to both to be able to lead an ordinary life. Similar parental preferences were found by Surrey Alliance AHDC survey and local service provider’s carer feedback reports.
Section 6.8: Disability, Play and OSC Reviews - Gaps in Research Evidence

Key Messages

1. There is no consistent definition of disability used in research studies.
2. There is a lack of knowledge of out-of-school lives of disabled children.
3. It is not clear what services are needed to provide for all levels of needs.
4. It is unknown how long benefits of interventions last and which services are cost-effective.
5. More information on what ECM Outcomes from positive activities mean in practise for disabled children.
6. Little is known about which services allow parents to work.
7. There is a lack of longitudinal studies and how interventions impact on long term outcomes.
8. Children (5-8 years), those with communication impairments or profound and multiple difficulties are under-represented in research.
9. There is a lack of knowledge in general around adolescent and transition services.
10. Most research has focused on Mothers and not the outcomes of services for the wider family, such as, Fathers and Siblings.
11. There may be different outcomes for segregated and integrated schemes and these affect ‘which services work best’ for certain groups of disabled children and their families.
12. Terms, such as Inclusion, Outcomes and Wellbeing, are poorly defined.
13. More research is needed on how inclusion is interpreted.
14. Research is needed in the role of play in reducing isolation, building friendships and long-term impact on lifespan development for disabled children.
15. More investigation is needed of the role of Playwork in relation to disability.
16. Some reviews indicate there may be significant economic benefits from play services and short break provision, but rigorous research is need on both the social and economics outcomes of out-of-school care provision for disabled children.

This section gives a detailed overview of the gaps in the evidence base that have been detailed in the following reports:

- C4EO published three Disability Research Reviews (DRRs) in 2009 on improving the wellbeing of disabled children:
  (Appendix 4 has a diagrammatical overview of the gaps in research evidence from the above reviews)
  - DRR4: increasing the quality and range of early years interventions (up to age 8), in conjunction with Barnardo’s Policy and Research Unit.
  - DRR 5: improving access to positive and inclusive activities, in conjunction with the Social Policy Research Unit (SPRU) at the University of York.
  - DRR 6: ensuring all disabled children, young people and their families receive services that are sufficiently differentiated to meet their diverse needs.
- Scottish Executive Education: Assessment of Benefits and Costs of Out-of-School Care.

Text in bold in the following sections, indicates that these points have helped to focus the research proposal.

In Sep 2008, the SPRU (University of York) held a conference to bring together some of the key researchers, funders, and policy makers in England, Scotland and Wales and to discuss the needs for future research on vulnerable children (including those with a disability), their families and wellbeing. The conference focused on research over the next ten years and worked within the five outcomes of the Every Child Matters framework, including ‘Enjoy and Achieve’, and identified the following gaps in existing research:

- National data sets on subjective wellbeing. In the past, children views have not formed part of National or International Surveys, and there is a lack of data from the children themselves. With limited data on the wellbeing of vulnerable children in the UK and in other countries, it is difficult to compare wellbeing across countries and across minority groups, as they get lost in the population averages.
- More knowledge is needed on circumstances of families with one or more disabled children and those with disabled parents.
- Lack of longitudinal studies around disabled children, their aspirations in childhood and the changes through childhood, adolescence through to adulthood.
- Comparisons on services across the UK since devolution (Scotland, N. Ireland, Wales and England). Each sector of the UK has diverged on policy and services since devolution of government to each country.
- Current research indicates that poverty, bad housing and lack of local leisure facilities negatively affect children’s lives. These major issues need to be addressed for many families with disabled children to achieve a ‘normal life’ and positive outcomes.
- **Lack of research on the effectiveness and outcomes for the child and family of different services (e.g. types of short breaks) and from this, their cost-effectiveness.** Commissioners and carers want to know ‘Should this service be used because it gives better outcomes and/or will reduce costs?’ Research needs to find out what works and why, for whom and in what circumstances e.g.
  - services that allow parents to work
  - services that facilitate inclusion in community life
  - services for teenagers when in transition to adult services.
- There is a need to develop outcome measures that include children’s and parent’s perspectives and that also take account of intermediate and longer term outcomes.
- There is limited research that includes disabled children’s own views, particularly from those children who cannot use language. Some UK researches have made efforts to develop methods to communicate with disabled children e.g. the Mosaic approach was originally developed for consulting preschool children and is now used for disabled children.
- Participation in decisions about treatment and service planning is low, particularly for disabled teenagers and children with complex needs or communication impairments. Research is needed on the outcomes from different ways of promoting disabled children participation and how this participation can be increased for disabled children. Participation may need to be redefined e.g. be at the level the child is able to engage and make choices, even if it is simple participation and simple choices.
6.8.3 DRR 4: Improving the wellbeing of disabled children of disabled children through early years interventions (age 0-8)

DRR4 (Newman et al, 2009) focused on the use of early interventions to improve the wellbeing of disabled children, aged 0-8 and their families, mainly in the health and education sector and thus, its research and conclusions cannot be used directly by this study; however, the review still provided useful research evidence and directions for future research.

The review found substantial evidence that early years interventions improve outcomes for children and families, but more UK empirical studies and long-term outcome studies focusing on disability, not social disadvantage, are needed; there are still major gaps in the evidence base:

- Most research has focused on the disabled child. What are the benefits of Positive Activities on the wider family unit (Mothers, Fathers and Siblings)?
- **Which services work best for which group of families.**
- Services – need more mainstream services investigated (often pilots projects are researched).
- Research has focused on preschool children aged 0-3 yrs. Research on children, aged 5-8 yrs is needed and also, the views of the younger children.
- Research results are difficult to interpret, as studies looked at a wide range of children and variation of outcomes.
- Research needs to take account of the differing views on service outcomes from parents and professionals.
- As SPRU conference (2008) noted, poverty and social exclusion may have greater impact than disability.
- How long does the benefit of an intervention last? Whether the gains are direct or indirect result of the intervention and whether simpler interventions deliver as much or more benefit.
- Research is mostly from the USA, though there are some UK studies.

6.8.4 DRR 5: improving the wellbeing of disabled children and young people through improving access to positive and inclusive activities

This review was particularly relevant to this literature review, as it sought to find research evidence on the following:

- What evidence is there of practice in children’s centres, extended schools and youth services in fully including 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?

As part of producing DRRS, the authors used Information Specialists to carry out an extensive literature search of the main online research databases (e.g. PsychINFO, Medline, Social Care Online etc) using keyword sets covering disabled children, short break services and play & leisure. From these searches, relevant literature was selected based on the above review questions.

The review found the following gaps in the evidence base:
• There is little known nationally about after-school lives of disabled children and the extent of opportunities for them to participate in positive activities.
• A lack of high quality research, in terms of the number of studies, their scope and quality.
• Few rigorous evaluations of the impact of participating in positive activities whether inclusive or segregated.
• Few studies have focused on the experience of children and young people with profound and multiple learning difficulties.
• Future research should evaluate the ways in which ‘inclusion’ is being interpreted and implemented by services.

6.8.5 DRR 6: Ensuring all disabled children and YP and their families receive services which are sufficiently differentiated to meet their diverse needs.

This review focused on whether services were sufficiently differentiated to meet the diverse needs of disabled children and young people, particularly those from black and ethnic minorities, refugee and asylum seeking families and children with high needs or who live away from home.

There is no single or combination of datasets able to give a definitive view of disabled children in England. From data available, it found that boys outnumber girls, some ethnic minority groups have a higher prevalence of certain impairments and disabled children are evenly distributed across age-band in the 5-18 group, though there is a ‘bulge’ in SEN statements in the 12-15 age group with much lower percentages of disabled children in the 0-4 group.

Its findings included:

• there is a lack of government-sponsored cross-sectional and longitudinal surveys designed specifically to collect data on childhood disability.
• a consistent definition of disability should be used in all surveys.
• there is a lack of research that differentiates between the needs of children with complex needs and other disabled children.
• more intervention studies are needed.
• more literature is needed on BME groups (other than South Asian children with learning disabilities) and disabled asylum-seeking children.


Manwaring and Taylor reviewed the research literature (2001 – 2006) on the benefits of Play and Playwork and the effects of the absence of play on all children and young people and identified a shortage of evidence based research into:

• Benefits of play amongst children over 5’s and teenagers, and those with special educational needs.
• Role of play services in reducing isolation of disabled children.
• Importance of friendships in children’s play
• Long-term research building on the extensive evidence base of the benefits of play in the early years that looks at the continued benefits of play on learning and education through 5 to 15 years.
• Long-term impacts on mental health of play deprivation on children and young people.
• Relevance of play to lifespan development; as a development process and facilitating development.
• Research that specifically identifies the costs / benefits of staffed play opportunities as opposed to childcare in general (which forms the bulk of the evidence in England)
• Research of the impact of staffed play provision, mobile play facilities or play rangers in economically, disadvantaged areas.
• Few studies on the impact of playwork (probably because it is a new profession) and adult-directed play on learning and physical activity.
• Nature and benefits of play and playwork.
• The role of playwork in relation to age, gender, ethnicity and disability.
• Research to assess the impact of the large voluntary workforce and their likelihood to move into paid employment in the playwork sector.
• The link between play, playwork and the community, including community cohesion and the impact of new play services on relationships within the community

6.8.7 Scottish Executive Education: Assessment of Benefits and Costs of Out-of-School Care.

The Scottish executive commissioned a review of UK and International research evidence into the outcomes of Out-of-School care (OSC), including weekend and holiday schemes, for all children and families. The report identified the economic benefits for carers, children, communities and employers (see Section 6.4.4) and also highlighted the need to conduct further research into the precise benefits and costs of OSC:

• Research that is evidence based and rigorous to demonstrate both the social and economic benefits of OSC provision.
• Research specifically identifying the costs/benefits of OSC as opposed to childcare in general.
• Research that takes into account other factors which may bring about benefits and which separates these out to focus solely on the benefits resulting from OSC.
• Future research would especially benefit from longitudinal studies as many benefits of OSC can only be measured in the longer term.
• Research with samples of parents accessing OSC provision to assess its likely impact on their work status.
• Future research should also take into account the differential impact of OSC on sections of the population, for example, differences in terms of socio-economic status, location and ethnicity.
Section 7: Research Study: Recommendations

Section 7.1: Overview

The scoping study identified that there is a significant lack of knowledge around what disabled children do outside school. The research proposes to use Surrey as a case study to address this gap in knowledge. Study 1 is a comprehensive survey of all families with disabled children in Surrey to gain more knowledge about their usage of short breaks and other play and leisure services.

The scoping study also found a policy and commissioning focus on increasing inclusive services for disabled children but there was professional and parental doubt around whether inclusive services were the best services for some groups of children. Study 2 proposes an investigation of holiday play schemes with a focus on how inclusion is delivered.

Figure 7.1: Overall context of proposed research studies – using Surrey as a case study.
Section 7.2: Research Studies

Study 1: One of the main issues identified during the study was the lack of knowledge surrounding the out-of-school lives of disabled children nationally. Although services exist for disabled children to participate in play and leisure, it is estimated that only 20% of families use local authority services and it is unknown how many families use mainstream provision directly. Some carer surveys have been undertaken by local authorities to advise on how AHDC funding should be directed but these surveys have focused on families who already use services and only provide feedback on the sort of activities these existing services should provide. Little is known about the leisure time of disabled children who do not use these services and whether they have access to any play and leisure outside school. It is possible that families are not aware of the schemes or their eligibility to use them and many schemes are still oversubscribed, so availability and transport to a scheme may still be factors. Again, it is not known how many families access more than one type of service or why or if this is a factor in limiting places for other families. Some research indicates and local stakeholders believe that some disabled children are still very isolated when not in school. The first research study seeks to provide more information in this area and is a carer survey of all families with a disabled child in Surrey, via specialist and mainstream schools with specialist provision:

What short break and/or play and leisure services do disabled children in Surrey participate in outside school and what factors determine this?

Study 2: The second main issue identified during the study was the government focus on social inclusion for disabled children and their families and the way inclusion is implemented by service providers. In recent years, both specialist and mainstream providers have taken active steps to implement inclusion in service provision. However, there are still many specialist segregated services in Surrey, both for all disabled children and also, for those with a specific disability such as autism, Down’s syndrome and epilepsy. Locally in Surrey, there is professional doubt as to whether inclusive services are appropriate for all disabled children and local parents of children with ASD and complex needs expressed a preference for not just segregated schemes that catered for all disabilities, but for segregated schemes that catered for children with similar disabilities.

In the mid-1990s, a major sociological study in London (Petrie et al, 2000), looked at how holiday play schemes included disabled children; the schemes ranged from a mainstream scheme where there was little effort to help disabled children to use the scheme fully, to a provider who had specialist premises that allowed non-disabled children to attend and incorporated activities to promote interaction between disabled and non-disabled children.

In Surrey, the AHDC commissioners are looking favourably on inclusive services for disabled children and a number of providers are introducing inclusion to their existing schemes. Also, legislation has encouraged mainstream providers to include disabled children in their out-of-school play schemes. Research indicates that play schemes interpret ‘inclusion’ in different ways and it is unclear on ‘inclusion’ is delivered by service providers. The study aims to address two questions:

What are the characteristics of a good ‘inclusive’ (integrated) play scheme?, in terms of staff, facilities, intentions, and parental and child perceived outcomes.

What are the characteristics and needs of the disabled child and their family who prefer and get perceived benefits from a segregated play scheme?

What are the characteristics and needs of the disabled child and their family who prefer and get perceived benefits from a integrated play scheme?
Appendix 1: Key Documents

   - **Looks at economics of investing in services to improve children’s well-being.**
   - **Includes consideration of children’s well-being in terms of ECM Outcomes.**
   - **Recommendations on joint working between NHS and LAs.**
   - **Surrey diversity Statistics.**
   - **Surrey diversity Statistics**
   - **Review of evidence on benefits of positive activities. Details gaps in evidence base.**
   - **It is unclear how ECM outcomes should be interpreted for disabled children. This research explored what outcomes disabled children and young people and their parents wish to achieve from service provision.**
   - **Well being index.**
• Well being index.
• Web-based progress maps for each review, which provide up-to-date evidence of current and emerging good practice.
• Postal questionnaire of 188 short break services in the UK in 2004/5.
• Details the goals, outcomes, aims, National Public Service Agreements (PSAs) and DCSF strategic objectives with National Indicators.
• Main report on government’s policies for children and vision for 2020.
• Informed the development of the IB pilots.
• Aims to provide evidence for DCSF policy for children 4-19 yrs in England. Examines the supply side of the Short Break market and its problems, including Play services.
• Consultation (including with children) on the future of Play for all children in the UK.
• Strategy for improving outside play space and facilities for all children in the UK.


35. DCSF & DH (2009), Healthy lives, brighter futures: the strategy for children and young people’s health.
- NHS Strategy for delivering on Children’s Plan vision, including short breaks.

36. DCSF & DH (2004), National Service Framework for Children, Young People and Maternity Services
- Lists the 11 national standards for improving children’s health between 2004 & 2014

37. DCSF & DH (2004), National Service Framework for Children, Young People and Maternity Services: Disabled Children and Young People and those with complex needs
- Details National Service Framework: Standard 8

- Guidance for LAs and PCT on delivery of Short Breaks Transformation programme. Details evidence for benefits of short breaks. Defines Full Service Offer (related to Core offer) on what a short break service should provide, service gaps, tool for costing social care processes.

39. DH (2009). Letters to Strategic Health Authority Chief Executives, Gateway Refs 11593 (2 Apr 09) & 12395 (21 Aug 09)
- DH requests for PCT statements (inc. Short Breaks).


- A Strategy to shape the future of children’s play across Guildford, for 3 -16 year olds.


- Originally due to publish questionnaire in Oct 2009 but delayed to 2010.

- Central government’s expectations on what SCC has to deliver and how it will be measured and monitored.

- Green paper on the future of children education, health and social services.

- Main report that outlines the AHDC objectives.


48. Kids (2009), FAQs about AHDC from those involved in the play pathfinder/playbuilder developments.
• Recommendations for linking these two funding schemes.


• Abstract Only: Survey of teachers, parents and staff at Saturday play scheme in Belfast.


• Recent study in London on social inclusion.


• Research review on play, including for inclusion.


• Consultation with children with complex health needs and their families, research review and survey of good practise in service provision.


• Patterns of usage and preference for different sorts of short breaks.


• Evaluates criteria for use and preferences of an adult short break scheme.


• Patterns of usage and preference for different sorts of short breaks.


• Review of evidence which services improve wellbeing in younger childrens. Details gaps in evidence base.


• Review of evidence which services improve wellbeing in younger childrens. Details gaps in evidence base.

58. Newman, T (2009), Disability Research Review 6. Ensuring all disabled children and young people and their families received services which are sufficiently differentiated to meet their diverse needs. C4EO & Barnardo’s Policy Research Unit.

• Review of evidence which services improve wellbeing in younger childrens. Maps priorities in improving services unto ECM Outcomes. Details gaps in evidence base.


60. NHS Confederation & EDCM (2009), ‘AHDC: delivering improved health services’.

• Reviews examples of current services that it believes meets users needs, responds to the government agenda and are effective from a quality and cost point of view. Includes The
Children’s Trust, Tadworth holiday play scheme and Kingston as an effective joint commissioning authority.


- Large study of summer play schemes in London


- Paper from the large study of summer play schemes in London above


- Reviews 4 pathfinder LAS who have linked short breaks and playbuilder funding and identifies key themes and recommendations.


- Sets out the government vision for improving life chance for disabled people by 2025. The recommendations were incorporated into government policy and are currently being taken forward through the Aiming High for Disabled Children programme. Include economic data breakdown – Individual Budget, Ordinary Life (Play), CAF.


- Literature review of costs and benefits of out-of-school care.

69. SCC & Surrey Children and Young People’s Commissioning Partnership, Surrey Children and Young People’s Plan 2009/10.

- Details the Priorities for children’s services in Surrey

70. SCC & Surrey Children and Young People’s Commissioning Partnership, Needs Analysis for Children with Complex Needs in Surrey.

- Informed commissioning of services for disabled children in Surrey. Included details of existing services at Appendix A (although it acknowledges that this is incomplete)


- The conference aimed to bring together some of the most influential and knowledgeable individuals and organisations involved in carrying out, funding and using research about children made vulnerable by disability, long-term health conditions, poverty or family crisis,
abuse and neglect. The conference focused on research over the next ten years and worked within the five outcomes of the Every Child Matters framework

75. Surrey Alliance, Surrey AHDC Short Breaks Programme Funding Guidance 2010-2011. Surrey County Council website:  
http://www.surreycc.gov.uk/sccwebsite/sccwplications.nsf/f2d920e015d1183d80256c670041a50b/54eb4a9f62dc6bbf802576480029399e/$FILE/AHDC%20Funding%20Guidance.doc


77. Surrey Alliance, AHDC Parent and Carer Questionnaire, April 2009.  
http://www.pwpsurrey.org/parent-and-carer-questionnaire.html

78. Surrey Alliance, AHDC Surrey, Children and Young People’s Short Breaks Questionnaire 2009.  
http://www.pwpsurrey.org/ahdc-introduction.html

• Children’s survey on what activities they want from short breaks.


• Found that Disabled children are not well represented in data.


• Reviews research literature related to respite care.


Appendix 2: Definitions

DISABILITY:

disability

‘A physical or mental impairment that has a substantial and long-term adverse effect on a person’s ability to carry out normal day-to-day activities’

Disability Discrimination Act (DDA) 1995

Note: disability is a broad concept as it covers all impairments and is open to wide interpretations; its usefulness is often questioned in the research literature.

disabled child

‘...blind, deaf or dumb or suffers from mental disorder of any kind, or is substantially and permanently handicapped by illness, injury or congenital or other such disability as may be prescribed’

Children Act 2004

The Social Model of Disability (increasingly used in policy and research)

Impairment is an injury, illness, or congenital condition that causes or is likely to cause a long-term effect on appearance and/or limitation of function of the individual.

Disability is the loss or limitation of opportunities to take part in society on an equal level with others due to social and environmental barriers

Impairments and chronic illness often pose real difficulties for disabled people but they are not the main problems. It is the ‘barriers’ that exist in society that create the main problems. The three main areas of barrier are:

- environment (including inaccessible buildings and services)
- attitudes (stereotyping, discrimination and prejudice)
- organisations which operate inflexible procedures and practices

Disabling barriers experienced in the past can continue to have an adverse effect. For example, disabled people who attended segregated schools may have gained lower academic qualifications than their non-disabled peers, because their ‘special’ school failed to provide a proper mainstream curriculum.


The Medical Model of Disability (traditionally used in policy and research)

The medical model is sometimes also known as the ‘personal model’. This is the traditional view that the inability of disabled people to fully participate in society is a direct result of having a disability, not a result of physical features of society. The individual is ‘impaired’ and the impairment is the problem to be overcome. This model relies on a strong notion of what is ‘normal’, thereby emphasising the ‘abnormality’ of impaired people.

This model is more likely to lead to the targeting of special welfare benefits, and the provision of segregated services for disabled people.
The focus of the medical profession is to alleviate the effects of impairments, and disabled people need to be treated and rehabilitated to enable them to participate more fully. This model suggests that disabled people should try, wherever possible, to live in the norms and patterns of mainstream society.


Inclusion
The meaning of inclusion is constantly evolving and the Council for Disabled Children (2008) have identified the following factors as being crucial:

‘being welcome; being part, not apart, going where you want to go; being actively involved, people expecting you; getting help when you need it’

Members of minority ethnic communities:
Black refers to a person of African, Caribbean or Asian origin.
Minority ethnic refers to a person who has a different ethnic origin from the majority community.
South Asian refers to a person originating from India, Pakistan or Bangladesh, and also to an East African migrant originating in the Indian subcontinent.
Disability Research Review 6 (Newman, 2009)

Outcomes
Considerable work has been carried out on defining this concept and how it should be interpreted. Within policy and service provision, it is often linked to the five Every Child Matters (ECM) outcomes: ‘be healthy, stay safe, enjoy and achieve, make a positive contribution and achieve economic wellbeing’.

Play: as widely accepted in the playwork field:
Freely chosen, personally directed and intrinsically motivated, i.e., performed for no external goal or reward

Playwork: (a relatively new concept and profession)
There were a number of definitions of Playwork within the evidence base that are used loosely and interchangeably:

‘working professionally with children’
‘a highly skilled profession that enriches and enhances children’s play’
‘the specific act of affecting the whole environment with the deliberate intention of improving opportunities for play’
‘a methodology i.e. distinct way of working with children – the art and science of facilitating children’s play’
‘ a service delivered by adults for children, either through people, places or a combination of both
Manwaring and Taylor, 2007
Play settings:
As there is huge diversity in service provision for children’s play, there is also diversity in the descriptions of Play Settings:

- settings primarily for play e.g. playgrounds, play centres and holiday play schemes.
- other non-play-specific settings e.g. hospitals, children’s homes, etc.
- outdoor environments where play is taken by play workers e.g. play rangers and mobile play provision.
- any out-of-school provision where play inevitably happens.

(Manwaring and Taylor, 2007)

Short breaks (formerly known as respite):
Short breaks usually provide opportunities for disabled children and young people to spend time away from their primary carers. These include day, evening, overnight or weekend activities and take place in the child’s own home, the home of an approved carer, or a residential or community setting. Short breaks can however also be provided through a temporary carer relieving the primary carer of their caring responsibilities without their being separated from the disabled child or young person. Short break provision is therefore fairly widely defined, and ranges from supporting disabled children and young people to access universal leisure-time services, through to providing specialist services. It can also include other forms of support for families such as direct payments.

DCSF definition used in Surrey Alliance, Surrey AHDC Funding Guidance

Wellbeing:
This is a multi-faceted and ambiguous concept that needs to distinguish between the concepts of adult and children’s wellbeing. Objective well-being refers to the material and social circumstances involved in well-being while subjective well-being is an individual’s self-assessment of their own well-being. Subjective well-being is often not measured for disabled children due to the challenges it presents to researchers but often it is the most important measurement.

(Office of National Statistic, 2009):

The NPC have listed a number of definitions of wellbeing as part of their work on developing a subjective well-being measure, e.g. well-being is multi-dimensional: it incorporates those aspects of life that we need to make us happy, including the physical, material and social; well-being is a positive concept, it is not merely the absence of negative aspects of life, such as illness or poverty, but must account for the presence of all the things one needs to lead a good life, such as good friendships and self-esteem.

(Nevill, 2009)

Well-being is about friends, also being healthy, independent and having a job, feeling safe and secure. We live in a very unequal society where some people have a lot, and too many people have too little. More well-being brings benefits to us as individuals and to society as a whole.

(Young Person’s Reference Group, Action for Children, 2009)
Appendix 3: Information Sources

Appendix 3.1: Visits to Service providers

There were 3 visits to Disability Challengers schemes:

- An initial visit to Guildford Challengers site to gain an overview of the play and leisure schemes provided in Surrey, the funding environment and the children and families who are helped by these schemes.
- A Saturday morning visit to the Guildford Play Scheme when the play workers and disabled children were attending to see how the children played and were looked after.
- A visit to 4 schemes, again on Saturday when all the schemes were open: Guildford Belllfields Youth Scheme, Epsom Play Scheme, Farnham Play Scheme and Farnham Youth Scheme. This gave the opportunity to see how play schemes operate in other premises, in a primary school building (Epsom) and a purpose built facility (Farnham).

A weekday visit (2-3 hrs) was made to the following residential short break providers (when no children were present) to gain an overview of the services offered and the environment the charities operates in:

- Cherry Trees in East Clandon, outside Guildford
- White Lodge in Chertsey
- The Children's Trust in Tadworth

Informal conversations with Service Providers who had stands at SCC AHDC Fun Day (March 2010):

- YMCA (Reigate & Redhill)
- Whizz-kidz

Appendix 3.2: Key Informants

The following key informants were interviewed about local services and their commissioning in Surrey:

- Sandy Thomas, Commissioning & Development Manager for AHDC, SCC
- Kathryn Winfield, Play Builder Project Manager, SCC
- Phil Olsborne, Head of Service, Early Years and Childcare Service, SCC (email only)
- Chris Hunt, Chair of Surrey Chief Leisure Officers Group (Surrey Districts & Boroughs)
- Jo James, Play Development Officer, GBC (email & telephone)
- Jean Roberts-Jones, Chief Executive, Surrey Community Action (Voluntary, Community & Faith Sector)
- Pauline Searle, Mayor of Guildford and local Councillor (GBC & SCC); Trustee of Disability Challengers
- Margaret Ward, Chief Executive, Disability Challengers, Guildford
- Jonathan Dobson & Laura Baxter, Disability Challengers, Guildford
- Peter Davey, Cherry Trees, Guildford
- Lesley Robbins & Marsha Wallace, Treetops Coordinator, White Lodge, Chertsey
- Rosie Andrews, Director of Development and Strategy & staff, The Children's Trust, Tadworth
Within the timescales of the scoping study, it was not possible to arrange meetings with the following key stakeholders:

- NHS Surrey – AHDC commissioners
- SCC Director of Children’s Services
- SCC Cabinet Member for Children and Young People
- Guildford MP
- Guildford Diocese Youth team
- Borough and Districts Play Co-ordinators

Appendix 3.3: Organisations identified in the scoping study

Government Departments involved in policy for disabled children

- Prime Minister’s Strategy Unit (PMSU)
- HM Treasury
- Department for Children, Schools & Families (DCSF)
- Department of Culture, Media & Sport (DCMS)
- Department of Health (DH)
- Audit Commission
- Inspectorates (OFSTED)
- Office for National Statistics

NGOs / Charities

- Action for Children
- Big Lottery
- Barnardo’s (poverty & social exclusion)
- BBC Children in Need
- Contact a Family (parent’s support network & Surveys)
- Council for Disabled Children
- Care Coordination Network UK (CCNUK)
- Disability Movement in Britain (UPIAS, 1976)
- Fair Play for Children
- Family Fund (grants to families with disabled children)
- London Play
- MENCAP
- National Autistic Society
- National Children’s Bureau
- NSPCC
- Play England
- Relate
- Save the Children
- Shared Care Network (short breaks)
- SCOPE
- Triangle (communication for disabled children)
- Together for Disabled Children (TDC) (AHDC partnership)
- UK Disabled People Council
Local organisations (Surrey)

- Carersnet  [www.carersnet.org.uk](http://www.carersnet.org.uk)
- Partnership with Parents (PwP) (with SCC)  [www.pwpsurrey.org](http://www.pwpsurrey.org)

Research Bodies

- Centre for Excellence and Outcomes in Children and Young People’s services (C4EO)
- Children’s Legal Centre
- Every Disabled Child Matters (EDCM)
- Joseph Rowntree Foundation
- New Economic Foundation (NEF)
- New Philanthropic Capital – What price an ordinary life?
- OnePlusOne
- Research in Practise
- Social Care Institute for Excellence (SCIE)
- Tavistock Centre
- The Children’s Fund
- The Special Needs Consultancy
- Treehouse

Universities

- University of Birmingham – Institute of Applied Social Studies
- University of Bristol – Dept. of Community Based Medicine & Norah Fry Institute
- Lancaster University – Centre for Disability Research (CeDR)
- University of Kent – The Tizard centre (P. McGill)
- University of London – Thomas Coran Institute (P.Petrie)
- University of Manchester – School of Nursing, Midwifery and Social Work
- Queen’s University of Belfast – Institute of Child Care Research
- University of Sussex – Social Work, Social Care & Social Policy
- University of Ulster – Institute of Nursing Research (R.McConkey)
- University of York - Social Policy Research Unit (B.Beresford)

Online Research Websites

- [www.intute.ac.uk](http://www.intute.ac.uk)  Research database that includes government documents
- [www.ark.ac.uk](http://www.ark.ac.uk)  Office of the First Minister & Deputy First Minister (NI)
- [www.scotland.gov.uk/topics/research](http://www.scotland.gov.uk/topics/research)  Scottish Executive
Appendix 4: Overview of gaps in research evidence base from C4EO Disability Reviews

Overall Factors Impacting: Poverty, Bad Housing, Social Exclusion, Lack of Services

Focus area for Study

Each age band - a different study

0-4
13-15
16-18
18-25

Preschool Services
Children Services: Medical Educational Therapeutic Leisure: Sport, Play ...

Outcomes
Disabled Child (e.g. Surestart)

Family Services
Family Support Services: Information, Support Groups, ...
Short Breaks (Overnight - Hospital, Residential, Carer Service at home/carer’s home;
Non-residential - holiday play schemes (some residential), play & leisure schemes, after-school clubs, buddy schemes)

Longitudinal Studies (for intermediate and long-term Outcomes)

Short Break Play and Leisure Services
- holidays in residential home, holiday play schemes in special premises or in mainstream premises, play/leisure schemes at special premises or at school premises

- segregated v Integrated Mainstream v Specialist...

Outcomes
Play & Leisure Service Outcomes
- ‘disabled child’ hierarchical OUTCOMES

- Physical Wellbeing
- Psychological Wellbeing
- Belonging
- Enjoyment: Excitement / Risk
- Social Outcomes: friendships (loyalty, & intimacy), self-identity
- Emotional support, Success
- Skills and Learning (sport, social, life skills e.g. decision making)
- Part of Community Participation in decisions

- ‘family’ Outcomes
- Stress (less depression)
- Self-efficacy
- Relationships (less breakdown)
- Improved financial basis – Allow parents to work
- less poverty
- Friendships & social network (less isolation, exclusion);
- Sibling school behaviour & academic success
- Fathers: emotional needs Siblings: aspirations

- Effectiveness & Outcomes (i.e. Cost-effectiveness)

- Professionals’ Outcomes

- Views on OUTCOMES

- Disabled Child, esp. those with communication impairments
- Carer(s)
- Professionals

1. What do disabled children do outside school? (SURVEY)
2. What types of services are needed to provide for all levels of need?
3. How long do the benefits of interventions last?
4. What do ECM Outcomes from positive activities mean in practice?
5. Definition of terms e.g. Inclusion, Outcomes etc.

KEY:
Purple = focus areas for research
Red = gaps in research evidence
## Appendix 5: Mapping of local services in Surrey

### Information Sources for Service Mapping (Jan – Mar 2010)

<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
<th>Website</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surrey AHDC Newsletters Partnership with Parents (PWP)</td>
<td>Autumn 2009 &amp; Winter 2009 Providing information, advice and support to parents of children with SEN at all stages of their child’s school life, from pre-school early diagnosis through to school leaving at 16 or 19 and for those with learning difficulties and/or disabilities to 25 (funded by SCC)</td>
<td><a href="http://www.surrey.gov.uk">www.surrey.gov.uk</a> <a href="http://www.pwpsurrey.org">www.pwpsurrey.org</a></td>
</tr>
<tr>
<td>Surrey Family Information Directory</td>
<td>SCC Information on services for families in Surrey - search on &quot;disabled children&quot; within Categories “Childcare” or “special needs” and “Things to do” produces a range of information resources, both printed and online, for disabled people in Surrey and beyond.</td>
<td><a href="http://parentknowhow.surreycc.gov.uk/fsd/start.jsp">http://parentknowhow.surreycc.gov.uk/fsd/start.jsp</a></td>
</tr>
<tr>
<td>Ask SID (Social Information on Disability)</td>
<td>Information on Living with a Disability in Surrey contains information on facilities in Surrey and beyond, which are available to individuals with a wide range of special or additional needs</td>
<td><a href="http://www.asksid.org.uk">www.asksid.org.uk</a></td>
</tr>
<tr>
<td>Ask ENID</td>
<td></td>
<td><a href="http://www.asksid.org.uk">www.asksid.org.uk</a></td>
</tr>
<tr>
<td>Short Term Breaks</td>
<td></td>
<td><a href="http://www.asksid.org.uk">www.asksid.org.uk</a></td>
</tr>
<tr>
<td>Shared Care Network</td>
<td>promotes family-based short breaks for disabled children and young people throughout Northern Ireland, England and Wales</td>
<td><a href="http://www.sharedcarenetwork.org.uk">www.sharedcarenetwork.org.uk</a></td>
</tr>
<tr>
<td>Surrey Community Action</td>
<td>offers advice, support and information to both voluntary and community groups</td>
<td><a href="http://www.surreyca.org.uk">www.surreyca.org.uk</a></td>
</tr>
<tr>
<td>Challenging Behaviour Foundation</td>
<td>Aims to see children with challenging behaviour, having the same life opportunities as everyone else, including home life, education, employment and leisure.</td>
<td><a href="http://www.thecbf.org.uk">www.thecbf.org.uk</a></td>
</tr>
<tr>
<td>Special Olympics Surrey</td>
<td>Special Olympics offers children and adults with learning disabilities the opportunity to develop physical fitness, learn new skills, make new friends and have fun</td>
<td><a href="http://www.sosurrey.org.uk">www.sosurrey.org.uk</a></td>
</tr>
<tr>
<td>SPREAD - Sport and Recreation Information for Disabled people in Surrey</td>
<td>Umbrella organisation for all disabled clubs in Surrey. No further investigation was carried out sports clubs.</td>
<td>No website; <a href="mailto:derek@bazmail.net">derek@bazmail.net</a></td>
</tr>
<tr>
<td>Active Surrey</td>
<td>Active Surrey is one of a network of 49 County Sports Partnerships (CSP) in England with a vision is to make Surrey a more active and successful sporting county.</td>
<td><a href="http://www.activesurrey.com">www.activesurrey.com</a></td>
</tr>
<tr>
<td>Districts and Boroughs in Surrey</td>
<td>Some of these run play &amp; leisure schemes in the school holidays but not possible to check all the websites and contact organisers to check the facilities and activities for disabled children.</td>
<td>See Appendix 5.1 below</td>
</tr>
<tr>
<td>Royal Borough of Kingston; other neighbouring boroughs and counties to Surrey not checked</td>
<td>Holiday schemes run by this borough need referral from their own social services; schemes run by voluntary organisations (e.g. YADAPA Art workshops in New Malden) may be open to Surrey residents</td>
<td><a href="http://www.kingston.gov.uk/holiday_playschemes.pdf">http://www.kingston.gov.uk/holiday_playschemes.pdf</a></td>
</tr>
<tr>
<td>EnhanceAble disabled Children's Information &amp; Advice Service (provided by Charity in Partnership with Kingston PCT and Royal Borough)</td>
<td>EnhanceAble provide a number of services for disabled adults and children in Kingston upon Thames and the surrounding areas (Inc. Elmbridge). Services include: an outreach service, an advice and information service for children, the Parent Partnership Officer for disabled children, an equipment loan scheme for children, a residential home.</td>
<td><a href="http://www.enhanceable.org">www.enhanceable.org</a></td>
</tr>
<tr>
<td>Google search: “holiday day camps surrey”</td>
<td>Only the top four mainstream summer camp companies were used.</td>
<td>N/A</td>
</tr>
</tbody>
</table>

The list of short break and play and leisure service providers in Surrey are held as a separate spreadsheet.
Appendix 5.1: Surrey Boroughs & Districts: Inclusive, segregated and integrated schemes

Holiday Play Schemes: some Borough & District councils in Surrey offer holiday schemes for all children:
- Elmbridge Borough Council
- Guildford Borough Council
- Woking Borough Council
- Runnymede Borough Council
- Tandridge Leisure Ltd (leisure trust now independent from the District Council)
- Reigate & Banstead Council

Inclusive and Segregated Schemes:
- Runnymede Borough Council and Elmbridge BC offer inclusive holiday play schemes.
- Mole Valley and Waverley run inclusive activities for the activity days delivered by their play rangers (funded by the BIG lottery and this will cease in the current financial year 2010/11).
- Woking BC offer a scheme, based at the leisure centre, and other specific courses at different locations.
- Tandridge Leisure ltd offer holiday schemes and some of these are specifically for children with disabilities.

In addition, many District and Borough Councils offer one day/week-long holiday activities through leisure services or their play ranger services (not always managed by leisure and not always “play”) and some are delivered by other organisations, such as theatres, sports & leisure centres and museums:
- Elmbridge Borough Council
- Guildford Borough Council
- Mole Valley District Council
- Reigate & Banstead Borough Council
- Runnymede Borough Council
- Surrey Heath Borough Council (via parks, leisure centres & Camberley theatre)
- Spelthorne BC promote schemes organised by other bodies and Spelthorne offer a voucher scheme to support children with disabilities and those on low incomes or vulnerable for other reasons on some schemes.
- Epsom & Ewell do not offer play schemes directly, although they do organise, or work with local partners to develop, a number of targeted activities that are mainly sports related and a number of these are aimed at, or include, children with disabilities.
## Appendix 5.2: Playbuilder Schemes in Surrey

<table>
<thead>
<tr>
<th>Scheme Name</th>
<th>Location</th>
<th>Year 1 (2009/2010)</th>
<th>Year 2 (2010/2011)</th>
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</thead>
<tbody>
<tr>
<td>Roman Way, Farnham</td>
<td>Waverley BC</td>
<td></td>
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<tr>
<td>Byfleet recreation ground</td>
<td>Woking BC</td>
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<tr>
<td>Frank Muir Field, Thorpe</td>
<td>Runnymede BC</td>
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<tr>
<td>Frimley Lodge Park</td>
<td>Surrey Heath BC</td>
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<tr>
<td>Chessington Road rec, Ewell</td>
<td>Epsom &amp; Ewell BC</td>
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<tr>
<td>Stafford Road rec, Caterham</td>
<td>Tandridge DC</td>
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<tr>
<td>Grange Meadow, Bletchingley</td>
<td>Tandridge DC</td>
<td></td>
<td></td>
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<tr>
<td>Horton Road rec, Stanwell</td>
<td>Spelthorne BC</td>
<td></td>
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<tr>
<td>Nuthatch Close, Stanwell</td>
<td>Spelthorne BC</td>
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<tr>
<td>Lakeside nature reserve, Ash</td>
<td>Guildford BC</td>
<td></td>
<td></td>
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<tr>
<td>Merstham</td>
<td>Reigate &amp; Banstead BC</td>
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<td></td>
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<tr>
<td>Peakfield, Frensham</td>
<td>Waverley BC</td>
<td></td>
<td></td>
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<tr>
<td>West Byfleet recreation gr</td>
<td>Woking BC</td>
<td></td>
<td></td>
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<tr>
<td>Elm Grove, Walton</td>
<td>Elmbridge BC</td>
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<tr>
<td>Grovelands, Molesey</td>
<td>Elmbridge BC</td>
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<tr>
<td>Sayes Court, Addlestone</td>
<td>Runnymede BC</td>
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<tr>
<td>Old Dean rec, Camberley</td>
<td>Surrey Heath BC</td>
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<tr>
<td>Merland Rise, Preston</td>
<td>Reigate &amp; Banstead BC</td>
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<tr>
<td>Redhill YMCA</td>
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<tr>
<td>Jenners' Field, Lingfield</td>
<td>Tandridge DC</td>
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<tr>
<td>Groveley Park, Ashford</td>
<td>Spelthorne BC</td>
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<tr>
<td>Westborough Woods, Westborough</td>
<td>Guildford BC</td>
<td></td>
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<tr>
<td>Gibraltar Road rec, Ewell</td>
<td>Epsom &amp; Ewell BC</td>
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<tr>
<td>Ashtead rec</td>
<td>Mole Valley DC</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meerbank, Beare Green</td>
<td>Mole Valley DC</td>
<td></td>
<td></td>
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</tbody>
</table>