

National policy drivers

Statutory:

The Disability Discrimination Act (DDA) 2005 describes disability as "a physical or mental impairment which has a substantial and long-term adverse effect on [a person's] ability to carry out normal day-to-day activities." The purpose of the DDA is to introduce and extend laws aimed at ending discrimination against disabled people and within the 2005 revised Act disabled people now also have rights in the areas of:

- **employment** – Employers may not discriminate against disabled employees or job applicants and must take reasonable steps to alleviate physical barriers to work.
- **education** – The DDA builds on existing legislation in which education providers must provide mainstream placements for children with disabilities, subject to the wishes of their parents, providing that the placement is appropriate to the needs of the child; does not conflict with the interests of other children in the school; and is an efficient use of resources. Schools must report back on the facilitation and equal opportunity provided to children with disabilities (DLF, 2006).
- **access to goods, facilities and services** - all organisations that provide goods, services or facilities to the general public must offer a service to disabled people equal to that offered to non-disabled people. This covers access to transport infrastructure.
- **buying or renting land or property**, including making it easier for disabled people to rent property and for tenants to make disability-related adaptations. For example, it is unlawful to charge a disabled person a higher deposit on rented accommodation; or to refuse him/her accommodation on the grounds of disability (DLF, 2006).
- **functions of public bodies**, e.g. issuing of licenses - public bodies must promote equality of opportunity for disabled people. This also covers setting of minimum standards so that disabled people can use public transport easily (Direct Gov, 2010b). For example, from 2005, all new buses and coaches must be wheelchair accessible (DLF, 2006).

The statutory guidance **Duty to provide information, advice and assistance: Guidance for local authorities (DCSF, Feb 2008)** informs local councils how to implement section 12 of the Childcare Act 2006. Councils should

- provide parents of children with disabilities and children with special educational needs with information on the services, facilities and publications that are available to them
- facilitate access to information for parents who might otherwise find it difficult to take up the services they need.

Chapter 6 of this guidance focuses particularly on information for parents of children with disabilities and annex 3 provides more detail on the type of information which should be provided

SEN Code of Practice

The SEN Code of Practice provides practical advice to Local Education Authorities, maintained schools, early education settings and others on carrying out their statutory duties to identify, assess and make provision for children's special educational needs

Fundamental Principles

1:5 The detailed guidance in this Code is informed by these general principles and should be read with them clearly in mind:

- _ a child with special educational needs should have their needs met
- _ the special educational needs of children will normally be met in mainstream schools or settings¹
- _ the views of the child should be sought and taken into account
- _ parents² have a vital role to play in supporting their child's education
- _ children with special educational needs should be offered full access to a broad, balanced and relevant education, including an appropriate curriculum for the foundation stage and the National Curriculum.

CHILDREN ACT 1989

PART III LOCAL AUTHORITY SUPPORT FOR CHILDREN AND FAMILIES

Provision of services for children and their families

17 Provision of services for children in need, their families and others

(1) It shall be the general duty of every local authority (in addition to the other duties imposed on them by this Part)—

(a) to safeguard and promote the welfare of children within their area who are in need; and

(b) so far as is consistent with that duty, to promote the upbringing of such children by their families,

by providing a range and level of services appropriate to those children's needs.

(10) For the purposes of this Part a child shall be taken to be in need if—

(a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority under this Part;

(b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or

(c) he is disabled,

and "family", in relation to such a child, includes any person who has parental responsibility for the child and any other person with whom he has been living.

Equalities Act 2010

Provision of services, etc.

(1) A person (a "service-provider") concerned with the provision of a service to the public or a section of the public (for payment or not) must not discriminate against a person requiring the service by not providing the person with the service.

(2) A service-provider (A) must not, in providing the service, discriminate against a person (B)—

(a) as to the terms on which A provides the service to B;

(b) by terminating the provision of the service to B;

(c) by subjecting B to any other detriment.

(3) A service-provider must not, in relation to the provision of the service, harass—

(a) a person requiring the service, or

(b) a person to whom the service-provider provides the service.

(4) A service-provider must not victimise a person requiring the service by not providing the person with the service.

(5) A service-provider (A) must not, in providing the service, victimise a person (B)—

(a) as to the terms on which A provides the service to B;

(b) by terminating the provision of the service to B;

(c) by subjecting B to any other detriment.

(6) A person must not, in the exercise of a public function that is not the provision of a service to the public or a section of the public, do anything that constitutes discrimination, harassment or victimisation.

(7) A duty to make reasonable adjustments applies to—

(a) a service-provider (and see also section 55(7));

(b) a person who exercises a public function that is not the provision of a service to the public or a section of the public.

(8) In the application of section 26 for the purposes of subsection (3), and subsection (6) as it relates to harassment, neither of the following is a relevant protected characteristic—

(a) religion or belief;

(b) sexual orientation.

(9) In the application of this section, so far as relating to race or religion or belief, to the granting of entry clearance (within the meaning of the Immigration Act 1971), it does not matter whether an act is done within or outside the United Kingdom.

(10) Subsection (9) does not affect the application of any other provision of this Act to conduct outside England and Wales or Scotland.

The new short breaks duty (EDCM briefing)

The Children and Young Persons Act 2008 adds the provision of short breaks for those who care for children with disabilities, by amending Schedule 2 of the 1989 (Children) Act so that it reads: 'every local authority (England and Wales) shall provide services designed to assist individuals who provide care for such children (ie children with disabilities) to continue to do so, or to do so more effectively, by giving them breaks from caring.'

The Children and Young Persons Act became law on 13 November 2008, when it received Royal Assent. However, most of the Act, including these key sections for children with disabilities, is not yet in force. The government has the power to bring these sections into force by making 'regulations'. EDCM understands that the regulations relating to short breaks will be made in time for 2011, when the short breaks funding from 'Aiming High for Children with disabilities'² is at its highest. The date when the government intends to bring into force the

duties to support children with disabilities placed away from home has not yet been confirmed.

Children's Act 1989 / Schedule 2: Local Authority Support for Children and Families / Part 1: Provision of Services for Families / Paragraph 2:

- (1) Every local authority shall open and maintain a register of children with disabilities within their area
- (2) The register may be kept by means of a computer

The official guidance and regulations to the Act state the following:

Registration of Children With Disabilities

2.19. The Act also continues but separates out the requirement placed on local authorities to keep registers of children with disabilities in their area (Schedule 2 paragraph 2). This provision, which is designed to help their service planning and monitoring, originated from directions made under the National Assistance Act 1948 in relation to disabled persons; if the register is to be of maximum use and benefit it has to be complete and avoid duplication with other registers. It is suggested that local authorities in conjunction with local education authorities and health authorities draw up a common register to assist collaboration and for use in their respective areas of responsibility. Local authorities should try to establish a system, particularly with local education and health authorities, for identifying the number and needs of children in their areas who are disabled through physical, sensory or mental disablement, mental disorders and chronic illness so that they may jointly plan their services for the short and long term. Registration is voluntary on the part of parents and children and not a precondition of service provision, but local authorities, in collaboration with health authorities, local education authorities and voluntary agencies in their area, need to publicise widely and positively the existence and purpose of registers to relevant professionals, parents and young people. The publicity should stress the usefulness of the register as an aid to planning the right level and mix of local services to help parents with children with disabilities. In the longer term, the register will also assist in planning services for when the children become adults. Registration should be encouraged for these reasons and on the grounds that it may improve access to other agency resources such as those provided in the voluntary sector and financial benefits such as social security benefits, tax relief (if registered blind) or assistance with text telephones (if registered deaf). Efforts made to keep accurate and comprehensive registers and to encourage registration will help to ensure that children with disabilities gain access to the services for which the Act makes provision.

A local education authority must arrange for the parent of any child in their area with special educational needs to be provided with advice and information about matters relating to those needs. LEAs must take whatever steps they consider appropriate to make parent partnership services known to parents, head teachers, schools and others they consider appropriate.

From Section 332A, Education Act 1996

SEN Code of Practice Chapter 2

2:16 All LEAs **must** make arrangements for parent partnership services. It is essential that parents are aware of the parent partnership service so that they know where they can obtain the information and advice they need. LEAs **must** therefore inform parents, schools and others about the arrangements for the service and how they can access it. LEAs **must** also remind parents about the parent partnership service and the availability of disagreement resolution services at the time a proposed statement or amendment notice is issued (see Chapter Eight).

2:17 LEAs do not necessarily have to provide a parent partnership service themselves. They may provide an entirely LEA-based parent partnership service if they wish, or 'buy-in' the service from another provider, or they may choose a mix of the two. In establishing parent partnership services, LEAs are encouraged to work with voluntary groups and organisations to deliver the services which best meet the needs of parents. Where the service is provided 'in-house', LEAs are encouraged to nevertheless ensure they are run at arms' length to ensure parental confidence. However the service is provided, LEAs should meet the **minimum standards** set out below.

2:18 In delivering effective parent partnership services LEAs are expected to:

- _ take responsibility for setting and monitoring the overall standard of the service
- and ensure it is subject to Best Value principles

- _ set out their funding and budgeting plans for the service (where appropriate the budget should be delegated to the parent partnership service)
 - _ ensure adequate resources and staffing to meet the needs of the parents in their area
 - _ ensure appropriate management structures for the service
 - _ ensure that the service has a development plan which sets out clear targets and is regularly reviewed; such plans should specify short, medium and long term strategies and arrangements for evaluation and quality assurance
 - _ ensure that the service is flexible and responsive to local changes
 - _ ensure that parents and schools are provided with clear information about the parent partnership service, and about the various other sources of support in their area, including statutory and voluntary agencies
 - _ ensure that the service is provided with accurate information on all SEN processes as set out in the Education Act 1996, relevant Regulations, the SEN Code of Practice and relevant information about the Disability Discrimination Act 1995
 - _ ensure, where the service is provided in-house, that the staff receive appropriate initial and ongoing training and development to enable them to carry out their role effectively
 - _ establish, where the service is outsourced either wholly or partially, a service level agreement for delivering the service which ensures sufficient levels of resources and training, and clearly set out the quality standards expected of, and the responsibilities delegated to, the provider
 - _ have, irrespective of whether it is outsourced or provided in-house, appropriate arrangements for overseeing and regularly monitoring and reviewing the service, taking account of best practice both locally and nationally
 - _ develop co-operative arrangements with the voluntary sector to ensure the mutual exchange of information and expertise
 - _ *promote and facilitate arrangements for the service to work in partnership with other agencies such as health and social services, using local planning structures such as the Education Development Plan, Early Years Development and Childcare Plan, Connexions Plan and Children's Service Plan.*
- Provisions under the Health Act 1999 allow LEAs and health and social services to pool*

budgetary and management resources; such arrangements might therefore

include the provision of joint information services

_ actively seek feedback from the service and service users to inform and influence

decisions on SEN policies, procedures and practices in order to improve communications and minimise the potential for misunderstandings and disagreements.

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2:19 *The aim of parent partnership services is to ensure parents of children with additional needs – including the very young – have access to information, advice and guidance in relation to the special educational needs of their children so they can make appropriate, informed decisions. The service should provide advice to the parents of all children with special educational needs not only those with statements. The prime role of parent partnership services is to help parents whose children have been identified as having special educational needs. However, there will be cases where parents believe that their child has special educational needs, but the school takes a different view. Parent partnership services should be flexible in their approach and handle such cases sensitively and sympathetically. They should consider parents' concerns carefully, try to help and support parents who want information, and not dismiss out of hand any enquiries for assistance or information.*

2:20 *Parent partnership services are expected to provide a range of flexible services, including access to an Independent Parental Supporter for all parents who want one, and referral to other agencies, voluntary organisations or parent support groups, which can offer advice and support. However, such referrals should only be made when there is prior agreement with the parent, and with the organisation or support group concerned about the nature and level of the service to be offered.*

2:21 *An effective parent partnership service is expected to meet the following **minimum standards** and ensure:*
_ the provision of a range of flexible services including using their best endeavours

to provide access to an Independent Parental Supporter for all parents who want one

- _ that practical support is offered to parents, either individually or in groups, to help them in their discussions with schools, LEAs and other statutory agencies
- _ that parents (including all those with parental responsibility for the child) are provided with accurate, neutral information on their rights, roles and responsibilities within the SEN process, and on the wide range of options that are available for their children's education
- _ that parents are informed about other agencies, such as Health Services, Social Services and voluntary organisations, which can offer information and advice about their child's particular SEN. This may be particularly important at the time the LEA issues a proposed statement
- _ that, where appropriate and in conjunction with their parents, the ascertainable views and wishes of the child are sought and taken into consideration
- _ that information about the available services is publicised widely in the area using a variety of means
- _ the provision of neutral, accurate information for parents on all SEN procedures as set out in SEN legislation and the SEN Code of Practice
- _ the interpretation of information published by schools, LEAs and other bodies interested in SEN
- _ that a wide range of information for parents is available in community languages, and to parents who may not be able to gain access to information through conventional means
- _ that advice on special educational needs procedures is made available to parents through information, support and training
- _ they use their best endeavours to recruit sufficient Independent Parental Supporters to meet the needs of parents in their area, including arrangements for appropriate training, ensuring that they are kept up to date with all relevant aspects of SEN policy and procedures so that they can fulfil their role effectively

- _ that training on good communication and relationships with parents is made available to teachers, governors and staff in SEN sections of the LEA
- _ they work with schools, LEA officers and other agencies to help them develop positive relationships with parents
- _ they establish and maintain links with voluntary organisations
- _ that parents' views are heard and understood, and inform and influence the development of local SEN policy and practice the regular review of the effectiveness of the service they provide, for instance by seeking feedback from user

Other guidance

In the UK the main driver for meeting the needs of children and young people with disabilities is Every Child Matters (ECM), which aims to ensure the child can develop, be happy and achieve their full potential via 5 ECM goals:

- enjoyment and achievement,
- being healthy,
- staying safe,
- making a positive contribution and
- achieving economic wellbeing (ECM, 2003).

The National Service Framework (NSF) for Children, Young People and Maternity Services sets out eleven standards for promoting the health and well-being of children and young people and for providing high quality services that meet their needs. Standard 8 of the NSF specifically addresses the needs of Children with disabilities and Young People and those with Complex Health Needs. This standard includes children and young people with learning disabilities, autistic spectrum disorders, sensory impairments, physical impairments and emotional/behavioural disorders (DES, 2004c). Children with complex health needs are defined as either children with severe and multiple impairments or children who require support from a complex network of agencies (C4EO, 2009b). Within this document the term 'children with disabilities' refers to children and young people who are disabled and/or those with complex health needs. Standard 8 states that:

Children and young people who are disabled or who have complex health needs receive co-ordinated, high-quality child and family-centred services which are based on assessed needs, which promote social inclusion and, where possible, which enable them and their families to live ordinary lives. (DES, 2004c)

The Valuing People White Paper (2001) defined Learning disability as:

"A person is considered to have a learning disability if he or she has a significantly reduced ability to understand new or complex information or to learn new skills, together with a reduced ability to cope independently. These problems will have started before adulthood and have had a lasting effect on the person's development. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence – such as some people with Asperger's Syndrome (DoH, 2001).

From this the Government have developed a "core offer" package which involves access to appropriate information at all stages of life,

transparency in support services with eligibility criteria clearly communicated, and involvement of children with disabilities and their families in the development of services. The health elements will involve signposting health care and support that is available for children with disabilities and complex health needs. Assessment processes will be integrated with shared information and the Common Assessment Framework (CAF) 'providing a gateway to more specialist assessments where necessary and more high level multi-agency assessments provided in the same place at the same time'. Service users will be given the necessary avenues for feedback and complaints procedures (DfES, 2004c).

ECM guidance is supported by Aiming High for the Disabled Child (AHDC) which seeks to ensure government development and investment for:

- improving access and empowerment – including developing a core offer incorporating minimum standards of information, transparency, assessment and feedback; enabling choice and control by developing individual budgets; and disseminating good practice.
- improving the responsiveness and timeliness of services and support – including developing a national indicator; evaluating and benchmarking good practice; more accurate data collection; continuation of the Early Support Programme for all children with disabilities aged 0-5; establishing a Transition Support Programme.
- improving quality and capacity – including allocation of specific grants to enable short breaks; providing accessible childcare and improved development; maximising opportunity for independence through equipment provision; commissioning the Children's Workforce Development Council to identify the gaps and barriers to improving the accessibility of universal services for children with disabilities (AHDC: better support for families, 2007).

The EDCM developed two charters, one for local authorities and one for PCTs. While it is not a statutory requirement to sign up to the charter, it has become an expectation in the Government's "Aiming High for Children with disabilities" programme and a significant number of PCTs and local authorities have signed up to it. In July 2009 NHS Brighton and Hove formally signed the Every Disabled Child Matters charter which is based upon Standard 8 of the National Service Framework for Children. This charter commits NHS Brighton and Hove to providing a range of services for children with disabilities and their families, and to addressing the needs of children with disabilities in strategic planning and local area agreements. There are nine areas for development and service improvement which NHS Brighton and Hove has pledged to address in the city, and these are monitored by the Children with disabilities's Strategic Partnership Board:

- We know how many children with disabilities live in our area and that we are planning future services on the basis of this knowledge.
- We have an identified children's lead with specific responsibility for services for children with disabilities and families.
- We can demonstrate that we work closely with our local authority partners and have had an input into all the Children and Young People's Plans in our area and are members of all relevant Strategic Partnership Boards.
- All staff have received disability equality training and training to ensure that they have core competencies to work with children with disabilities; relevant staff have received specialist training and other staff know how to contact them.
- Parents, young people and carers in our area are getting accurate and timely information and advice on the services available to them.
- Children with disabilities are involved in drawing up our Disability Equality Scheme and monitoring its effectiveness in eliminating discrimination, including involvement in the planning, commissioning and monitoring of health services in our area.
- We are working to reform our community equipment and wheelchair service to improve the quality of the equipment available, and to address the holistic and changing needs of children and young people in a timely way.
- We are commissioning comprehensive specialist medical, nursing and therapy services for children with palliative care and complex health needs, and are working with all commissioners and local authorities in our area to integrate these services into wider children's services.
- We can demonstrate an effective partnership with disabled young people and adult service providers in our area to ensure a smooth transition to adult services for disabled young people (NHS Brighton and Hove, 2009).

The implementation of the 9 areas within the EDCM PCT charter will contribute towards achieving world class commissioning (WCC) and the Tier 3 vital sign on improving the experience of services for children with a disability and their families. This charter logically overlaps significantly with the Local Authority EDCM charter objectives that:

- We know how many children with disabilities live in our area and that all agencies in our area are planning services based on this knowledge
- There is a key worker service in our authority providing support to families who are accessing more than one specialist service

- Our parent partnership service is sufficiently resources to provide advice, information and support to parents of children with disabilities and young people who have been excluded from school
- Parents and carers in our area are getting accurate and timely information and advice on the full range of services available to them and their families
- All staff have received both disability equality training and training to ensure they have core competencies to work with children with disabilities; relevant staff have received specialist training and other staff know how to contact them for information
- Children with disabilities are involved in drawing up our Disability Equality Scheme and also in monitoring its effectiveness in eliminating discrimination
- Our Children and Young People's Plan explains how we will provide specialist services and also make all universal services including extended schools and children's centre accessible to children with disabilities
- Our Local Area Agreement includes targets for the level of service to be delivered to families with a disabled child
- Children with disabilities and families are involved in the planning, commissioning and monitoring of services in our area, including both specialist and universal services (NHS Brighton and Hove, 2009).

The Every Child Matters: Change for Children programme aims to put in place a national framework to support the joining up of services so that every child can achieve the five Every Child Matters outcomes.

The ten key elements of the national framework are:

1. The duty to cooperate to promote the well-being of children and young people
2. The duty to make arrangements to safeguard and promote the welfare of children and young people
3. The development of statutory local safeguarding children boards (LSCBs) to replace non-statutory area child protection committees (ACPCs)
4. The appointment of local directors of children services

5. The National Service Framework for Children, Young People and Maternity Services
6. The Outcomes Framework
7. The development of an integrated inspection framework
8. The appointment of a Children's Commissioner
9. The development of a Common Assessment Framework
10. Workforce reform to help develop skills and ensure staffing levels

Social services play a central role in trying to improve outcomes for the most vulnerable and a key measure of success will be achieving change through closing the gap between their outcomes and those of the majority of children and young people.

Core Offer Implementation Materials DCSF

The statutory guidance *Duty to provide information, advice and assistance: Guidance for local authorities* (DCSF, Feb 2008) informs local councils how to implement section 12 of the Childcare Act 2006. Councils should

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force. The government has the power to bring these sections into force by making 'regulations'. EDCM understands that the regulations relating to short breaks will be made in time for 2011, when the short breaks funding from 'Aiming High for Children with disabilities'² is at its highest. The date when the government intends to bring into force the duties to support children with disabilities placed away from home has not yet been confirmed.

Full Service Offer

The Full Service Offer sets out the Government's expectations of what should be available by March 2011 in terms of short breaks to all families of severely children with disabilities including those with complex health needs. The main points of the Full Service Offer are set out below.

A Full Service Offer Should:

1. Be based on a needs assessment of the local population
2. Offer significantly increased volume of short breaks compared to 2007/08
3. Use fair, understandable and transparent eligibility criteria
4. Ensure sufficient provision that meets the needs of severely children with disabilities and their families, including those with complex health needs;
5. Ensure age appropriate provision that ensures the following groups are not disadvantaged in accessing short breaks:
 6. children and young people with a diagnosis of severe Autistic Spectrum Disorder, children and young people with complex health needs, including the technology dependent child and those requiring palliative care; children and young people up to 18 with moving and handling needs that will require equipment and adaptations, children and young people with challenging behaviour as a result of their impairment ,severely disabled young people 14+.
7. Provide a wide range of short breaks, tailored to families' needs and including:

- overnight breaks, with care available in both the child's own home and elsewhere;
 - breaks during the day, with care available in the child's own home and elsewhere;
 - breaks in universal settings, delivered through the support of a befriending, sitting or sessional service;
8. Ensure culturally appropriate provision that is sympathetic to the racial, cultural and religious background of children with disabilities and their families;

Ensure provision that is available at the times when families and young people, need breaks - this should include evenings, weekends and holiday provision, and be capable of responding to urgent care requirements

