

department for

education and skills



*National Service Framework for Children,
Young People and Maternity Services*

Disabled Children and Young People and those with Complex Health Needs



Change for Children - Every Child Matters



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Standard 8: Disabled Children and Young People and those with Complex Health Needs

1. Introduction

1.1 The National Service Framework for Children, Young People and Maternity Services establishes clear standards for promoting the health and well-being of children and young people and for providing high quality services that meet their needs.

1.2 There are eleven standards, of which this is the eighth. They cover the following areas:

Standard 1 Promoting Health and Well-being, Identifying Needs and Intervening Early

Standard 2 Supporting Parenting

Standard 3 Child, Young Person and Family-centred Services

Standard 4 Growing Up into Adulthood

Standard 5 Safeguarding and Promoting the Welfare and Children and Young People

Standard 6 Children and Young People who are Ill

Standard 7 Children and Young People in Hospital

Standard 8 **Disabled Children and Young People and those with Complex Health Needs**

Standard 9 The Mental Health and Psychological Well-being of Children and Young People

Standard 10 Medicines for Children and Young People

Standard 11 Maternity Services

- 1.3 This standard addresses the requirements of children and young people who are disabled and/or who have complex health needs, and their families. It is cross-referenced with Standard 6, which addresses the needs of children and young people who are ill.
- 1.4 It is recognised that the needs of children and young people, and their families, are not always clearly defined: Standards 6 and 8 have therefore been written to be read together. Both need to be read in conjunction with Standards 1-5. The care of children and young people when they are in hospital is covered in Standard 7. The mental health and psychological well-being of disabled children and young people, particularly those with learning disability, are addressed in Standard 9.

A Note on Terminology

- 1.5 This standard relates to children and young people who are disabled and/or those with complex health needs, including children and young people with learning disabilities, autistic spectrum disorders, sensory impairments, physical impairments and emotional/behavioural disorders. Many disabled children have no need for ongoing health interventions; others require ongoing treatment and/or nursing care and help with the everyday activities. Some disabled children will also be children in special circumstances. *See Standard 1*
- 1.6 In order to present a readable document, the term 'disabled children' has been used to refer to children and young people who are disabled and/or those with complex health needs.

Vision

We want to see:

- > Children and young people who are disabled or who have complex health needs, supported to participate in family and community activities and facilities.
- > Health, education and social care services organised around the needs of children and young people and their families, with co-ordinated multi-agency assessments leading to prompt, convenient, responsive and high-quality multi-agency interventions that maximise the child's ability to reach his or her full potential.
- > Children and young people and their families actively involved in all decisions affecting them and in shaping local services.

Standard:

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.

Markers of Good Practice

1. Disabled children are able to access all mainstream children's services. These promote active participation and inclusion in childhood, family and community activities.
2. Disabled children and young people receive child-centred multi-agency co-ordinated services from the point of referral through identification and assessment to delivery.
3. Early identification and intervention are provided through clinical diagnosis and the *Framework for the Assessment of Children in Need and their Families*¹. Interventions support optimal physical, cognitive and social development, and are provided as early as possible with minimum waiting times.
4. Disabled children and young people who require ongoing health interventions have access to high quality, evidence-based care, delivered by staff who have the right skills for diagnosis, assessment, treatment and ongoing care and support.
5. Families are offered a range of appropriate family support services that are flexible and responsive to their needs and that promote their inclusion in the local community. The option of direct payments is available and promoted.
6. Disabled children and young people and their families are routinely involved and supported in making informed decisions about their treatment, care and support, and in shaping services.
7. Area Child Protection Committees (Local Safeguarding Children Boards) have strategies and protocols to ensure that disabled children and young people are safeguarded from emotional, physical, sexual abuse and neglect, in line with *Working Together to Safeguard Children*².
8. Multi-agency transition planning and services focus on meeting the hopes, aspirations and potential of disabled young people, including maximising inclusive provision, education, training and employment opportunities.
9. A range of flexible, sensitive services available to support those affected by the death of a disabled child or a child with a life-limiting illness.

2. Rationale

- 2.1 The *Family Resources Survey 2002-3*³ estimates that there are approximately 700,000 disabled children under 16 in Great Britain. In the past ten years, the prevalence of severe disability and complex needs has risen. This is due to a number of factors, including increased survival of pre-term babies and increased survival of children after severe trauma or illness. There are up to 6,000 children living at home who are dependent on assistive technology. Children and young people with life-limiting conditions, such as cystic fibrosis, have better life expectancy and improved quality of life, due to improved treatment and support. The number of children identified with autistic spectrum disorders has risen over the last ten years. An estimated 1.2 million pupils have special educational needs (14 per cent of all pupils), of whom some 250,000 have statements of special educational need (three per cent of all pupils).
- 2.2 A third of parents with a severely disabled child under two years old use more than three pieces of equipment daily to provide basic care. Four out of five 12 to 14 year old severely disabled children need help with self-care e.g. eating, washing, dressing, going to the toilet. For many of these children, their needs are long-term. The majority of children live with their families, who carry day-to-day responsibility for caring for their child.
- 2.3 In addition to focusing on improving the health interventions/support given to these children, there is a need to address the many other barriers that often result in them being excluded from family and community activities. It is not only disabled children's impairments that determine their quality of life, but also poverty, negative attitudes and a disabling environment, for example, unequal access to education, healthcare, leisure activities, transport and housing.
- 2.4 Disabled children and young people are first and foremost children, with all the rights, needs and aspirations of all children and young people. Ensuring their rights are met requires providing services for them that are in line with the *United Nations Convention on the Rights of the Child*⁴; the *Human Rights Act 1998*⁵ and the *Disability Discrimination Act 1995*⁶.

2.5 Disabled children are very clear about what is important to them, See Box 1.

Box 1. What children and young people say they want

Young people say they want to:

- > Be listened to when decisions are made about their lives;
- > Have friends of the same age or who share similar experiences;
- > Do the same things as other children and young people of their age – shopping, going to a cinema, clubbing, going to youth and sport clubs, playing football etc;
- > Have the opportunity to be involved in out-of-school activities;
- > Be safe from harassment and bullying;
- > Have control of spending money, and have enough money to enjoy life, and
- > Live in a society where they don't face prejudice.

2.6 This standard locates the experience of disabled children and young people, and their families, within the wider community. It promotes their inclusion and their ability to live as ordinary a life as possible through effective partnerships with them, joint working between agencies, and a commitment to extending and improving services to meet their needs collectively and individually.

Interventions

3. Promoting Social Inclusion

The Impact of Poverty

- 3.1 Poverty is one of the main causes of social exclusion. Around 55 per cent of families of disabled children have a low income. It has been estimated that the annual costs of bringing up a disabled child are three times greater than those for a child who is not disabled.
- 3.2 Parents commonly report difficulties in finding out about and claiming benefits. Some research indicates a significant under-application for Disability Living Allowance, with the most disadvantaged families, especially families from minority ethnic backgrounds, being the least likely to apply for and to receive benefits. Following targeted action by the Department for Work and Pensions, Local Authorities and the Voluntary Sector, there has been a significant increase in the numbers of children receiving DLA over the past couple of years.
- 3.3 The care demands on parents, multiple appointments with services, and lack of childcare affects their ability to work. Mothers of disabled children are less likely to have paid employment than other mothers, and fathers' employment and earnings are reduced. *See Standard 1*



Local Authorities, Primary Care Trusts and NHS Trusts ensure that there is a multi-agency strategy in place to improve the provision of childcare services that can be used by families with disabled children. The strategy includes:

- > Making best use of the Special Educational Needs and Disability strand of the General Sure Start Grant;
- > Promoting the use of direct payments for parents to organise their own childcare;
- > Recognising that disabled children are likely to need to use child care services for longer than children and young people who are not disabled;
- > Plans for the development of Children's Centres and extended schools to improve childcare services for disabled children;
- > An information strategy for parents about what support and childcare is available;
- > Promotion of information to families about the benefits to which they are entitled and help in completing benefit applications;
- > Development of accessible play and leisure services, and
- > Ensuring child care provision complies with the Disability Discrimination Act 1995⁶.

Access to Services

3.4 Families of disabled children commonly experience exclusion from ordinary child and family activities, as well as some mainstream and community services. Disabled children and their families should not be excluded from using mainstream children's services, and services should be delivered in such a way as to minimise negative impact on family life. Commissioners and service providers should be aware of their responsibilities towards disabled children under the *Disability Discrimination Act 1995*⁶ and the *Special Educational Needs and Disability Act 2001*⁷. With DfES funding the Council for Disabled Children have produced a practical guide *Come on in (CDC 2004)*⁸ on implementing the DDA and improving access and inclusion for disabled children.

3.5 Families from minority ethnic backgrounds and asylum-seeking families have particular difficulties in obtaining services. They report high levels of exclusion and unmet need and lower levels of services than white families.

- 3.6 Disabled children often use specialist services that are not provided in the communities in which they live, often resulting in them not having opportunities for play and socialisation with non-disabled children. Consequently, when the opportunity does occur, many disabled children find these interactions difficult. *See Standard 3*
- 3.7 Research shows that disabled children are sometimes excluded unnecessarily from services because of worries over risk to staff health. With funding from DfES, the Council for Disabled Children have produced a practical guide *Dignity at Risk (CDC 2004)*⁹, looking at risk protocols in relation to invasive and intimate care, moving and handling and restrictive physical interventions and challenging behaviour.

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > Policies, practices and procedures of all services are regularly reviewed, in partnership with children and their parents, to remove barriers and progressively improve access, and to ensure that disabled children and their families are not disadvantaged;
- > Providers of services fulfil their duties under the *Disability Discrimination Act 1995*⁶ to remove barriers and progressively improve access to services; to take reasonable steps to remove or alter physical features (incorporating specialist advice) which may make it difficult for disabled people to access the service or to consider how the service can be provided by a reasonable alternative;
- > Services are regularly reviewed, in partnership with minority ethnic children and their parents, to ensure that they are culturally sensitive and responsive to the needs of minority ethnic communities; services are targeted at reaching communities where English is the second language, and
- > They have risk management protocols agreed between agencies, which include guidance on invasive care, manual handling and management of challenging behaviour.

Access to Hospital/Primary Health Care Services

3.8 Disabled children often attend the same hospital two or three times in the same week; this can affect the family's wider health needs and be disruptive to family, school and working life. Those children and young people who find it hard to wait for long periods in waiting rooms often cannot get primary care appointments that meet their needs.

Primary Care Trusts and NHS Trusts ensure that:

- > Access to services is regularly reviewed and improved, in partnership with disabled children and their parents;
- > Hospital departments and clinics synchronise their appointment systems as far as possible, so that families make a minimum number of visits to hospitals/clinics. For example, when multiple appointments are required, these are offered for the same day;
- > Wherever possible, children and young people are offered appointments at school or outside school hours, to ensure a minimum absence from school;
- > Children and young people with complex health care needs who are prone to health crises are seen urgently on request;
- > Systems are in place to ensure that children and young people who find it hard to wait, e.g. those with autistic spectrum disorder or with learning disabilities, do not have to wait unduly at outpatient clinics, general practice surgeries or child development centres. Where appropriate, double booking times or first/last appointment times are available for disabled children; and
- > Facilities for giving personal care in privacy are available in all locations in health, social care and education services that are used by families with a child with personal/health care needs.

Access to Child and Adolescent Mental Health Services

- 3.9** Many children and young people with complex health needs or life-limiting illnesses need psychological and emotional support to minimise stress. In addition, these children and young people are significantly more vulnerable to mental health problems than other children.
- 3.10** Disabled children have often found it difficult to access child and adolescent mental health services. There have been particular difficulties for children and young people who have autistic spectrum disorders or learning disabilities.
- 3.11** Commissioning of services for low incidence conditions needs to be co-ordinated on a regional or national basis. *See Standards 3 and 9*

Local Authorities, Primary Care Trusts, Child and Adolescent Mental Health Services ensure that:

- > Disabled children have equal access to Child and Adolescent Mental Health services;
- > Appropriate mental health services are available for:
 - disabled children suffering from traumatic accidental injury;
 - children and young people with complex health needs and life-limiting illnesses, and
 - the siblings of disabled children;
- > Assessments and services for children and young people with learning disability and mental health needs are provided by professionals with expertise in learning disability and children and young people's mental health;
- > Services are planned and commissioned on a multi-agency basis, and
- > Local Child and Adolescent Mental Health service development strategies include plans for improvement in services for children with a learning disability across all four tiers of provision.

Access to Rehabilitation – Therapy Services

- 3.12** Children's and young people's access to rehabilitation and therapy services is inconsistent across regions, with long waits in some areas. Waiting long periods for rehabilitation and therapy can greatly harm the educational attainment and wider development of individual children and young people. It can result in loss of function and ability. Reducing these delays will require local authorities and health authorities to clarify and implement their joint and individual responsibilities for providing rehabilitation and therapy services.
- 3.13** Parents or carers have a key role in providing some forms of therapy in the home. It is crucial that they receive training and support from health, education and social services professionals to do this confidently and effectively.
- 3.14** Good collaborative arrangements are required between therapists and other professionals to extend current support given to disabled children, and also to minimise disruption to their education. Therapists have a role in educating and supporting childcare, nursery and school staff to build in therapy throughout the child or young person's daily routine.



3.15 Additional funding has been made available to increase overall capacity in the NHS. This will enable Primary Care Trusts, who identify this as a priority area, to increase the capacity of the allied health professionals' workforce to help meet identified need, alongside the role and service redesign that is also required to improve access to services and reduce waiting times.

Local Authorities and Primary Care Trusts ensure that:

- > Parents or carers, children and young people are active partners in decisions about rehabilitation or therapy services, with agreed goals for what it is intended to achieve and how they can help;
- > Therapeutic interventions are agreed and overseen by specialist paediatric therapists;
- > Therapy is delivered in the most appropriate setting, which may include the home if this suits the child or young person; or where children and young people attend educational settings it is offered within that setting, and strategies are developed with teachers who support the child's full learning experience;
- > Protocols are agreed for the delivery of interventions by teachers and learning assistants;
- > Review local therapy services in order to:
 - a) Promote self-referral, simplifying the care pathway, and reduce excessive waits that may affect a child's development;
 - b) Improve administrative systems and processes for referral and discharge, and the effectiveness of outcomes of different therapeutic regimes, such as group sessions, and
 - c) Ensure that the supply of timely therapy services is sufficient to meet the needs of children and young people who require it, based on assessed needs. This may involve increased capacity to ensure that all children and young people attending early education settings and mainstream or special schools have equal access to therapy.

Access to Social Services

3.16 Social services are provided under the *Children Act 1989*¹⁰, following an assessment under the *Framework for the Assessment of Children in Need and their Families*¹ and the associated Practice Guidance. Parents have often found the threshold for provision of family support confusing and difficult, and others report that some Local Authorities provide services only for certain impairments.

Local Authorities develop threshold criteria in partnership with health and education and voluntary sector providers.

These are based on the impact the disability or complex health need has on the child and family, with a view to providing the child and family with services in order to give children maximum opportunities to participate in family life and to achieve their optimal development.

Threshold criteria for service provision are transparent, published and shared with families and voluntary sector providers.

Managers monitor decisions following initial and core assessments under *section 17* of the *Children Act 1989*¹⁰, and ensure that decisions are being made fairly and consistently for all children. Service users with similar needs receive packages of care that are capable of achieving broadly similar outcomes.

Disabled children and their families are involved regularly in decisions about service planning, commissioning, innovation and re-design.

Access to Housing, Equipment and Assistive Technology

- 3.17** Living in suitable housing and having appropriate equipment and assistive technology are key factors in promoting the well-being of families with disabled children. These factors support optimal development and help children to enjoy childhood activities such as play, developing independence and contributing to family life. Nine out of ten families report at least one difficulty with their housing, with many reporting multiple problems.
- 3.18** Successful communication is central to social inclusion. It is particularly important to the increasing number of disabled children who use alternative communication systems to speech, such as symbol boards/books and computer-assisted systems. Yet many children have access to their communication systems only at school, and not at home or in other settings.
- 3.19** When a disabled child or young person is living away from home, for instance, being looked after by a local authority, placed with a foster carer or a residential school, it is important to ensure that their needs are met within their placement.
- 3.20** The provision of effective and efficient housing adaptations, equipment and assistive technology services requires close interagency co-ordination. Agencies will need to agree on a range of issues including assessment, maintenance, funding, insurance, risk management, timely supplies of medication and equipment, hospital discharge and community support and

short-term breaks. *See Standard 6*

Local Authorities and Primary Care Trusts ensure that:

- > Commissioning of services for disabled children and their families includes consideration of their housing, community equipment and wheelchair needs. Local Authorities map the housing needs of children and their families strategically, and plan multi-agency resources and responses accordingly;
- > Disabled children are able to use/access the equipment and assistive technology they need in all places they typically spend time (e.g. school, home, short-term care settings). Equipment and assistive technology is tailored to the individual needs of the child and their future development. Parents and other carers are given training and support in the use of the equipment and assistive technology, including who to contact in an emergency and out-of-hours;
- > Services are in place to meet the particular housing, equipment and wheelchair and transport needs of looked after children;
- > Community Equipment Services are integrated across health, social services and education and develop multi-agency protocols that set benchmarks for the assessment and provision of children's equipment, including wheelchairs. Pooled budgets and the use of other *Health Act 1999*¹¹ flexibilities are used to integrate and improve services, and
- > Multi-agency arrangements are in place for the provision and maintenance of equipment and supplies. Deliveries of bulky health equipment and supplies are sufficiently frequent so that families are not required to store large amounts in the family home. Local emergency stocks of health equipment/supplies are obtainable 24 hours a day.

Access to Transport and Leisure

- 3.21 The lack of inclusive sport and leisure activities often leads to disabled children becoming isolated, lonely, and missing out on childhood activities which are fun and which provide opportunities to make friends and learn new skills. *See Standard 1*
- 3.22 One of the key barriers to the participation of these children is a lack of accessible transport. The pivotal role of transport and leisure services in promoting inclusion needs to be reflected both at the strategic/management level and at the assessment/service delivery level.

Local Authorities and Primary Care Trusts ensure that:

- > Services for disabled children include those that promote friendships and independence, and offer them and their families the opportunities to go out into the community, join in a wide range of leisure activities, and develop skills in a fun setting;
- > Services and facilities comply with their responsibilities under the *Disability Discrimination Act 1995*⁶. Issues to consider in developing services include:
 - a) Taking the views of disabled children and their families into account;
 - b) Local Authorities using the Government guidance *Developing Accessible Play Spaces*¹² to make parks and other open spaces accessible for families with disabled children;
 - c) Making holiday play schemes, other holiday activities and after-school clubs accessible to all children, and
 - d) Local transport being accessible and flexible so that disabled children can attend the events and services they wish to go to, and
- > Youth services provision is inclusive of disabled children and young people; access strategies ensure that services are fully accessible to them.

4. Early Years/Strong Foundations

Early Identification

- 4.1 Early identification of health conditions, impairments, social and physical barriers to inclusion is vital to a child's development and life chances. The timing for identification varies between conditions. For some, it is possible to identify problems through the screening offered to parents ante-natally in the core Child Health Promotion Programme (*see Standard 1*), whilst other conditions are identified by alternative means, including:
- > Response to parents' concerns;
 - > Planned follow-up of high-risk newborn babies;
 - > A follow-up of children after neurological damage; and
 - > A multi-disciplinary/multi-agency approach.
- 4.2 Health and local authority systems also need to plan for identifying and meeting the needs of children with low incidence and rare conditions.
- 4.3 Many children with learning disabilities will not receive a specific medical diagnosis, and even when there is a diagnosis, accurately predicting future needs can be difficult. This is where a good multi-agency assessment of need is essential as the catalyst for early intervention. *See Standards 1 and 6*

Health visitors work in partnership with other early years staff to raise awareness and understanding of children's health and development needs and in encouraging referral to the primary care team, or other services such as therapy services, if they or the parents are concerned about a child.

Good multi-agency diagnostic practice and procedures are in place with adequate consideration of the common co-morbid conditions.

Parents have early access to paediatricians who are expert in child health and paediatric neurology.

Professionals are skilled in sharing concerns and choices with parents as part of an emerging diagnosis. *See Right from the Start Template*¹³

Integrated Diagnosis and Assessment Process

4.4 Disabled children may be subject to multiple assessments by different people, each collecting similar information. These cause considerable frustration for parents.

See Standard 3 section 8.8, and Standard 6 sections 7 and 8

Box 2. Example of possible diagnosis and assessments for developmental delay

A child with developmental delay will require:

- > Paediatric assessment;
- > Developmental assessment;
- > Audiological assessment;
- > Visual assessment, and
- > Other assessments of physical problems that present at diagnosis, and

May also require:

- > Physical and physiotherapy assessment;
- > Occupational therapy assessment;
- > Speech therapy assessment of communication or feeding, and
- > Specialist or tertiary care for rare conditions.

And:

Social care/family support and education needs assessment – see *The Framework for the Assessment of Children in Need and their Families*¹, and the *Special Educational Needs (SEN) Code of Practice*¹⁴.

- 4.5 Research on the implementation of the *Framework for the Assessment of Children in Need and their Families*¹ found that parents of disabled children were very positive about the areas covered by this assessment. For some, this was the first time they had been asked about particular areas that they considered important.

Local Authorities, Primary Care Trusts, NHS Trusts and schools ensure that:

- > Children with possible impairments have prompt access to a diagnostic and assessment facility that is as close to the child's home as possible. Where appropriate, multi-agency assessments are carried out in convenient settings, such as the child's home or school; and services are co-located to aid access for families e.g. in child development centres, children's centres, extended schools, or one-stop shops;
- > Diagnosis and identification of disability or complex health needs (which may not be a single consultative event) is followed quickly by a multi-agency comprehensive needs assessment which follows the *Framework for the Assessment of Children in Need and their Families*¹, and for children from birth to third birthday the *Together from the Start Guidance*¹⁵;
- > Assessments record the child's abilities and strengths as well as difficulties, and lead to plans that aim to maximise the child's developmental progress and achievement, and promote the child's inclusion in family and community life, and
- > Assessments include parents' needs for support with caring for a child with, for example, sleep, behavioural or emotional problems, breathing difficulties or fits. Assessments include considering needs around mobility, access to leisure, play and education, seating, eating, housing, equipment and other requirements for living. They also address the support needs of siblings.

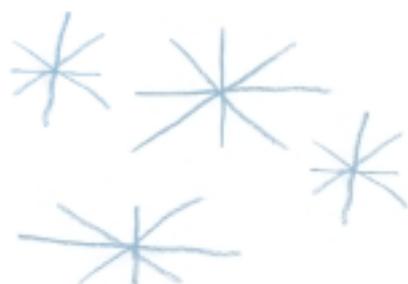
See Standards 3 and 6

Early Interventions

4.6 Children are growing and developing. Delaying early intervention can result in irretrievable loss of function or ability (e.g. postural management) or the intervention being less effective (e.g. speech and language therapy). Early intervention has a positive effect both in terms of promoting development, and minimising decline or regression among children with developmental disabilities. *See Standard 1*

Local Authorities, Primary Care Trusts, NHS Trusts, early years and day care providers:

- > Use the service audit resource developed as part of the Early Support Programme (ESP)¹⁶ to review jointly and to evaluate the standard of service they provide for disabled children under three and their families (see www.espp.org.uk);
- > Use the ESP professional and family toolkits to improve the services in consultation with local parents of disabled children;
- > Develop portage and other home-based learning services to support families in their own homes; and
- > Provide interventions to support optimal physical and cognitive development (such as physiotherapy, occupational therapy, speech and language therapy, play and educational programmes) and which promote the child's inclusion to their local community.



Early Support Programme

ESP is a programme to improve services for babies and very young disabled children and their families. It has been developing best practice in:

- > effective multi-agency support so that families get a co-ordinated service;
- > involvement of parents in planning and delivery of services;
- > developing the role of key workers to support parents and families, and
- > improving professionals' skills and knowledge.

The ESP has developed toolkits for professionals and families to help improve services and the Government has committed to spreading these tools and best practice to all local authorities and Children's Trusts.

Co-ordination of Health Care

- 4.7 The care for disabled children often involves several healthcare disciplines (at primary, secondary and tertiary level involvement) and other agencies. Close liaison between tertiary and local services to discuss best ways of implementing recommendations is essential.
- 4.8 The quality of the care that these children and young people receive, and the quality of their and their families' lives, depends on good multi-disciplinary care planning and treatment. Furthermore, seamless integrated working becomes more important as a condition progresses. *See Standard 3 and 6*

Interagency Care Pathways and care packages are used to facilitate continuity of care and anticipate service provision as the child or young person grows older and/or their disability or health condition changes. *See Standard 6 and 3*

5. Supporting Parents/Strengthening Families

- 5.1 Families with disabled children often face high levels of day-to-day stress, and many have high levels of unmet need for support services. This can lead to higher levels of stress and ill health than those experienced by other parents. Research shows that children's behaviour and sleep problems are key factors in parental stress.
- 5.2 Some families also need high levels of health/nursing support, but do not always receive this. In particular, families of children with learning disabilities show greater levels of unmet need than those with children who are not disabled. Children with multiple disabilities such as deaf-blind children need particular support. With funding from DFES, SENSE have produced a practical guide on improving services for deaf-blind children. See *Reaching out to Deaf-blind children* (Sense 2004) www.sense.org.uk
- 5.3 Lowering stress levels in families is important for the well-being of the whole family, and is also likely to reduce the number of children who require residential placements. Fathers play an integral role in the family when a child is disabled or has complex health needs. However, research shows that many feel excluded from certain aspects of their child's care. Improved support, information and opportunities to access services can lead to a father feeling much more involved in the care of his child.
- 5.4 Parents/carers, even if carrying out much of the care themselves, need effective support, help with complex nursing care in the home and opportunities for short term breaks from caring. This is an area of care in which health, social services, education and the voluntary sector should work closely together in planning, funding, and commissioning to provide integrated services. There is evidence of interventions that have been successful in helping parents deal with these problems, resulting in improved outcomes for children and parents. See *Standard 2 and Standard 6 section 13*

- 5.5 Direct payments, under the Carers and Disabled Children Act 2000 have proved to be an effective way of increasing users' independence and choice by giving them control over the way the children's social services they receive are delivered. With funding from the DfES, the Council for Disabled Children have produced a practical guide *Direct Experience*¹⁷ (CDC 2004) reference on developing a direct payments service.

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > Families are offered a range of appropriate family support services, through multi-agency packages of care, (including domiciliary care, community nursing and other health support, play, leisure, childcare and skills training e.g. in health care interventions, behavioural techniques);
- > These packages are flexible and responsive to children's and families' needs (including those of fathers and siblings), provide positive and stimulating experiences for disabled children, and promote their inclusion in the local community. Services are provided by both universal and specialist agencies, and are available for all disabled children, including those with complex health needs, autistic spectrum disorders and multiple disabilities such as deaf-blind children;
- > The options of receiving direct payments or services are equally available;
- > Training in managing sleep and behaviour problems is offered at an early stage to parents who need it, and
- > Children leaving hospital and requiring continuing care receive co-ordinated multi-agency packages of care according to individual need, by applying similar principles to those identified in the *Health Service Circular/Local Authority Circular HSC 2001/015: LAC (2001)*¹⁸.

Short Term Breaks

- 5.6 A break from caring is one of parents' most frequently reported unmet needs, and many children also appreciate a break away from their family. Short-term breaks can provide a positive experience for children by enabling friendships to form with other children and by encouraging social activities, new experiences and supportive relationships with carers. Good short-term break services are associated with reductions in maternal stress and reduction in marital problems and breakdowns.

5.7 Families often need breaks, especially at weekends and during school holidays, that are flexible and offer choice. There is often a particular need for services for children with complex health needs, challenging behaviour or autistic spectrum disorders, and children from minority ethnic families. With funding from the DfES the Shared Care Network have produced a practical guide *All Kinds of Short Breaks*¹⁹(2004) which focuses on these three groups as well as giving examples of best practice on overnight short breaks, day care, sitting and overnight sitting services, inclusive leisure and the use of direct payments to purchase services. *See Standard 6*

Local Authorities and Primary Care Trusts ensure that:

- > All children and their families who are assessed as having needs that can be met by short term breaks are offered without undue delay a range of services from which to choose. This includes home and community-based breaks as well as family-based and residential breaks and access to childcare and sitting services;
- > Parents are offered the choice of having these provided through direct payments;
- > Access to emergency short-term breaks is available;
- > Regular audits of current short break services are carried out. These include:
 - a) The quality of children's experience;
 - b) The number of children and young people receiving services and those waiting for them;
 - c) The characteristics of children and young people waiting for provision; and
 - d) The types of short breaks families want.
- > A strategy is agreed to recruit more short break carers for 'hard to place' children, building on work arising from the Choice Protects initiative and in partnership with local Shared Care Network groups, and
- > Flexible and easily accessible home care and child care services are available for all families assessed as requiring them, to meet the individual needs of the child and their family.

Key Workers

- 5.8 Parents of severely disabled children or those with high levels of need require a single point of contact with services and an effective, trusted and informed named person (a 'key worker' or Care Manager) to help them obtain the services they require. Studies of key workers consistently report positive effects on relationships with services, fewer unmet needs and greater family well-being. However, fewer than a third of families with severely disabled children have a key worker.

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > Families caring for a disabled child with high levels of need have a key worker/care manager to oversee and manage the delivery of services from all agencies involved in the care and support of the child and family, and to ensure that the family has access to appropriate services, and
- > The key worker services is provided in line with the guidance in *Together from the Start*¹⁵ and the *New Standards for Key Working*²⁰ and supported by cross-agency senior management commitment.

Information for Parents and Children

- 5.9 Information is one of the most valued services, and parents and disabled children and young people consistently request more information about services and about the child's condition and treatment. Parents from minority ethnic groups are least well-informed. Efforts need to be made to provide information in appropriate formats and language. Duties under the Disability Discrimination Act need to be taken into consideration when considering the provision of information in appropriate formats and language (including sign language). *See Standards 2, 3, 6 and 10*

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > Timely, appropriate, accessible and accurate information is provided to enable children and young people, parents or carers to make choices about the treatment, care and services they wish to use;
- > Specific information is provided to siblings of disabled children;
- > Information is provided in community languages and appropriate formats;
- > Specific information pertinent to particular conditions is provided, and
- > Contact details for key national support organisations, such as the Family Fund (www.familyfund.org.uk) and Contact a Family (www.cafamily.org.uk), are provided.

Listening to and Responding to Children and their Families

5.10 Disabled children want staff to listen to them, ask them for their ideas, take notice of what they say and give them choices. Children can contribute unique and essential knowledge during decision-making. Parents of disabled children also want to be involved in decisions about the services and treatments their children receive. Involvement of children and their parents in planning services results in the provision of more appropriate services. However, disabled children are less actively involved in decision-making than children who are not disabled. Therefore, professionals should ensure that disabled children, especially children with high communication needs, are not excluded from the decision-making process. In particular, professionals should consider the needs of children who rely on communication equipment or who use non-verbal communication such as sign language. *See Standard 3*

With DfES funding, Contact a Family and the Council for Disabled Children, have produced a practical guide *Parent Participation (CaF 2004)*²¹ on how professionals can involve parents in planning and developing services.

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > Disabled children and their parents are routinely involved and supported in making informed decisions about their treatment, care and services, and in shaping services;
- > They have an ongoing service user involvement programme for disabled children and young people, in line with the *NHS Patient and Public Involvement*²² and *Building on the Best; Choice, Responsiveness and Equity in the NHS*²³ guidance. This includes targeted support for minority ethnic families;
- > NHS Patient Advice and Liaison Services ensure that their services are promoted to, and accessible by disabled children and young people, and their families; and they are included as representatives on the local Patient and Public Involvement Forum, and
- > Facilities, equipment, and skilled workers are available to enable children who do not use speech, children who find engagement and interaction difficult, and very young children to participate in assessment and decision-making processes, and
- > Systems are in place to provide interpreting and translation services and bilingual advocates in the main locations where health, social care and education services are provided. *See Standard 3*

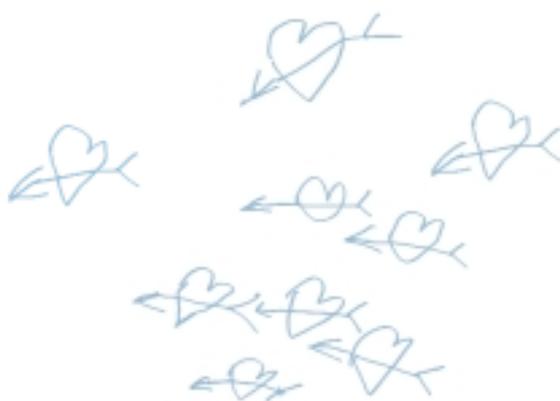
The Expert Patient Programme

5.11 As well as contributing to family support packages of care, the NHS Expert Patient Programme has great potential for increasing the quality of life for disabled children who have health needs. Parents or carers, children and young people can benefit from becoming experts in the child or young person's specific condition. *See Standard 6*

Education

5.12 Many disabled children have special educational needs that impact on their education. Some miss out on educational opportunities due to prolonged absences from school because of ill health and because of frequent attendance at clinic or hospitals. For these children, taking part fully in school life, whether in mainstream or special schools, requires good communication between health, social care and education services so that the child's needs are understood and met. The right school policy or approach can transform the life of these children.

5.13 Disabled children are over-represented in the population of looked after children and are more likely to be placed in residential settings. Family stress is a key factor in requests for residential placements. Costs for residential special school places are two to three times higher than costs for providing for similar needs in day special schools. *See Standard 6*



Local Authorities, Primary Care Trusts, NHS Trusts and schools ensure that disabled children are able to access the full range of opportunities provided by the education service, wherever possible in mainstream settings.

In line with the aims of the *Every Child Matters*²⁴, the *Special Educational Needs Strategy Removing Barriers to Achievement*²⁵ and the *Children Act 1989*¹⁰, agencies develop inclusive local strategies between health, education and social care services to maximise children's participation in school life and to ensure that :

- > Children's needs are identified and that they are helped to achieve their potential;
- > The balance of provision is shifted towards prevention, and
- > Support is provided well before children reach crisis point.

Agencies jointly review and agree arrangements for referrals to, and support for, disabled children in residential placements. Appropriate local educational support and provision is available, so that parental requests for residential education are not made on the basis of lack of support and practical help in their community. All decisions to place a child or young person in residential placement are based on multi-disciplinary/multi-agency assessments of the child's needs.

Where children are placed in residential settings, local protocols are in place for maintaining family contact and undertaking statutory reviews in line with the *Children Act 1989 Regulations*²⁶. Children placed away from home have a communication plan which ensures that, whatever their level of communication, their basic needs are understood and met.

See Standard 6 for interventions on supporting pupils with medical needs.

Palliative Care

5.14 Palliative care is an essential part of care for many disabled children who have complex health needs. For some children and young people, palliative care is needed only for a short time; for others, it will be the only focus of care from the time a life-threatening or life limiting condition has been diagnosed. Palliative care services can include short-term breaks, counselling, family support services, pain management and symptom control. When services are provided, it is particularly important that these are easily accessible, timely and in the setting of the family's choice.

5.15 High quality palliative care services should be available for all children and young people who need them. Palliative care services are provided by a network of agencies, including the NHS, children's hospices, the voluntary sector and social care and education services. Co-ordination and close liaison between agencies is therefore essential. It is important to recognise the changing needs of young people receiving palliative care as they move from children's services. The *Health Select Committee report on Palliative Care*²⁷ has identified the importance of transition from children's to adult services.

See Standards 4, 6 and 10

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > Palliative care services provide high quality, sensitive support that takes account of the physical, emotional and practical needs of the child or young person and their family, including siblings. Services are sensitive to the cultural and spiritual needs of the child, young person and family;
- > Services maximise choice, independence and creativity (access to preferred interests or activities) to promote quality of life;
- > Services are delivered where the child and family want, for example in the home, hospital, hospice or other setting;
- > Services include the prompt availability of equipment to support care, access to appropriate translation services, and workers skilled in using communication aids;

- > Palliative and terminal care services are regularly reviewed with parents or carers, children and young people, and gaps in provision identified and addressed;
- > Short term breaks, palliative and community health and social care services for children and young people with life-limiting conditions and/or complex health needs is planned in partnership with voluntary sector providers and children and young people's hospices in localities where these exist;
- > Provision of services includes, where appropriate:
 - a) 24-hour access to expertise in paediatric and family care (often provided by local community children and young people's services to enable continuity of care) is available;
 - b) 24-hour expertise in paediatric palliative care (provided by those with specialist palliative care training) is available;
 - c) Pain and symptom control;
 - d) Psychological and social support;
 - e) Spiritual support which takes account of the needs of the whole family;
 - f) Where required, formal counselling or therapy;
 - g) Arrangements to avoid unnecessary emergency admission to hospital are in place;
 - h) Protocols for immediate access to hospital, if needed, are in place, and
 - i) A process for keeping the general practitioner informed.
- > The care of children and young people with life-threatening diseases is informed by evidence of best practice.

Death of a Child

- 5.16** Death in childhood may be sudden and unexpected, for example, as a result of a road accident, or may occur at the end of a long-term illness. Whatever their circumstances, it is very important that families receive care which is sensitive, and appropriate to their individual needs.

5.17 Parents should be supported in making their own decisions about what happens to their child. They will also need support to deal with the host of practical considerations surrounding a death, which can be extremely difficult for grieving relatives to manage.

5.18 Information and support may also be very important in helping the family make sense of why a death has occurred, and in understanding the differing grief reactions of family members. *See Standard 11*

Local Authorities, Primary Care Trusts, NHS Trusts ensure that:

- > Following a bereavement, parents and families are given the time, space and information to make practical arrangements and decisions, and receive ongoing support to cope with their loss, and
- > When a child dies unexpectedly, appropriate investigations are undertaken according to best professional practice.

6. Safeguarding Children

6.1 Disabled children are more likely to experience abuse than non-disabled children. Children living away from home are particularly vulnerable.
See Standard 5

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > The local Area Child Protection Committee (to be superseded by the Local Safeguarding Children Board) has a system in place to ensure that all disabled children are safeguarded from emotional, physical and sexual abuse and neglect, and
- > The specific needs of disabled children are addressed in safeguarding children protocols in line with *Working Together to Safeguard Children and Their Families?*

- 6.2 Inter-agency safeguarding children protocols need to be comprehensive, as set out in Box 3.

Box 3. Developing comprehensive safeguarding protocols

Safeguarding protocols include agreement in relation to:

- > Consulting with disabled children, and organisations advocating on their behalf, about how best to safeguard them;
- > The development of emergency placement services for disabled children who are moved from abusive situations;
- > The systematic collection and analysis of data on disabled children subject to child protection processes;
- > Safeguarding guidance and procedures for professional staff working with disabled children;
- > Training for all staff to enable them to respond appropriately to signs and symptoms of abuse or neglect in disabled children;
- > Guidance on contributing to assessment, planning and intervention and child protection conferences and reviews;
- > Disability equality training for managers and staff involved in safeguarding children work; and
- > Regular reviews and updating of all policies and procedures relating to disabled children.

7. Transition into Adulthood

- 7.1 Assessment and planning for transition from child to adult services is often unsatisfactory. For many, there is a lack of co-ordination between the relevant agencies and little involvement from the young person. Some disabled young people are not transferred from children's to adult services with adequate care plans, resulting in their exclusion from adult services. In addition, some disabled young people experience a decline in the services they receive. This can lead to a regression in their achievement and/or deterioration in their condition. Disabled young people need high quality, multi-agency support to allow them to have choice and control over life decisions, and to be aware of what opportunities are open to them and the range of support they may need to access.
- 7.2 Disabled young people who are looked after have the same entitlement to care when leaving services as other looked after young people. They need a pathway plan setting out the services they will require to achieve their potential as young adults. *See Standard 4*



Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > Transition planning has as its main focus the fulfilment of the hopes, dreams and potential of the disabled young person, in particular to maximise education, training and employment opportunities, to enjoy social relationships and to live independently. Transition plans take a person-centred planning approach, as described in *Towards Person-Centred Approaches – guidance*²⁸, and which is consistent with the *Special Educational Needs Code of Practice*¹⁴.
- > A multi-agency Transition Group is in place. This could be taken on by an existing group that has developed a multi-agency transition strategy. The group:
 - a) Includes a Transition Champion from the Learning Disability Partnership Board;
 - b) Has representatives from Connexions Service, the local authority including social care, education and housing, the Learning and Skills Council, health, user representatives and voluntary organisations, and
 - c) Assumes responsibility for overseeing transitional arrangements at both strategic and operational level and for agreeing inter-agency protocols;
- > Young disabled people aged 16 years and above are supported to use direct payments;
- > Specific arrangements are made for managing the transition of those with high levels of need, those in residential schools/living away from home, looked after young people leaving care, and those with rare conditions;
- > Agencies develop local strategies to widen education, training and employment opportunities for disabled young people, and
- > Health services develop appropriate adolescent/young persons services with a view to enabling smooth transition to comprehensive adult multi-disciplinary care.

8. Planning and Commissioning Services

- 8.1 Families of disabled children have contact with an average of 10 different professionals and over 20 visits per year to hospitals and clinics. To achieve an integration of services that truly supports a child's journey, planning and commissioning needs to be more than usually focussed on the goal of providing personalised, child-centred care. This change can best be achieved by agencies focusing on a shared vision of a clear set of intended outcomes, developed with engagement from disabled children and their families.

See Standard 3

Local Authorities, Primary Care Trusts and NHS Trusts ensure that:

- > All commissioners and service providers are aware of their responsibilities under the *Disability Discrimination Act 1995*⁶, the *Special Educational Needs and Disability Act 2001*⁷ and the *Children Act 1989*¹⁰.
- > There are arrangements which encourage multi-agency strategic planning of services for disabled children, possibly through a Children's Trust, including the joint commissioning and delivery of services, making maximum use of pooled budgets and other Health Act flexibilities;
- > These arrangements include the involvement of senior managers from all main agencies, adult services and other appropriate representatives e.g. from housing, leisure and transport services, and key local voluntary organisations;
- > The arrangements maximise the involvement of disabled young people and their families or has 'parallel' consultation groups;
- > The arrangements allow for the development and implementation of a locally based multi-agency database containing core data on disabled children, based on shared and agreed definitions; the data is used to monitor take-up of services against what is known about the local population, including take-up by minority ethnic groups, and for planning/evaluation of services.

9. Training and Development

9.1 Delivering this standard requires staff in a very broad range of disciplines to have the right skills to understand and meet the specific needs of disabled children and their families.

9.2 Agencies need to further develop multi-disciplinary and multi-agency specialist teams to care for disabled children and young people, including health visitors, social workers, psychologists, paediatricians, nurses and allied health professions. A range of new or extended roles may be appropriate within these teams, for example:

- > Extended specialist roles for nurses in areas such as nutrition, continence and management techniques, to help children who are disabled or who have complex health needs to reach their full potential;
- > Extended therapy roles;
- > New support roles within therapy services; and
- > Support roles for staff working with children in education settings.

See Standard 6

All specialist and mainstream staff whose roles include responsibility for disabled children are competent in the core of skills, knowledge and competencies set out under Standard 3.

Multi-disciplinary and multi-agency specialist teams are further developed to meet the needs of disabled children at home and at school.

Training in the needs of disabled children is delivered to all staff working in specialist and mainstream settings in health, social care, early years and education.

This includes training in:

- > Understanding the particular needs of disabled children, young people and their families;
- > Disability equality and inclusion issues;
- > The diversity of disability, including invisible disabilities such as autism, learning disabilities and low incidence disabilities; and
- > Communicating with children with specific communication needs.

Wherever possible, joint training initiatives between health, education, and social services staff are implemented.

Local strategies are in place to have sufficient numbers of therapists, social workers, community paediatricians and paediatric nurses.

In addition, staff also need training as appropriate in:

- > The health conditions and impairments that they are directly working with;
- > The availability and scope of local services, including in the voluntary sector;
- > Communicating with children who do not use speech to communicate and children who find interaction difficult;
- > Identifying, and responding appropriately to, suspected or known abuse or neglect in disabled children;
- > Managing risk;
- > Medical and technological advances in the care of the disabled child;
- > Managing technological equipment in the home for nurses and therapists in the community.
- > Specialist palliative care training for those working in paediatric palliative care.

- ¹ Department of Health, Department for Education and Employment and the Home Office *Framework for the assessment of children in need and their families* The Stationery Office 2000 www.dh.gov.uk
- ² Department of Health, Department for Education and Employment, Home Office *Working together to safeguard children: a guide to inter-agency working to safeguard and promote the welfare of children* The Stationery Office 1999 www.dh.gov.uk
- ³ Department for Work and Pensions *Family Resources Survey 2002-3 2004* www.dwp.gov.uk/asd/frs/
- ⁴ United Nations *Convention for the Rights of the Child* 1989 [Ratified by the UK government in 1991]
- ⁵ *Human Rights Act 1998* The Stationery Office
- ⁶ *Disability Discrimination Act 1995* The Stationery Office
- ⁷ *Special Educational Needs and Disability Act 2001* The Stationery Office
- ⁸ Council for Disabled Children *Come on in: a practical guide for children's services - The Disability Discrimination Act 1995 Part 3 - Access to goods and services* 2004
- ⁹ Council for Disabled Children *Dignity at Risk: a practical handbook for professionals working with disabled children and their families* 2004
- ¹⁰ Department of Health *Children Act 1989* The Stationery Office
- ¹¹ Department of Health *Act 1999* The Stationery Office
- ¹² Office of the Deputy Prime Minister *Developing Accessible Play Spaces – A Good Practice Guide* 2003 www.odpm.gov.uk/stellent/groups/odpm_urbanpolicy/documents/page/odpm_urbpol_026876.hcsp
- ¹³ SCOPE *Right from the Start Report 1994 The Template* Right from the Start Working Group Revised 2003
- ¹⁴ Department for Education and Skills *Special Educational Needs (SEN) Code of Practice* November 2001 www.teachernet.gov.uk/management/atoz/s/senpolicy/
- ¹⁵ Department for Education and Skills, Department of Health *Together from the Start- Practical guidance for professionals working with disabled children (birth*

- to third birthday) and their families* Department for Education and Skills May 2003 www.deafnessatbirth.org.uk/pilot/guidance/1/
- ¹⁶ Department for Education and Skills *Early Support Programme (ESP)* www.espp.org.uk
- ¹⁷ Council for Disabled Children *Direct experience: a guide to councils on the implementation of direct payments in Children's services* 2004
- ¹⁸ Department of Health *Continuing care: NHS and local councils' responsibilities* HSC 2001/015, LAC (2001) 18 2001 www.dh.gov.uk
- ¹⁹ Shared Care Network *All Kinds of Short Breaks* 2004 www.sharedcarenetwork.co.uk
- ²⁰ Care Co-ordination Network UK *New Standards for Key Working* 2004 www.york.ac.uk/inst/spru/ccnukstandards.htm
- ²¹ Contact a Family *Parent Participation: improving services for disabled children* 2004 www.cafamily.org.uk
- ²² House of Commons Health Committee *NHS Patient and Public Involvement* The Stationery Office HC 679 2003
- ²³ Department of Health *Building on the Best; Choice, Responsiveness and Equity in the NHS* The Stationery Office December 2003 www.dh.gov.uk
- ²⁴ Department for Education and Skills *Every Child Matters* The Stationery Office September 2003 www.dfes.gov.uk/everychildmatters/
- ²⁵ Department for Education and Skills *Removing Barriers to Achievement: The government's strategy for SEN* February 2004 www.teachernet.gov.uk/wholeschool/sen/senstrategy/
- ²⁶ Department of Health *The Children Act 1989 - Guidance and Regulations* The Stationery Office 1991
- ²⁷ House of Commons Health Committee *Palliative Care* HC 454-1 The Stationery Office July 2004
- ²⁸ Department of Health *Valuing People: a new strategy for learning disability for the 21st Century: Towards Person-Centred Approaches – guidance* 2002 www.valuingpeople.gov.uk/pcp.htm

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