# Support for Disabled Children and Young People and their Families in Essex

Guidance for working together with disabled children, young people and families to provide early help, targeted and specialist support





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### 1. Introduction

This guidance sets out framework eligibility criteria for how Essex County Council social care and education and Essex Health services, working together, will meet the health, care and education needs of disabled children and young people and offer support to their families.

This guidance sets out the types of support available for disabled children and young people, up to age 25, in Essex at the four levels of need and provides additional guidance to the overarching document Effective Support for Children and Families in Essex.

This guidance will complement and form part of the Local Offer, to be introduced in September 2014, and promotes access to early support and intervention for children and young people with disabilities and their families. Where children and young people have complex needs that require a multi-agency response an Education, Health and Care (EHC) plan will be developed.

We recognise that disabled children and young people can have specialist needs above those of other children and will sometimes require additional support for themselves and their family. We aim to promote secure and nurturing care which develops resilience and independence for all children and young people.

In line with the Essex Special Educational Needs and Disability (SEND) strategy and the NHS Mandate this is best achieved by children living at home with their family.

Each child and young person's support is based on their own individual circumstances and this guidance is intended to help practitioners carry out good holistic assessments and develop tailor-made plans to support each child/young person and their family. It will also help us arrive at fair and consistent decisions about packages of support for children and young people and their families.

Our aim is to ensure that the available resources from Health, Education, Social Care and partner agencies are targeted to benefit those in most need, including those at risk of significant harm, whilst ensuring that all children and young people with a disability have access to universal and additional services such as education, primary health and mental health care, extended school activities, and holiday play schemes. Where disabled children or young people have additional needs, we encourage families to access a range of services either directly or through a health professional, school or short breaks programme.



# 2. Key principles

### The Child/Young Person's View

Listening to children and young people is fundamental to good assessment and the development of an Education, Health and Care plan that meets his/her needs. It is even more important when a child is disabled and may not be able to hear, understand or express their views easily.

Disabled children and young people should be given the opportunity and support to participate as fully as possible in making decisions and choices about their lives. Every effort will be made to ascertain the views of each child and young person, taking into account their age and methods of communication in the assessment process.

### **Support for Families**

Parents and other family members are the most important people in the lives of all children and young people. Parents with a disabled child often need extra support. For many children and young people this extra support can be accessed directly from school, holiday play schemes, short breaks and additional services, without the need for assessment.

We recognise that the needs of some disabled children and young people are such that they need specialist support beyond that which their family and additional services are able to provide. Specialist support is available based on assessed needs from Health, Education and/or Social Care.

### **Our Aims and Values**

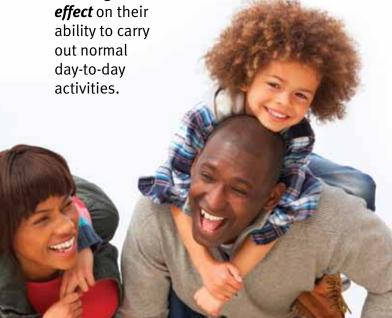
individuals

- Families will be supported and encouraged to identify their own challenges, needs and solutions and to access local universal and additional services
- Our aim is always to build resilience and capacity in children and young people to give them the skills and support to develop into adulthood as confident

- We seek to offer early help and support to children and families in a co-ordinated way responding to health, care and learning needs arising from a disability with advice and information and practical help
- When we are made aware that a child or young person has needs beyond those that can be met by their family and direct access to universal and additional services, we will talk and listen to that child/young person and their family, offer advice and support to meet that need, and develop a plan of support
- We will seek to support children and young people to live at home and attend the most suitable local school. Where children and young people need to be supported overnight or long-term away from home, we will seek to provide that support in a familial setting such as foster care wherever possible
- Support will always be provided in proportion to the needs identified. We will seek to provide support that promotes independence and resilience for the disabled young person and their family, and avoids creating dependency

### **Definition of Disability**

 The definition of disabled children and young people is set out in the <u>Equality Act 2010</u>: that is a child and young person who has a physical or mental impairment that has a *substantial* and long-term adverse



### 3. Direct Access Services

We want to encourage families and young people to access services themselves directly. Information about what is available can be found via the Essex SNAP (Special Needs and Parents) information gateway at:

http://www.snapcharity.org/ E-Mail info@snapcharity.org Telephone: 01277 211300

In addition a number of other services, some of which can be accessed directly, are available through Early Support and Short Breaks.

### **Early Support**

Early Support is an ethos and approach that seeks to get everyone - families and professionals - working effectively together at the earliest opportunity. Early Support is usually delivered through a key working approach that co-ordinates information and support. Early Support is for a wide range of children and young people and their families such as:

- Families with young babies leaving hospital with medical and support needs
- Young children where the need for extra help becomes clear only in the second or third year of life
- Children and young people who have obvious and multi-significant factors affecting their development and learning

The Early Support materials and resources are intended for anyone who works with families, as well as for parents and carers and for young people with disabilities themselves. They are designed to keep families at the centre of discussions and decision making about their child/young person. They have been developed to be used flexibly; helping both practitioners and families to co-ordinate service provision and navigate the system in a way that suits them. The materials and resources include:

 Family Pack (including the family file and range of information booklets)

- Range of information for parents booklets
- Multi-agency planning tool
- Developmental journals
- Training courses

Further information on Early Support services is available at: Early Support

### **Short breaks**

The Short Breaks programme provides information and access to a range of support, much of which is directly accessible by families. A short break can include day, evening, and weekend activities from a couple of hours to all day. Short breaks are designed to give children and young people with disabilities enjoyable experiences that contribute to their personal and social development, as well as enabling parents and families to have a break from their caring responsibilities.

Access to services is dependent on the level of need of the child or young person and the amount of support needed. As a general rule, services offering engagement in clubs or activities can be accessed directly. It will be the job of the service provider to assess the degree of need and establish whether the service is appropriate. However, if the family would like assistance with identifying how the needs of their child can be met, a professional who knows them, such as a health visitor, GP or teacher, can help them by liaising with other professions in the family's network in a Team Around the Family approach. This will support a family to access the right kind of short break provision or help make referral on to an appropriate community resource or agency.

Where a child or young person has specialist needs that may best be met by overnight and/or high level care support, they and their family will require a social care 'child in need' assessment undertaken by a social worker. This is arranged through making a referral to social care outlined on page 12. The child in need assessment will lead to a child in need care plan which sets out how family, social worker and agreed service provision will work together to meet the child's care needs.

More information about Short Breaks is available at: Short Breaks for Disabled Children. To discuss anything related to Short Breaks for disabled children/young people, please contact: <a href="mailto:shortbreaks@essex.gov.uk">shortbreaks@essex.gov.uk</a> Telephone: **01245 436864** 

### **Support with Education**

For children and young people who require specialist support with their education, parents can access additional help or special education support through their child's school. The Special Educational Needs (SEN) and Additional Educational Needs (AEN) services give advice, guidance and training to schools about the provision of quality support for all children and young people. In addition, there are teams of specialists – statutory assessment, educational psychology, personal advisers and specialist teachers - who may visit schools to offer advice about children and young people's needs and appropriate teaching approaches and strategies.

Essex County Council, in consultation with parents, young people and schools has developed a new strategy for children and young people with Special Educational Needs and Disabilities (SEND) in preparation for the SEN reforms that come into force from September 2014. A link to the SEND strategy is available in Appendix 1. The services also work with pre-school children when there are particular concerns about their educational needs, visiting the home to provide advice to parents and carers, workers in pre-school settings, and preparing children for entry to school.

It is recognised that the SEN reforms will bring about major change to current systems and will lead to more integrated support for children, young people and their families through Education, Health and Care (EHC) plans. There will also be a published 'Local Offer' which this guidance will form part.

Students aged 16 and over with high needs are currently entitled to a Learning Difficulty Assessment (LDA) which may allow access to further education funding.

There is a Parent Partnership Service helpline where information and support can be accessed by parents and carers of pupils who have SEN (see Appendix 1 for on-line links).

### **Support with Health Needs**

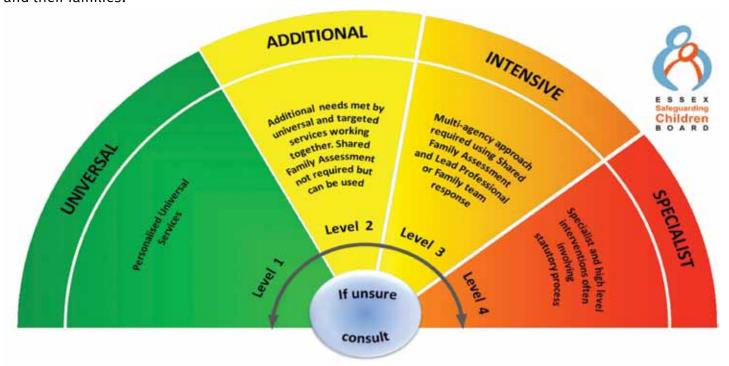
Access to community health services, Child and Adolescent Mental Health Service (CAMHS), adult mental health services (for young adults) or specialist paediatric or other health support for disabled children and young people is through the child/young person's GP.

Where it is needed, a link to joint agency assessment and panel processes will be made, including for continuing health care for children and young people. If specific health needs are identified a Continuing Health Care checklist may be completed to indicate whether a full Continuing Health Care assessment is required.



### 4. Levels of need

The Effective Support Windscreen below illustrates how Universal, Early Help (Additional and Intensive) and Specialist services in Essex are provided and how support is made available at each level of need for children and young people and their families.



The table on the following page provides information about meeting the needs of disabled children and young people and is supplementary to guidance found in <a href="Effective Support for Children">Effective Support for Children</a> and <a href="Families in Essex">Families in Essex</a>.

It is intended to provide guidance in relation to the levels of need in the windscreen and types of support for a child/young person with a disability and their family, together with service routes that practitioners and agencies can consider to access support. The examples in the table below are illustrative, rather than hard and fast rules. In carrying out assessment and in care planning the importance of open discussion with each child and their family and the role of analysis to arrive at professional judgement cannot be over emphasised. Similarly, it is important the professional is able to make use of good communication skills to listen to and observe the child they are working with, especially where the child's communication is limited.

The adult social care eligibility criteria in Essex for young people aged 18 and over, outlined in the eligibility factsheet, can be accessed via the following link:

Adult Social Care Services in Essex Eligibility
Factsheet 2013



### Levels of Needs for children and young people with a disability

Levels and Referral Routes	Needs	Services (examples)
Level 1 Universal Open access to all provision in Essex	Any disability or sensory impairment or learning difficulty which does not impact significantly on child/YP's ability to carry out normal tasks. Parental advice and training may be required	Early years, mainstream school, GP and health visitor, housing, community health care, youth centres, leisure services Children's centres, advice and information
Additional  Two or three services work together to meet children and young people and family needs, co-ordinated by a service that knows the children and young people/family best.  Early Help and Advice Hub/Early Support  A Shared Family Assessment, Lead Professional and/or Team around the Family meeting is not usually needed but can be used.	A Child/YP with moderate needs  Additional support to prevent impairment of health or development and / or alleviate stress in the family  Some developmental delay/behavioural problems  Families who are isolated in their communities by a child/YP's disability  Additional support to access education or where a child is at risk of exclusion  Children/YP with recently diagnosed serious impairment or illness that may result in a life threatening condition  Children/YP with SEN statement in mainstream or (former) MLD school  Children /YP with moderate challenging behaviour as a result of their learning disability or Autistic Spectrum Disorder (ASD)	Parenting support; school holiday and after school clubs; short breaks direct access provision; sitting service Early Support Behavioural support; additional learning support Youth and leisure services CAMHS tier 2 support to schools Speech and Language Therapy Children's centres Physiotherapy Sensory aids and minor equipment School Action/School Action + or One Plan Child Development Centres

Levels and Referral Routes	Needs	Services (examples)
Level 3 Intensive Shared Family Assessment (SFA) Lead Professional, Team around the Family, Multi- disciplinary / agency approach Family Solutions	Where there are <b>substantial</b> needs  Without support there would likely be significant impairment to child/ YP's health or development  Moderate level of additional care needs during the day as a result of disability (e.g. feeding, clinical tasks, and intimate care), beyond which the family can meet  Significant challenging behaviour and/or self-injurious behaviour arising from the disability  Children and young people with Life limiting conditions  Children and young people with SEN statement in (former) SLD school	Because of the complexity of needs a multidisciplinary / agency co-ordinated plan developed with the family may be needed  Early Support  CAMHS tier 2 Or 3; child in need assessment (social care); Direct Payment; Paediatric health services; OT equipment and minor adaptations  Overnight short-breaks (up to 30 nights) / direct payments / personal budget  Statement of special educational needs because of disability / Education, Health and Care (EHC) plan / Special school
Level 4	Where <b>critical</b> needs are evident	Tier 3 and 4 CAMHS
Children 's Social Care Child Protection Care Proceedings Hospital in-patient Residential SEN school	A child/YP likely to suffer significant harm in the family environment  A child/YP for whom the family are unable to provide care  Child/YP with complex medical needs requiring frequent attention e.g. medication, turning and /or intubation  Severe behavioural difficulties related to disability, impacting on ability of family to provide care at home  Child/YP whose high needs require education and care in residential school	In patient and/or continuing health care/ End of life care Fostering and residential care Specialist health care for children and young people with life limiting illness Overnight short breaks (over 30 nights per year) Residential school Health, Education and Care plan Major adaptations to home

# 5. Children and young people's Social Care

#### **Assessment**

All disabled children and young people who meet the Equality Act definition (see Page 4) are entitled to a social care assessment as 'children in need'. Where disabled children /YP and their families can meet their own support needs or directly access services at levels one and two (universal and additional), they are encouraged to do so. Essex County Council has a wide range of directly accessible services and sources of support available as outlined previously, for which a social care assessment is not required

Where a child/YP or family requests an assessment, this is carried out by talking and listening to the child/YP and their family and gathering information, with family consent, from professionals who know the child, such as GP, school and health visitor. The assessment will consider the specific needs of parents and other family members in their role as carers.

The assessment will enable us to make a judgement about the level of social care support required or whether the support needed can be provided by universal or additional services. The child/YP and their family will be given a copy of the completed assessment and be able to comment on it.

Where social care support is needed the assessment will lead to a 'child in need' plan which will set out what social care, other professionals and the family itself agree to do to address the needs identified. This will include what care and support is to be made available to the family either through a direct service or through a direct payment/personal budget.

Occupational Therapists (OTs) in social care also carry out assessments for equipment and adaptations using the same 4 level framework of need and principles.



### Principles informing child in need plan

- Social care will meet the assessed care and support needs of disabled children / YP and their families at levels three and four (intensive and complex) where these needs are beyond the capacity of the family to meet through their own and local community resources.
- Wherever possible we will seek to meet these needs through support in the family's own home.
- Where children/YP need overnight short breaks or longer term care outside the home, we will seek, wherever possible, to provide this in a normal family setting through foster care in the first instance and in a way that helps maintain strong connections to their family.

Some assessed needs may be met through a direct payment or personal budget. This will be agreed in the child in need plan. The direct payment/personal budget will be for the agreed level of social care support beyond and above that which the family are able to provide themselves or arrange through their own resources.

For some children and young people with Level 4 – Specialist needs, social care may use a tool called the Resource Allocation System (RAS) to help work out the level of service required to meet the needs assessed. This happens once the social care assessment, including any carer's assessment, is completed. The child/YP and family will be involved in completing the RAS with the social worker. This is particularly used for children with very high level needs.

### **Overnight short breaks (respite care)**

Normally short-breaks for carers are arranged during the day when children and young people can attend play, sport or other leisure activities. Parents can also be supported by sitting services and similar (often funded through direct payments) in the evenings. However, the complexity of some children/YP's needs is such that overnight short breaks may be required to support the child/YP and their family. It is usually in the child/YP's best interest that this occurs in a family setting such as with a regular foster carer or through a family friend or relative.

Residential short breaks are reserved for those children and young people with the most

complex physical and health care needs and/or challenging behaviour that require care from a staff team.

### **Child Protection**

The Children Act 1989 gives children's social care a statutory duty to carry out, with partner agencies including the Police, a Section 47 child protection assessment where there is information that a child has or is likely to suffer significant harm. This duty applies equally to disabled children as it does to all other children. Section 47 and subsequent child protection work will follow the processes set out in the Southend Essex and Thurrock child protection procedures. For young adults there are similar adult safeguarding duties and procedures and duties on social workers.

### **Accommodation**

Under section 20 of the Children Act, children's social care also has a responsibility to provide accommodation for any child where the person responsible for that child is unable to provide care for him or her. This duty also applies to disabled children. Children's social care will always work with parents to provide family support to prevent the need for any child, including disabled children, coming into local authority care.

Where disabled children are in overnight short break care for over 75 nights a year, they will usually be considered 'accommodated' under Section 20 and receive statutory child care reviews.

#### **Reviews**

Where a care plan has been agreed and is in place for a child in need, this plan and the services provided will be regularly reviewed at a minimum of every 6 months (annually for young adults). The review will involve a discussion with the child/YP and family, and other professionals, about the current needs. It will look at how effectively the care plan and services provided are addressing those needs, whether they are still needed and whether any changes to the plan and service provision are required. A review is, in effect, an updated assessment and care plan.

For children subject to a child protection plan or who are in care, there is a more formal multiagency review process chaired by a professional independent child's social worker or manager.

### Referrals to Children's Social Care

It is the responsibility of professionals in all agencies and the public in general to refer a child to children's social care when it is believed or suspected that the child:

- has suffered significant harm child protection
- is likely to suffer significant harm child protection
- has significant developmental or disability needs which are likely only to be met through provision of children's social care (with agreement of the child's parent) – a child in need

All referrals regarding a child in need or child protection should be made to Essex County Council's **Initial Response Team** (IRT) on **0845 603 7627**. Unless there is immediate likelihood of significant harm, the family should be consulted by the referrer and informed of the referral. The referrer can always ask to discuss their concerns with a qualified social worker in IRT if they are uncertain before they make a referral. For young adults aged 18+ referral should be made to adult social care on **0845 603 7630**.

Additional information or concerns on open cases in Children with Disabilities (CWD), or Young People with Disabilities (16 to 25) teams should be made to the allocated social worker (or in their absence the team manager or the duty social worker for that team).

If you are unsure who the social worker or team is, you can contact IRT on the number above.

### **Moving to Adulthood**

Both education and social care have a responsibility to support young people with a disability moving into adulthood. This work commences with the Personal Adviser attending the year 9 annual review at school where transition planning will begin. At this point, social care agrees which young people with a statement meet the disability definition and informs them and their families. These young people are entitled to a social care assessment in their final year at school (for some this will not be until aged 19).

Young People are also currently entitled to a Learning Difficulty Assessment when leaving school and moving onto education, employment or training. This will take place from age 16 and results in a plan, produced with the young person, that identifies the most appropriate provision and progression route, including any necessary support to make that progression a success.

Joint planning for disabled young people who are likely to require support from adult services will begin as early as possible and will engage with the young person to help them identify and plan for their life aspirations.

### **Advocacy and Complaints**

All children and young people old enough to understand and who are receiving a service should be told how they can access the advocacy service. The Advocacy Service is provided by Barnardo's and a link to their leaflet is at The Advocacy Service.

Children, young people and parents should be informed at the outset of social care involvement of their right to complain about any aspect of the service received, be it the assessment, the care plan or the support provided. They can complain by contacting the Customer Care Team, Essex County Council, PO Box 297, County Hall, Chelmsford CM1 1YS.

### **Parent Partnerships**

Close liaison and signposting of support with parent groups is important and actively promoted. Further details can be found at Face-Essex.org

# **Appendix**

#### **Useful Weblinks**

Effective Support to Children and Families - main document

Effective Support for Children and Families in Essex

Advice or guidance on Special Educational Need or Children with Additional needs

Special educational needs

Essex SEND strategy

Special Educational Needs strategy 2014 -19

Essex Safeguarding Children Board

Information related to safeguarding and promoting the welfare of children and young people

Details of training and development

www.escb.co.uk

**NHS Foundation Trusts** 

South and West Essex areas <a href="http://www.sept.nhs.uk/Our-Services/About-Us.aspx">http://www.sept.nhs.uk/Our-Services/About-Us.aspx</a>

Mid Essex areas <a href="http://www.cecs.org.uk/">http://www.cecs.org.uk/</a>

North Essex http://www.nepft.nhs.uk/ <a href="http://www.hertschs.nhs.uk/">http://www.hertschs.nhs.uk/</a>

Information on children's centres Children's centres

Early Help and Advice Hub <a href="https://www.essex.gov.uk/familysolutions">www.essex.gov.uk/familysolutions</a>

CAMHS - The Essex Provider Directory is a downloadable, searchable, up-to-date directory of services for

children, young people and families accessing CAMHS.

www.essexpartnershipportal.org.uk/live/partnership/73

https://ecclms.co.uk/goecclms.asp

Essex Schools info link

Information specifically for schools

Essex schools info link

Additional information is available through the on-line disability services in Essex at

Children with disabilities or special needs

Further details on Transitions Services can be found at:

**Transitions Services** 

#### Guidance

Information sharing guidance <u>Information Sharing guidance doc</u>

Lead Professional guidance The lead professional - Children and young people

Adult Social Care Services in Essex Eligibility Factsheet

Eligibility guidance

**NHS Mandate** 

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/213131/mandate.

pdf

**Essex County Council.** 

You can contact us in the following ways:

By email:

Transition.pathwayservice@essex.gov.uk

Visit our website:

www.essex.gov.uk

By telephone:

01245 430411

By post:

Room AGo8, County Hall, Chelmsford, CM1 1QH

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