

caring for children with special needs

Bringing up a child is always demanding. Caring for a child who has a special need – whether a learning disability, physical disability, medical condition, rare syndrome, life-threatening condition or behavioural problem – is even **more challenging**.

You may be unsure where to go for information and advice or be confused about **your rights** and those of your child. You may feel isolated and not know who to approach for support.

This factsheet helps clarify these issues and gives sources of further information and advice. The booklet *When your child has additional needs* covers some of the points in more detail. It is available from **Contact a Family** (freephone: 0808 808 3555 or www.cafamily.org.uk/whenyourchild).

You may also find the factsheet *Caring for people with learning disabilities* **useful**.



Your rights

The statutory authorities (health, education and social services) have legal obligations to identify and assess children with special needs under the Education Act 1993 and the Children Act 1989.

Health services

Medical assessment is carried out by a paediatrician following referral by the GP, health visitor or community paediatrician, usually at birth, after an accident or illness or as soon as a developmental problem is identified.

If you have concerns about your child's health or development you can contact a **health visitor** via your doctor's surgery or by attending the nearest **child health clinic**. The health visitor will check your child's development, discuss any problems with you and make a referral to a paediatrician or other services if necessary. Contact your doctor's surgery to find out details of your nearest clinic and session times.

The list below briefly describes how health services for children are organised within Brent.

- The **Brent Child Development Team** provides services to children with special health and education needs. These include physiotherapy, speech and language therapy, occupational therapy and orthotics.
- **Paediatric speech and language therapists** (020 8795 6331) help children who are experiencing difficulties with any aspect of the development of their ability to communicate, including early communication skills, speaking and non-verbal communication. They also assess and treat physical difficulties with eating and drinking. With very young children, the therapist may focus on developing play skills and early interactions with carers. Open referral.
- A child with complex medical needs will receive specialist nursing from the **Community Children's Nurses**. Carers will receive support and training in looking after their children to enable them to be discharged from hospital.
- **Community paediatric doctors** work within a number of multidisciplinary teams to assess and meet the health needs of children and young people with disabilities or special needs.
- Children with mental health problems are assessed and treated by the **Child and Family Service**.
- Dentists in the **Community Dental Service** (020 8795 6313/6315) are skilled at treating children with special needs.



- The **Wheelchair Service** (020 8438 7292) provides mobility equipment for children who have serious and permanent difficulties in walking, including manual and powered wheelchairs and children's buggies.
- The **Brent Continence Service** can provide support with toilet training for special needs children, both day and night, and access to continence products after assessment by a health visitor. Your health visitor can refer you to the service.

Information and support about specific conditions

Contact a Family (0808 808 3555, info@cafamily.org.uk, www.cafamily.org.uk) has information about national groups and specific conditions. Brent Carers Centre (020 8795 6240) can also help.

Education

ASSESSMENT

Even if your child is not yet at school, if you or a professional (such as the GP or health visitor) thinks she or he may have special needs you can ask the Special Educational Needs Assessment Service (SENAS: 020 8937 3215) to carry out a **statutory assessment**.

If SENAS decides an assessment is necessary you will be sent written notification, which you should receive 29 days before the assessment begins, to give you an opportunity to comment.

The assessment usually includes reports from the school, nursery or education adviser, an educational psychologist, other health professionals and yourself.

If SENAS decides an assessment is not necessary they should tell you why.

If, after the assessment, SENAS decides further action is needed, they may issue a **Statement of Special**

Educational Needs (see below), setting out your child's needs and recommending how they should be met.

If SENAS decides not to issue a statement, they should give you a **note in lieu of a statement**, setting out the reasons.

The whole process from the initial letter requesting a statement should take no longer than 26 weeks, but there are some exceptions to this rule.

The local authority should tell you the name of the person to contact for further information. Details from SENAS 020 8937 3215 or follow links from www.brent.gov.uk ('A-Z Council Services').

You can also get support, information and help from the independent **Brent Parent Partnership** (020 8937 3434, info@brentparentpartnership.co.uk).

STATEMENT OF SPECIAL EDUCATIONAL NEEDS

A statement sets out your child's needs, and recommends the special help she or he should have. This could be extra support within a mainstream school, or attending a special school or a special unit attached to a school (for example for children with speech problems). Brent has five special schools and five special units. The statement should include your child's non-educational needs, such as transport to school. It must be reviewed at least once a year.

Although Brent will make the final decision, **you have the right in the draft statement to express a preference** for which state school you want your child to attend, including one outside the borough.

Time spent researching suitable schools is time well spent. Brent has two nursery centres for children with a range of needs in addition to the nursery schools attached to primary schools. Social services also runs four nurseries (see 'Social services'). *Brent Primary School Guide* and *Brent Secondary School Guide*, which give comprehensive information about all schools and the education system in the borough, are available from the Education Information Service (020 8937 3000) and can be downloaded from www.brent.gov.uk/Educ.nsf/vwAllDocs/schools?open.

Information is also available on the **ChildCareLink** website www.childcarelink.gov.uk.

Another good route is often through a national society for your child's disability or condition (see 'Information about specific conditions').

SCHOOL

Each school must have a **written policy** for special needs, including admission arrangements.

PORTAGE

This is a home teaching scheme for any child from the age of six months who has a developmental delay. Referral is via **SENAS** (020 8937 3215). Further information is available from the **Brent Portage Service** (020 8937 3307). For general information about portage see www.portage.org.uk.

COMPLAINTS

If you are concerned with any aspect of the assessment process, including a decision *not* to do an assessment, or *not* to produce a statement, or the school named in the statement, you should first ask the Named Officer for an explanation, or contact the complaints manager on 020 8937 3241. If you are still concerned, you have the right to appeal to the **Special Educational Needs and Disability Tribunal**, Procession House, 55 Ludgate Hill, London EC4M 7JW (Helpline: 0870 241 2555, www.sendist.gov.uk).

FURTHER INFORMATION

- Booklets on the SENAS services are available from the **Education Information Shop** (020 8937 3000) or follow links to Special Educational Needs from www.brent.gov.uk ('A-Z Council Services').
- **Advisory Centre for Education** (0808 800 5793: 2pm-5pm, www.ace-ed.org.uk) – free guidance and advice on all aspects of state education. Publishes *Asking for a statutory assessment*, available from the website.
- **Brent Education Tuition Service** (020 8937 3330) – information about services for children with statements.
- **Centre for Studies on Inclusive Education** (0117 328 4007, <http://inclusion.uwe.ac.uk/csie>) – information and advice about educating children with special needs within ordinary schools.
- **Contact a Family** publishes the factsheet *Special educational needs, England*, available from 0808 808 3555, or www.cafamily.org.uk/factsheets.
- **Independent Panel for Special Education Advice** (0800 0184016, www.ipsea.org.uk) – independent advice for parents who are uncertain about, or disagree with, the education department's interpretation of their child's special educational needs.
- **Parents for Inclusion** (helpline 020 7582 5008 or freephone 0800 652 3145 Monday and Thursday, 10am-noon and 1pm-3pm, info@parentsforinclusion.org, www.parentsforinclusion.org) – helps parents get disabled children into mainstream schools.

- The parents and carers area of the **teachernet** website (www.teachernet.gov.uk/wholeschool/sen/parentcarers/) has answers to common questions and provides useful information. Users can order special educational needs publications online and download *SEN: a guide for parents and carers*, which sets out the main points of the SEN code of practice and explains procedures and rights.

Social services

ASSESSMENT

Brent Social Services Department has a duty to assess any child in need, which includes children with disabilities who may need extra support. Assessments are carried out by the **Disabled Children and Young Persons' Team** within Children's Services. You also have the right to ask for a carer's assessment – an assessment of your needs as the child's carer (see the factsheet *Social services* for details).

To request an assessment, either for your child or yourself, contact the One Stop Shop (020 8937 1200). Explain that you are caring for a child with a disability and would like an assessment of need.

Based on the assessment of need, the social worker will prepare a care plan, which should cover the services Brent is going to offer you, for example, respite including overnight and/or day care at a care centre, care at home, access to special needs playschemes and social work support for the family. The social worker can also make recommendations regarding Brent's social services nurseries.

If the team identifies other needs they will refer you on to the appropriate service, for example Occupational Therapy if your child needs special equipment, or adaptations need to be made to your home.

Respite and recreation

RESPITE

Respite care (formal care of your child while you take a break) includes care at home, day care away from home, residential breaks and family link schemes.

As part of social services' assessment of the family's needs (see 'Social services') your social worker will allocate you a number of respite days for the coming year, and agree transport arrangements.

Respite care for children with special needs can be provided in one of two Brent-run establishments.

- **Crawford Avenue** in Wembley has respite care places for children and young people with a severe learning disability and associated challenging behaviour.

- **Clement Close** in Kensal Rise provides fully accessible accommodation for children and young people with profound physical disabilities and complex medical needs.'

The **Family Links Unit** matches up families for home-based family breaks, whereby a child with a physical and/or learning disability goes to another family for a short break. Access is via the child's social worker.

Brent Short Break Scheme (020 8459 5298, brentscheme@nas.org.uk) provides short breaks (three hours a week, in blocks of 12 weeks) for the carers of people with autistic spectrum disorders.

NURSERIES

Social services runs a number of nurseries with facilities for children with special needs. Referral is through social services, via the One Stop Shop (020 8937 1200). These nurseries are in addition to those run by the education department (see 'Education').

The **Children's Information Service** (020 8937 3001) has lists of nurseries, childminders and playgroups in the borough. You can also search by area on **ChildCare Link** website www.childcarelink.gov.uk.

RECREATION AND PLAYSCHEMES

The **Aspire National Training Centre** (020 8954 5759, info@aspire.org.uk, www.aspire.org.uk) runs a number of activities accessible for children with a disability, including classes, courses and children's camps, and has an accessible gym and a swimming pool with ramped access. Also runs an integrated children's summer camp for disabled and non-disabled children.

Brent Children's Play Service (020 8810 9126) has a multi-sensory room, particularly suitable for stimulating children with perceptual disabilities. The room is fully wheelchair and hoist accessible. The Service also runs integrated holiday playschemes in each school holiday. Referrals for special needs places on playschemes are based on the **Child in Need assessment** made by social services' Disabled Children and Young Person's Team. To arrange an assessment contact the One Stop Shop (020 8937 1200).

Brent Mencap (020 8451 5278) coordinates a range of activities for children with a learning disability.

Hands in Unity (07985 465 722, handsinunity@aol.com) provides a range of free social activities for young people with learning disabilities.

Willesden Green Library (020 8937 3400, willesdengreenlibrary@brent.gov.uk) runs a toy library, where you can borrow toys suitable for children with special needs.



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HOLIDAYS, PLAY AND LEISURE

Some of the organisations listed in the factsheet *Time for yourself* should be able to give you helpful information. The leaflet *Holidays*, published by Contact a Family, (0808 808 3555, www.cafamily.org) is another useful source.

The **National Holiday Fund for Sick and Disabled Children** (01341 280 486, nhfoffice@aol.com, www.nhfcharity.co.uk) provides holidays for chronically or terminally ill children, and temporarily or permanently physically disabled children aged between 8 and 18 years.

The **Family Holiday Association** (020 7436 3304, info@fhaonline.org.uk, www.fhaonline.org.uk) provides grants to enable families to take a one week holiday break together. Referral must come from social services, the health authority or another welfare agency; families cannot apply themselves.

Voluntary organisations

Brent Carers Centre (020 8795 6240) provides advice, support and information to parent carers. It runs support groups and a Young Carers project and publishes a quarterly newsletter. See the factsheet *About this pack* for details.

Home-Start Brent (020 8937 3337, brenthomestart@aol.com, www.homestartbrent.org.uk) provides support to families with a child under five who are experiencing difficulties caused by isolation, illness, disability, economic or social problems.

Mencap runs the **Learning Disability Helpline** (freephone 0808 808 111, help@mencap.org.uk, www.mencap.org.uk/helpline), which gives information and advice on a range of issues for people with a learning disability, parents, carers and social care professionals.

Contact a Family (CaF) (freephone 0808 808 3555, www.cafamily.org.uk) provides advice on all issues facing families who care for a child with a disability or any kind of special needs.

CaF's website www.MakingContact.org enables families to get in touch with others who are affected by the same or similar disabilities or medical conditions.

Government initiatives

There are a number of government-funded organisations working in all or specific parts of Brent that can provide advice and support, including Surestart, Healthy Harlesden and Connexions. Contact Brent Carers Centre (020 8795 6240) for further information.

Aids and adaptations

There is a range of aids, equipment and adaptations to your home that can make your life easier and promote your child's independence and mobility.

They are covered in the factsheets *Housing*, *Health issues* and *Social services*.

Financial support

You and your child may be entitled to certain social security benefits.

The majority are listed in the factsheet *Money matters*; those specifically for children are listed below. The system is quite complicated, but you can get advice about your entitlements and help with completing forms from the **Benefits Enquiry Line** (0800 88 22 00) or **Brent Carers Centre** (020 8795 6240). **Contact a Family's** factsheet *Benefits, tax credits and other financial assistance*, gives information on help available to families with disabled children. It is available from CAF's helpline (0808 808 3555) or www.cafamily.org.uk/factsheets.

- **Disability Living Allowance (DLA)** is the main benefit for anyone with an illness or disability who needs help with getting around and/or help with personal care. To claim you need to complete the form **DLA1 Child**, available from local social security or Jobcentre Plus offices (see the factsheet *Useful contacts*), www.direct.gov.uk/DisabledPeople (follow the links), the Benefits Enquiry Line (0800 88 22 00) and Brent Carers Centre (020 8795 6240).

- If your child receives DLA you may be entitled to **Carer's Allowance**.

If you receive Income Support, Housing Benefit or Council Tax Benefit you may be entitled to **Disabled Child's Premium** or the **Enhanced Disability Premium** if your child receives DLA.

Other possible sources of financial support include the **Family Fund Trust** (0845 130 4542, textphone 01904 652625, info@familyfundtrust.org.uk, www.familyfundtrust.org.uk), which can cover items needed to help relieve the stress of caring for a disabled or seriously ill child under 16. Grants can cover a range of items, including holidays, leisure, laundry equipment, transport expenses and driving lessons.

**Remember that other factsheets in this pack
may also include information useful to you**

