

Parent carers: National organisations

This factsheet lists national organisations that offer support and advice to parents and carers of a child or young person with special educational needs and/or a disability (SEND).

If your child has a diagnosis of disability there may also be a national organisation that can offer advice and provide information specific to your child's condition.

There are also a number of internet sites that have been set up by parents who have found themselves in a similar situation to yourself. Many, such as www.specialneedsjungle.com, can offer valuable information based upon personal experience. It is important, however, to check that these sites are reliable. Check that the information they contain is current and which sites they are linked to. Reputable websites often link to each other.

CDC - Council for Disabled Children

An umbrella organisation connecting professionals, practitioners and policy-makers. The CDC is unable to advise on individual cases but provides an online library of resources about disability policy and practice written specifically for parents:

- Parent carer guide to the SEND Code of Practice
- Disabled Children: A Legal Handbook
- Expert Parent Programme
- A family guide to the SEN system
- My Rights, Your Responsibility leaflets
- Requirements to provide Health Advice in relation to an Education, Health and Care plan within six weeks

cdc@ncb.org.uk

www.councilfordisabledchildren.org.uk

Cerebra

A charity providing support for families with a child (from birth to 16 years) with a brain condition. A 'brain condition' is any disorder or disability that affects the brain, including those caused by illness, genetics or traumatic injury. Brain conditions include (but are not limited to) autism, ADHD, Down's syndrome, learning disabilities, cerebral palsy, epilepsy and developmental delay. Cerebra operate a free helpline, a sleep advice service, a postal lending library for books and DVDs, a legal rights service, and provide free to download factsheets and guides on the following topics:



Cerebra continued

- Carers' Assessments
- Disability Living Allowance Mythbuster
- Education
- Emotional Wellbeing
- Finding and Assessing Sources of Legal Help
- Money Matters
- School transport
- Sensory Processing
- Sleep
- Social Care
- Toilet Training
- Transition to Adulthood

Telephone: 0800 328 1159

www.cerebra.org.uk

Contact

A charity offering guidance and information for families with disabled children. Provides a free helpline for parents and carers with a disabled child (with or without a diagnosis) aged from birth to 25 years; a Listening Ear service for practical and emotional support; Workshops and events. Free guides and factsheets can be downloaded. A print version of any of the parent guides may also be requested. Their publication "Our helpful guide for disabled children" provides an overview of all the help available. Information is available on the following subjects:

- Cost of living advice
- Covid-19 & families with disabled children
- Early years support
- Benefits and tax credits
- Education & learning
- Social care
- Health and medical info
- Family life, work & childcare
- Preparing for adult life
- Helpline

Their Fledglings online shop sells toys, clothing and sensory products.

Telephone: 0808 808 3555 (Monday to Friday 9.30am – 5pm)

helpline@contact.org.uk

www.contact.org.uk



IPSEA - Independent Provider of Special Education Advice

Offers free and independent legally based information, advice and support on any educational issue that is a result of a child's SEND. Provides an Advice Line, Tribunal Helpline, Call-in Helpline, Tribunal Support Service and Information Service. Free legal guides and resources can be downloaded from their website together with model letters that can be amended to meet specific needs. Information is available on the following subjects:

- What are special educational needs?
- How should the local authority help?
- How should your nursery, school or college help?
- Exclusion and children out of school.
- Education, Health and Care plans.
- Choosing a school or college.
- Transport to school or college.
- Young people (aged 16 – 25 years)
- Model letters.
- SEN and disability law.
- Making a complaint or challenging a decision.
- Health and social care.

Telephone: 01799 582 030 (Admin Office, Monday to Friday 9am to 5pm)

Helpline: 0300 222 5899 (Friday, 10am to 3pm) office@ipsea.net www.ipsea.org.uk

Mencap

A national charity supporting people with a learning disability and their families and carers. Provides a free learning disability helpline, cost of living information, downloadable information and advice factsheets including:

- Information on Coronavirus (Covid-19)
- Everyday living (benefits, education, skills, work, social care, transport)
- Friendships and relationships (befriending, bullying, safeguarding, sexuality)
- Early years and children (diagnosis, education, children & young people)

Mencap services also include the Wills and Trusts Service, Supported living service, Short breaks & respite, Local groups are more.

Telephone: 0808 808 1111 (Learning Disability Helpline, Monday to Friday 10am – 3pm)
helpline@mencap.org.uk www.mencap.org.uk



Sibs

The only UK charity offering information and support to adults, children and young people growing up with a brother or sister who is disabled, has special educational needs or a serious long-term condition. The information they provide aims to help siblings support each other and understand their feelings, attention, and understanding of the disability or additional needs. They also offer an online support and information service for children and young people aged 7 – 17 years (www.youngsibs.org.uk).

Sibs runs online events, workshops, and currently FREE mindfulness course for adult sibling carers, whereas Young Sibs offers information and advice catered to a younger group. The young person can also ask questions to a sibling advisor via its website.

Telephone: 01535 645 453
www.sibs.org.uk

info@sibs.org.uk
www.sibs.org.uk/youngsibs

Please note: inclusion on our list does not imply recommendation or endorsement by Carers' Resource.

Carers' Resource has produced a range of factsheets that you may also find useful:

- Parent carers: a guide to grants
- Parent carers: support and activities in the Bradford District
- Parent carers: support and activities in the Craven area
- Parent carers: support and activities in the Harrogate, Knaresborough and Ripon areas

If you would like a copy, please contact your local office - details below - or download from www.carersresource.org.

If you need further information or would like to discuss any aspect of your caring role, please contact Carers' Resource:

Harrogate 01423 500555

Unit 3, Grove Park Court, Grove Park Terrace, Harrogate, HG1 4DP

Bradford 01274 449660

15 Park View Court, St Paul's Road, Shipley, BD18 3DZ

Skipton 01756 700888

Ronaldsway House, 36 Brook Street, Skipton, BD23 1PP

info@carersresource.org

www.carersresource.org

We can provide this information in another format. Please contact us to discuss your requirements.

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