Information about Useful Contacts and Organisations
This resource gives details of a range of organisations that offer information, advice, guidance, advocacy and support. Some of the information will be relevant to all families while others are specific to certain ages, ethnic groups or disabilities/conditions. It’s not exhaustive but it is extensive. We hope you find it useful.

Contents

Ability Net................................................................. 6
Action for Children ........................................................ 6
Action on Hearing Loss ..................................................... 6
Advisory Centre for Education (ACE) .................................. 7
Afasic ........................................................................... 7
Aiming High for Disabled Children (AHDC) ......................... 7
Ambitious about Autism ................................................... 8
Association of Speech and Language Therapists in Independent ........................................... 8
Barnardo’s .................................................................. 8
Benefit Enquiry Line (BEL) ................................................. 9
Bliss ............................................................................ 9
Blissymbol Communication UK ........................................ 9
British Association for Counselling and Psychotherapy (BACP) .............................................. 10
British Deaf Association (BDA) .......................................... 10
British Institute for Learning Disabilities (BILD) .......................... 10
Bullying UK .................................................................. 11
Carers Trust .................................................................. 11
Carers UK ..................................................................... 11
Cerebra ........................................................................ 11
Challenging Behaviour Foundation .................................... 12
CHANGE ...................................................................... 12
Changing Faces ................................................................ 13
CHARGE Family Support Group ......................................... 13
Child Death Helpline ....................................................... 13
The Children’s Sleep Charity .............................................. 13
Citizens Advice Bureau .................................................... 14
The Communications Trust .............................................. 14
Contact a Family ................................................................ 14
Coram .......................................................................... 15
Background information - Useful contacts and organisations

Council for Disabled Children ................................................................. 15
Counselling Directory ........................................................................ 15
Daycare Trust ...................................................................................... 16
Deafax .................................................................................................... 16
Department for Education .................................................................. 16
Disability, Pregnancy and Parenthood International ....................... 17
Disability Rights UK ........................................................................... 17
Disabled Information and Advice Line (DIAL UK) ......................... 17
Disabled Living Foundation and Shaw Trust Partnership ............... 18
Disabled Persons Transport Advisory Committee (DPTAC) ......... 18
Down’s Heart Group .......................................................................... 18
Down’s Syndrome Association (DSA) ............................................... 19
Down Syndrome Education International (Downsed) ..................... 19
Early Years Equality ............................................................................ 19
Education and Resources for Improving Childhood Continence (ERIC) ................................................................. 20
Epilepsy Action .................................................................................... 20
Epilepsy Society .................................................................................. 20
Equality Advisory and Support Service (EASS) ................................ 21
Equality and Human Rights Commission ........................................ 21
Every Disabled Child Matters (EDCM) ............................................ 21
Family Action ....................................................................................... 21
Family and Childcare Trust ............................................................... 22
Family Fund ........................................................................................ 22
Family Information Service (FIS) ....................................................... 23
Family Rights Group .......................................................................... 23
Fledglings ............................................................................................. 23
Foundations ......................................................................................... 23
Foundation for people with learning disabilities .......................... 24
Genetic Alliance ................................................................................... 24
Genetic Interest Group (GIG) ............................................................ 25
Gingerbread .......................................................................................... 25
Go Kids Go! ......................................................................................... 25
Gov.uk ................................................................................................ 26
Guide Dogs .......................................................................................... 26
HemiHelp .............................................................................................. 26
Home-Start UK .................................................................................... 26
I CAN .................................................................................................... 27
Include Me Too .......................................................................................................................... 27
Independent Parental Special Education Advice (IPSEA) ............................................................. 27
Independent Support ................................................................................................................. 27
Information Advice and Support Services Network (IASSN) ......................................................... 28
KIDS ........................................................................................................................................ 28
Kidscape ..................................................................................................................................... 28
Law Centres Network ............................................................................................................... 29
Letterbox Library .................................................................................................................... 29
Local Government Ombudsman ............................................................................................... 29
LOOK ........................................................................................................................................ 30
The Makaton Charity ................................................................................................................ 30
Marriage Care .......................................................................................................................... 31
Mencap ....................................................................................................................................... 31
Meningitis Trust ....................................................................................................................... 31
Mosaic Down Syndrome .......................................................................................................... 32
Nasen .......................................................................................................................................... 32
National Autistic Society (NAS) ................................................................................................. 32
National Blind Children’s Society ............................................................................................. 33
National Childminding Association (NCMA) ........................................................................... 33
National Children’s Bureau (NCB) ........................................................................................... 33
National Consortium on Deaf-Blindness (NCDB) .................................................................... 34
The National Deaf Children’s Society (NDCS) ......................................................................... 34
The National Institute of Neurological Disorders and Stroke .................................................. 34
Natspec ..................................................................................................................................... 35
NHS Direct ............................................................................................................................... 35
The National Children’s Bureau ............................................................................................... 35
The National Network of Parent Carer Forums (NNPCF) ........................................................... 36
National Portage Association (NPA) ......................................................................................... 36
Ofsted ........................................................................................................................................ 37
Orphanet ..................................................................................................................................... 37
The Patients Association .......................................................................................................... 38
Preparing for Adulthood ......................................................................................................... 38
Pre-school Learning Alliance .................................................................................................... 38
RP Fighting Blindness ................................................................................................................ 39
The Royal College of Psychiatrists ............................................................................................ 39
The Royal National Institute of Blind People (RNIB) ............................................................... 40
Background information - Useful contacts and organisations

Scope........................................................................................................................................40
Sense.........................................................................................................................................40
Sibs.............................................................................................................................................41
SOS!SEN.....................................................................................................................................41
Tax Credit Helpline ....................................................................................................................41
Together for Short Lives .............................................................................................................41
Tourism for All............................................................................................................................42
Transition Information Network (TIN) .........................................................................................42
Treacher Collins Family Support Group .......................................................................................43
Turn2Us.......................................................................................................................................43
Twin and Multiple Birth Association (TAMBA) .........................................................................43
Whizz-Kidz .................................................................................................................................44
Winston’s Wish ............................................................................................................................44
Working Families .........................................................................................................................44
YoungMinds ...............................................................................................................................45
YourLocalCinema.com ...............................................................................................................45
**Ability Net**
Offers advice and information on computers and software for disabled people. It has community partners in various locations across the UK.
www.abilitynet.org.uk
enquiries@abilitynet.org.uk
0800 269545
Minicom: 01926 312847

**Action for Children**
Campaigns for quality care for disabled and disadvantaged children. It provides short breaks, advocacy and key working, and early years support and resources about making the transition to adulthood.
3 The Boulevard
Ascot Road
Watford
WD18 8AG
www.actionforchildren.org.uk
ask.us@actionforchildren.org.uk
0300 1232112

*Action for Children - Growing Our Strengths* – A project We’re working on a number of ways to help organisations improve their skills, demonstrate their impact and improve outcomes for children and families.
http://www.actionforchildren.org.uk/growing-our-strengths

**Action on Hearing Loss**
Action on Hearing Loss is the new name for RNID. The organisation aims to achieve a better quality of life for deaf and hard of hearing people. It does this by campaigning, lobbying and raising awareness of deafness, and by providing services.
19-23 Featherstone Street
London
EC1Y 8SL
www.actiononhearingloss.org.uk
informationline@hearingloss.org.uk
Freephone information line: 0808 808 0123  Textphone: 0808 808 9000
Text: 0780 0000360
Advisory Centre for Education (ACE)
They are set up by ex-staff to continue some of the advice and training services provided by The Advisory Centre for Education. They offer information about state education in England and Wales. Although most of its information relates to children over five, it can advise on special education for younger children.
ACE Education Advice & ACE Education Training
72 Durnsford Road
London
N11 2EJ
www.ace-ed.org.uk
enquiries@ace-ed.org.uk
020 8888 3377 (Telephone for business enquiries only)

Afasic
A parent-led organisation representing children and young people with speech and language impairments. It works for their inclusion in society and supports their parents and carers. Afasic offers publications, local groups, an online forum, a programme of training and conferences, and activities for young people. It has a national helpline.
1st Floor
20 Bowling Green Lane
London
EC1R 0BD
www.afasic.org.uk
info@afasic.org.uk
Helpline: 0845 3555577
020 74909410

Aiming High for Disabled Children (AHDC)
A government programme offering information, resources and materials for parents and carers of children with additional needs.
www.education.gov.uk/childrenandyoungpeople/send/ahdc/b0070490/aiming-high-for-disabled-children-ahdc
Ambitious about Autism
A national charity for children and young people with autism. It provides services, raises awareness and understanding, and campaigns for change. It also offers specialist education and support.
c/o The Pears National Centre for Autism Education
Woodside Avenue
London
N10 3JA
www.ambitiousaboutautism.org.uk
info@ambitiousaboutautism.org.uk
School enquiries: 020 88155424
General enquiries: 020 88155444

Association of Speech and Language Therapists in Independent Practice (ASLTIP)
This is a professional body for speech and language therapists who work independently. All members are registered and qualified therapists. The association provides information on independent speech and language therapy throughout the United Kingdom, including local contacts.
Coleheath Bottom
Speen
Princes Risborough
Buckinghamshire
HP27 0SZ
www.helpwithtalking.com
01494 488306 (answerphone)

Barnardo’s
Provides services across the UK working with vulnerable children, young people, families and communities.
Tanners Lane
Barkingside
Ilford
Essex
IG6 1QG
www.barnardos.org.uk
supportercare@barnardos.org.uk
020 85508822
Benefit Enquiry Line (BEL)
A confidential telephone service for people with disabilities, their representatives and their carers. General advice is available on benefits available for people with disabilities, as well as forms and leaflets.
Warbreck House
Warbreck Hill Road
Blackpool
FY2 0YE
www.direct.gov.uk/disability-money
bel-customer-services@dwp.gsi.gov.uk
Helpline: 0800 882200 Textphone helpline: 0800 243 355

You can also claim for benefits (such as Disability Living Allowance) via the Department for Work and Pensions online service: www.dwp.gov.uk/eservice/.

Bliss
A UK charity that helps care for premature and sick babies. It supports families, funds cutting-edge research and campaigns for improved hospital resources.
2nd Floor
9 Holyrood Street
London
SE1 2EL
www.bliss.org.uk
hello@bliss.org.uk
Free help and advice line: 0500 618140 & 020 73781122

Blissymbol Communication UK
Provides information and resources about the Blissymbol communication system for people with language, communication and learning difficulties. It also works to promote Blissymbols and publish the symbols.
c/o ACE Centre
92 Windmill Road
Oxford
OX3 7DR
www.blissymbols.co.uk
info@blissymbols.co.uk
07811 452444
British Association for Counselling and Psychotherapy (BACP)
The association aims to promote counselling, maintain and raise standards, provide information, advice and lists of counsellors, and represent counselling and psychotherapy at national level.
BACP House
15 St John’s Business Park
Lutterworth
Leicestershire
LE17 4HB
www.bacp.co.uk
bacp@bacp.co.uk
0870 4435252
Minicom: 0870 4435162

British Deaf Association (BDA)
The BDA is the UK’s largest national organisation run by deaf people, for deaf people. The BDA works to increase deaf people’s access to facilities and lifestyles that most hearing people take for granted, and ensures greater awareness of their rights and responsibilities as members of society.
18 Leather Lane
London
EC1N 7SU
www.bda.org.uk
admin@bda.org.uk
08451 302851

British Institute for Learning Disabilities (BILD)
Offers a range of services to support those working with people with learning disabilities and their families. These services include training for professionals, information services and one-day events and conferences.
Campion House, Green Street
Kidderminster
Worcestershire
DY10 1JL
www.bild.org.uk
enquiries@bild.org.uk
01562 723010
Bullying UK
This is part of the charity called Family Lives. It provides support and information to young people and adults who have been bullied and their families.
CAN Mezzanine
49-51 East Road
London
N1 6AH
www.bullying.co.uk
parentsupport@familylives.org.uk
Helpline: 0808 8002222

Carers Trust
Carers Trust is a new charity that was formed by the merger of The Princess Royal Trust for Carers and Crossroads Care in April 2012. It works to improve support, services and recognition for anyone living with the challenges of being an unpaid carer for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.
32-36 Loman Street
London
SE1 0EH
www.carers.org
info@carers.org
0844 8004361

Carers UK
A registered charity that provides support to anyone who is a carer. It offers information and advice, produces a range of publications and also campaigns for carers’ rights.
20 Great Dover Street
London
SE1 4LXP
www.carersuk.org adviceline@carersuk.org
Advice line: 0808 8087777 020 73784999

Cerebra
A unique charity set up to help improve the lives of children and young people with brain-related conditions through researching, educating and directly supporting children and their carers.
FREEPOST SWC3360
Carmarthen
SA31 1ZY
www.cerebra.org.uk
info@cerebra.org.uk
Parent support helpline: 0800 3281159

**Challenging Behaviour Foundation**
The foundation provides information and support to parents and carers of individuals with severe learning disabilities who are described as having challenging behaviour. Resources include information sheets/packs and DVDs, which are free for unpaid carers. There is also a Family Support Network and a professional email network for sharing best practice.
c/o The Old Courthouse
New Road Avenue
Chatham
Kent
ME4 6BE
www.challengingbehaviour.org.uk
support@thecbf.org.uk
Family support line: 0845 6027885

**CHANGE**
An international organisation for people with learning disabilities. CHANGE makes information accessible through the use of short words and pictures. It offers consultancy work and publications.
Unit 11, Shine
Harehills Road
Leeds
LS8 5HS
www.changepeople.co.uk
info@change-people.co.uk
0113 3880011
Changing Faces
A charity for people and families who are living with conditions, marks or scars that affect their appearance. They give practical and emotional support to adults, children and their families. We also provide training, support and advice to professionals in health and education.
The Squire Centre,
33-37 University Street,
London,
WC1E 6JN.
www.changingfaces.org.uk
info@changingfaces.org.uk
Queries: 0845 4500 275 or 0207 391 9270 Fax 0845 4500 276

CHARGE Family Support Group
A registered charity for people with CHARGE syndrome and their families. The group has a network of families who aim to promote and support all activities leading to an improved quality of life for their children. The first point of contact in England for new families is Simon Howard.
59 Elmer Road
London SE6 2HA
www.chargesyndrome.org.uk
info@chargesyndrome.org.uk
020 82653604

Child Death Helpline
Trained volunteers, who are all bereaved parents, supported and supervised by professionals, provide a freephone telephone listening service for anyone affected by the death of a child of any age, under any circumstances.
www.childdeathhelpline.org.uk
contact@childdeathhelpline.org
Helpline: 0800 282986
Freephone for mobiles: 0808 8006019

The Children’s Sleep Charity
They offer different training packages around sleep and train both parents and professionals. They run sleep clinics and a sleep practitioner course, a sleep tight workshop, a sleep success workshop and a foster carer’s sleep training.
http://www.thechildrenssleepcharity.org.uk/
info@thechildrenssleepcharity.org.uk 07912 667676
**Citizens Advice Bureau**
Helps people resolve their legal, money and other problems by providing free, confidential and impartial information and advice. It has a number of field offices across England.
Myddelton House,
115-123 Pentonville Road,
London
N1 9LZ
www.citizensadvice.org.uk (for local offices); www.adviceguide.org.uk
020 78332181 (admin only)

**The Communications Trust**
The Communication Trust is a coalition of over 50 not-for-profit organisations that works with children and young people in England to support their speech, language and communication. Their work focuses on supporting children and young people who struggle to communicate because they have speech, language and communication needs (SLCN) as well as supporting all children and young people to communicate to the best of their ability.
The Communication Trust
8 Wakley Street
London
EC1V 7QE
http://www.thecommunicationtrust.org.uk/
enquiries@thecommunicationtrust.org.uk
0207 843 2526

**Contact a Family**
A UK-wide charity providing support, advice and information for families with children with additional needs. It runs a helpline for family members and can help you get in touch with other parents of disabled children living near you.
209-211 City Road
London EC1V 1JN
www.cafamily.org.uk
helpline@cafamily.org.uk
Helpline: 0808 8083555 (9:30am-5pm, weekdays)
020 76088700
Coram

(Coram Children’s Legal Centre)
Coram Children’s Legal Centre, part of the Coram group of charities, specialises in law and policy affecting children and young people. They provide free legal information, advice and representation to children, young people, their families, carers and professionals, as well as international consultancy on child law and children’s rights.
Coram Children's Legal Centre
Riverside Office Centre
Century House North
North Station Road
Colchester,
CO1 1RE
info@coramclc.org.uk
01206 714 650 (NB: we can not give free legal advice on this number). Fax: 01206 714 660

Council for Disabled Children
A national forum for the discussion, development and dissemination of a wide range of policy and practice issues relating to service provision for children and young people with disabilities and special educational needs. Membership is drawn from a wide range of professional, voluntary and statutory organisations and includes parent representatives and representatives of disabled people.
8 Wakley Street
London
EC1V 7QE
www.councilfordisabledchildren.org.uk
cdc@ncb.org.uk
020 78431900

Counselling Directory
They provide counselling advice and information - connecting those in distress with the largest support network in the UK.
Counselling Directory, Coliseum
Riverside Way,
Camberley
Surrey, GU15 3YL
http://www.counselling-directory.org.uk/
0844 8030 240

**Daycare Trust**
A national childcare charity working to promote high-quality, affordable childcare for everyone. It provides information about all aspects of childcare.
2nd Floor, The Bridge
73-81 Southwark Bridge Road
London
SE1 0NQ
www.daycaretrust.org.uk; www.payingforchildcare.org.uk
info@daycaretrust.org.uk
020 79407528 (admin only)

**Deafax**
Deafax exists to empower deaf people by offering them access to new and innovative technologies.
The Saunderton Estate
Wycombe Road
Saunderton
Buckinghamshire
HP14 4BF
www.deafax.org
info@deafax.org
0149 4568885

**Department for Education**
The Department for Education is responsible for education and children’s services in England. We work to achieve a highly educated society in which opportunity is equal for children and young people, no matter what their background or family circumstances. DfE is a ministerial department, supported by 9 agencies and public bodies.
Ministerial and Public Communications Division
Department for Education
Piccadilly Gate
Store Street
Manchester
M1 2WD
Disability, Pregnancy and Parenthood International
Offers a national information service and publications on all aspects of disability, pregnancy and parenthood. The London resource centre also offers face-to-face appointments.
336 Brixton Road
London
SW9 7AA
www.dppi.org.uk
info@dppi.org.uk
Freephone: 0800 0184730
Minicom: 0800 0189949

Disability Rights UK
A national, pan-disability organisation led by disabled people. It provides advice, publications and a number of helplines for disabled people.
12 City Forum
250 City Road
London
EC1V 8AF
www.disabilityrightsuk.org
skill4disabledstudents@disabilityrightsuk.org
Disabled students helpline: 0800 3285050
Independent living advice line: 0845 0264748
020 72503222 (admin only)

Disabled Information and Advice Line (DIAL UK)
A national network of advice agencies for people with disabilities. The website includes fact sheets and a search facility to find local contacts.
www.dialuk.info
informationenquiries@dialuk.org.uk
01302 310123
Textphone: 01302 310123
Disabled Living Foundation and Shaw Trust Partnership

The Disabled Living Foundation (DLF), a national charity providing impartial advice, information and training on independent living for over 40 years, has joined forces with Shaw Trust. The charities will merge at the end of November and DLF will retain its name, identity and staff.

Disabled Living Foundation,
Ground Floor, Landmark House,
Hammersmith Bridge Road,
London,
W6 9EJ
020 7289 6111, 9am - 5pm, Mon-Fri
http://www.dlf.org.uk/node/712
General email: info@dlf.org.uk
Helpline: 0300 999 0004 email helpline@dlf.org.uk 10 a.m. - 4 p.m., Mon-Fri
Training: 020 7432 8010 or email training@dlf.org.uk

Disabled Persons Transport Advisory Committee (DPTAC)

A travel guide for disabled people.
2/17 Great Minster House
33 Horseferry Road
London
SW1P 4DR
www.dptac.gov.uk/door-to-door
dptac@dft.gsi.gov.uk

Down’s Heart Group

A charity offering support and information relating to heart conditions associated with Down’s Syndrome. All their information publications have been written by Down’s Heart Group from a parent's perspective and as well as being evidence based.

Down's Heart Group
PO Box 4260
Dunstable
Beds
LU6 2ZT
http://www.dhg.org.uk/
info@dhg.org.uk
0844 288 4800
**Down’s Syndrome Association (DSA)**

Provides information and support on all aspects of living with Down’s syndrome. It also works to champion the rights of people with Down’s syndrome, by campaigning for change and challenging discrimination. A wide range of Down’s Syndrome Association publications can be downloaded free of charge from its website. Printed copies are available for a small fee. Single copies of most leaflets and information sheets are available free of charge to members.

The Langdon Down Centre
2A Langdon Park
Teddington
Middlesex
TW11 9PS
www.downs-syndrome.org.uk
info@downs-syndrome.org.uk
0333 1212300

**Down Syndrome Education International (Downsed)**

Downsed focuses on the education and development of individuals with Down’s syndrome. It undertakes innovative scientific research, publishes practical information, organizes conferences and workshops, and provides advice and consultancy services. Downsed has specialist knowledge in early years intervention and inclusive education. It also operates a mail order service selling a comprehensive range of books and teaching resources for children with Down’s syndrome.

6 Underley Business Centre
Kirkby Lonsdale
Cumbria LA6 2DY
www.dseinternational.org
info@dseinternational.org
030 03300750

**Early Years Equality**

Provides disability equality and other protected characteristic equality support, guidance, advice, discrimination casework and training to children, families, organisations, providers and policy makers across the UK.

www.earlyyearsequality.org.uk
enquiries@earlyyearsequality.org.uk
0114 2700214
Education and Resources for Improving Childhood Continence (ERIC)
Provides support and information for children and their families on childhood Bed-wetting, daytime wetting, soiling and constipation.
36 Old School House
Britannia Road
Kingswood
Bristol
BS15 8DB
www.eric.org.uk; www.ericshop.org.uk
info@eric.org.uk
Helpline: 0845 3708008 (10am-4pm, weekdays)

Epilepsy Action
Campaigns to improve epilepsy services and raise awareness of the condition. It offers assistance to people in a number of ways, including a national network of branches, accredited volunteers, regular regional conferences and freephone and email helplines.
New Anstey House
Gate Way Drive
Yeadon
LEEDS
LS19 7XY
www.epilepsy.org.uk
helpline@epilepsy.org.uk
Freephone helpline: 0808 8005050 (10am-4pm, weekdays)
Text Helpline: 07797 805390
0113 2108800

Epilepsy Society
Provides care, medical services, research, and a wide range of information, education and training to people with epilepsy, their families, friends and professionals involved in their care.
Chesham Lane
Chalfont St Peter
Buckinghamshire SL9 0RJ
www.epilepsysociety.org.uk
enquiries@epilepsysociety.org.uk
Helpline: 01494 601400
01494 601300
Equality Advisory and Support Service (EASS)
This service replaces the Equality and Human Rights Commission helpline and is aimed at individuals who need more expert advice and support on discrimination than advice agencies and other local organisations can provide. It explains legal rights and remedies within discrimination legislation.
FREEPOST
Equality Advisory Support Service
FPN4431
www.equalityadvisoryservice.com
adviceline@equalityadvisoryservice.com
0800 444205
Textphone: 0800 444206

Equality and Human Rights Commission
Its statutory remit is to promote and monitor human rights, and to protect, enforce and promote equality across the nine ‘protected’ grounds – age, disability, gender, race, religion and belief, pregnancy and maternity, marriage and civil partnership, sexual orientation and gender reassignment.
www.equalityhumanrights.com
0800 444205
Textphone: 0800 444206

Every Disabled Child Matters (EDCM)
A campaign to get rights and justice for every disabled child. The campaign works closely with the disabled children's sector and its supporters, to lobby government to ensure disabled children and their families have the services and support they need to lead ordinary lives.
8 Wakley Street
London
EC1V7QE
www.edcm.org.uk
info@edcm.org.uk
020 78436082

Family Action
Provides a wide range of support to children, young people and families living with poverty, ill-health and in social isolation. Help includes specialist work with children with additional needs and financial support to families.
Background information - Useful contacts and organisations

501-505 Kingsland Road
London
Dalston
E8 4AU
www.family-action.org.uk
020 72546251 (Tue, Wed and Thu, 2-4pm)

Family and Childcare Trust
They work through research, campaigning and information provision, and working with government, employers and parents to reduce pressures on family life. This means campaigning for quality childcare that is affordable and accessible to parents, and ensuring families get a better work-life balance through our campaign to promote working rights for parents.
Family and Childcare Trust,
The Bridge,
81 Southwark Bridge Road,
London
SE1 0NQ
http://www.familyandchildcaretrust.org/
info@familyandchildcaretrust.org
020 7940 7510

Family Fund
An independent organisation mainly funded by the government administrations of England, Scotland, Northern Ireland and Wales. Family Fund can give grants and information to families caring for a severely disabled child aged 17 or under.
4 Alpha Court
Monks Cross Drive
Huntington
York
YO32 9WN
www.familyfund.org.uk
info@familyfund.org.uk
08449 744099
Textphone: 01904 658 085
**Family Information Service (FIS)**

The FIS can give you information about the full range of childcare and other services for children, young people and families available in the area. You can contact the FIS through your local authority office or find your local FIS contact details at the following website. [www.daycaretrust.org.uk/findyourFIS](http://www.daycaretrust.org.uk/findyourFIS)

**Family Rights Group**

Provides advice and support for families whose children are involved with social services.

Second Floor  
The Print House  
18 Ashwin Street  
London E8 3DL  
[www.frg.org.uk](http://www.frg.org.uk)  
advice@frg.org.uk  
Advice line: 0808 8010366 (10am-3pm, weekdays)  
020 79232628

**Fledglings**

Fledglings is a national charity that finds and sells products that improve the lives of disabled children and their families. We understand that life with a disabled child can be challenging, and we help by providing practical, affordable, good quality products that address everyday problems faced by children with disabilities such as cerebral palsy and autism. Whether you are a parent or carer of a disabled child, grandparent or family friend, teacher or health professional, Fledglings can help make life a little bit easier.

Fledglings, Wenden Court  
Station Approach, Wendens Ambo,  
Saffron Walden,  
CB11 4LB  
enquiries@fledglings.org.uk  
[http://www.fledglings.org.uk](http://www.fledglings.org.uk)  
Helpline: 0845 458 1124 / 01799 541 807 (Open Monday to Friday 9am to 5pm)  
Fax: 0845 280 1530

**Foundations**

The national coordinating body for home improvement agencies (HIAs) in England. HIAs are not-for-profit, locally based organisations that assist vulnerable homeowners (including disabled people) to repair, improve or adapt their home.

Bleaklow House
Foundation for people with learning disabilities
The organisation raises awareness of learning disability issues amongst the wider public, in order to breakdown stigma and discrimination. They aim to break down the economic and social barriers and prejudices that people with learning disabilities face throughout their lives, as well as providing information, resources and services that can help them lead fuller, more independent lives.

1st Floor
Colechurch House
1 London Bridge Walk
London
SE1 2SX
http://www.learningdisabilities.org.uk/
020 7803 1100

Genetic Alliance
They aim to improve the lives of people affected by genetic conditions by ensuring that high quality services and information are available to all who need them. They raise awareness of genetic conditions, work to improve the quality of services and information available to patients and families and campaign to influence governments, policy makers, industry and care providers such as the National Health Service.

Genetic Alliance UK
4D Leroy House
436 Essex Road
London N1 3QP
http://www.geneticalliance.org.uk
contactus@geneticalliance.org.uk
020 7704 3141
Genetic Interest Group (GiG)
A national alliance of organisations that supports children, young people, families and individuals affected by genetic disorders. Its primary goal is to promote awareness and understanding of genetic disorders so that high-quality services for people affected by genetic conditions are developed and made available to all who need them. GIG publishes a quarterly newsletter and seeks to educate and raise awareness.
Unit 4D
Leroy House
436 Essex Road
London
N1 3QP
www.gig.org.uk
contactus@geneticalliance.org.uk
020 77043141

Gingerbread
Gingerbread is a charity working nationally and locally, for and with single parent families, to improve their lives. It achieves change by championing their voices and needs, and providing support services.
520 Highgate Studios
53-79 Highgate Road
London
NW5 1TL
www.gingerbread.org.uk
info@gingerbread.org.uk
Freephone: 0808 8020925 helpline 020 74285400

Go Kids Go!
Runs free training courses that teach children and young people the skills that support independent use of wheelchairs.
206 Norwood
Beverly
East Yorkshire
HU17 9JA
www.go-kids-go.org.uk
roy@go-kids-go.org.uk
01482 887163
**Gov.uk**
The government website with a section on childcare for a disabled child. The site signposts services for childcare as well as costs.
www.gov.uk/help-for-disabled-child/childcare

**Guide Dogs**
They provide mobility and freedom to blind and partially sighted people and campaign for the rights of people with visual impairment, educate the public about eye care and fund eye disease research.
Hillfields, Burghfield Common,
Reading,
Berkshire
RG7 3YG
http://www.guidedogs.org.uk/
guidedogs@guidedogs.org.uk
Supporter Care Enquiries: 08702 406 993

**HemiHelp**
A UK-based charity for people with hemiplegia and their families.
6 Market Road
London
N7 9PW
www.hemihelp.org.uk
info@hemihelp.org.uk
Helpline: 0845 1232372 (10am-1pm, weekdays, term time)
0845 120 3713

**Home-Start UK**
Supports tens of thousands of vulnerable children across the UK every year. It helps them cope with post-natal illness, isolation, bereavement, disability, domestic violence and much more.
8-10 West Walk
Leicester
LE1 7NA
www.home-start.org.uk
info@home-start.org.uk
0116 2587900
Freephone information line: 0800 0686368

**I CAN**
A charity that helps children with speech and language difficulties. It provides a unique combination of specialist therapy, teaching and care for children, information for families, and training for teachers and other professionals.
8 Wakley Street
London
EC1V 7QE
[www.ican.org.uk](http://www.ican.org.uk); [www.talkingpoint.org.uk](http://www.talkingpoint.org.uk)
[info@ican.org.uk](mailto:info@ican.org.uk)
0845 2254073

**Include Me Too**
Supports disabled children, young people and their families from black, ethnic minority and other marginalised backgrounds, and aims to promote and support all disabled children and young people’s rights.
[www.includemetoo.org.uk](http://www.includemetoo.org.uk)
01902 711604

**Independent Parental Special Education Advice (IPSEA)**
Provides free independent advice on all aspects of special education, including help with second opinions on a child’s educational needs. It can help with appeals to the Special Educational Needs and Disability Tribunal, including representation in some cases.
Hunters Court
Debden Road
Saffron Walden
CB11 4AA
[www.ipsea.org.uk](http://www.ipsea.org.uk)
Helpline: 0800 0184016 Tribunal Helpline: 0845 6029579

**Independent Support**
Independent Support is a programme that supports young people and their parents during the Special Educational Needs and Disabilities (SEND) reforms. Under new legislation, children with Special Educational Needs (SEN) will be transitioning to an Education,
Health and Care (EHC) plan. Independent Supporters help children and young people gather information for drafting their EHC plan.

**Information Advice and Support Services Network (IASSN)**

The Information, Advice and Support Services Network (IASS Network) provide training and support to local Information Advice and Support (IAS) Services across England. The IASS Network was previously known as the National Parent Partnership Network (NPPN), who undertook a similar role with local Parent Partnership Services.

**Information, Advice and Support Services Network**

Council for Disabled Children
8 Wakley Street
London
EC1V 7QE
http://www.iassnetwork.org.uk/
iassn@ncb.org.uk

**KIDS**

A national charity dedicated to helping children and young people with disabilities and special needs develop their skills and abilities, and realise their potential. Kids works in close partnership with parents, carers and children to deliver an extensive range of services.

49 Mecklenburgh Square
London
WC1N 2NY
www.kids.org.uk
enquiries@kids.org.uk
020 7520 0405

**Kidscape**

It is committed to keeping children safe from abuse. Kidscape is the first charity in the UK established specifically to prevent bullying and child sexual abuse. It works UK-wide to provide individuals and organisations with the practical skills and resources necessary to keep children safe from harm. It works with children and young people under the age of 16, their parents and carers, and those who work with them. It has a helpline for parents of children who have been bullied.

2 Grosvenor Gardens
London
Background information - Useful contacts and organisations

SW1W 0DH
www.kidscape.org.uk
info@kidscape.org.uk
Helpline for parents of bullied children: 08451 205204 (10am-8pm, mon; 10am-4pm, Tue-Fri)
020 77303300

Law Centres Network
They help to set up new Law Centres, initiate new services, and champion the model of free and independent legal advice and representation. They also support and develop special projects. Currently, these include legal services for young people, promoting equality and human rights and tackling discrimination.
Floor 1,
Tavis House,
1-6 Tavistock Square,
London
WC1H 9NA
020 3637 1330 (NB: this is not an advice line)
http://www.lawcentres.org.uk/

Letterbox Library
Provides multi-cultural, non-sexist and special-issue books for children. Themes included are: disability and illness; black history; fostering and adoption; bereavement; and the environment.
Unit 151 Stratford Workshops
Burford Road
Stratford
London
E15 2SP
www.letterboxlibrary.com
info@letterboxlibrary.com
020 75034801

Local Government Ombudsman
The Local Government Ombudsman looks at complaints about councils and some other authorities and organisations, including education admissions appeal panels and adult social
care providers (such as care homes and home care providers). It is a free service and investigates complaints in a fair and independent way.

The Local Government Ombudsman
PO Box 4771
Coventry
CV4 0EH
http://www.lgo.org.uk/
Complaints 0300 061 0614 - Monday to Friday from 8.30am to 5.00pm.
Fax: 024 7682 0001
You can also text 'call back' to 0762 481 1595.

LOOK
A charity that provides information, support and activities to help families with visually impaired children. LOOK links parents together so they can share experiences and support each other, either as individuals or as part of local parent groups. The LOOK Youth Project promotes independence among young visually impaired.
c/o Look National Office
Queen Alexandra College
49 Court Oak Road
Harborne
Birmingham
B17 9TG
www.look-uk.org
office@look-uk.org
0121 4285038

The Makaton Charity
Makaton is a recognised approach to teaching communication skills for those with communication and learning difficulties of all ages. Makaton provides access to education, training and public information through the use of symbols and signs with speech. Resources, training and translation are also available.
Manor House
46 London Road
Blackwater
Camberley Surrey
GU17 0AA
Background information - Useful contacts and organisations

www.makaton.org
info@makaton.org
01276 606760

**Marriage Care**
They help couples and individuals to build and sustain strong, fulfilling healthy relationships, as well as providing counselling support in times of relationship difficulty. And we’ve been doing this for over 65 years.
Marriage Care,
Bishops Park House
25-29 Fulham High Street
London
SW6 3JH
http://www.marriagecare.org.uk/ 0207 371 1341

**Mencap**
The Royal MENCAP Society is a registered charity that offers services to children, young people and adults with learning disabilities. It offers help and advice on benefits, housing and employment. It also offers help and advice to anyone with any other issues, or will direct them to the right place. It can also provide information and support for leisure, recreational services (Gateway Clubs), residential services and holidays.
123 Golden Lane
London
EC1Y 0RT
www.mencap.org.uk
help@mencap.org.uk
Helpline: 0808 8081111 or 020 74540454

**Meningitis Trust**
Offers facts, information, literature and support to people affected by meningitis and meningococcal disease. Support services include financial support grants, counselling, one-to-one contact and home visits. It works closely with volunteers to raise awareness and funds for the Trust.
Fern House
Bath Road
STROUD
Gloucestershire
GL5 3TJ
www.meningitis-trust.org
info@meningitis-trust.org
Helpline: 0808 8010388 (24-hour)

Mosaic Down Syndrome
They assist new parents of children with Mosaic Down Syndrome (which is when not all the cells in the body have trisomy 21), wherever you may be in the world.
http://www.mosaicdownsyndrome.org/
judy.green@blueyonder.co.uk bill.green@blueyonder.co.uk

Nasen
Promotes the development of children and young people with special educational needs, and supports those who work with them. It organises local, regional and national events throughout the UK.
4/5 Amber Business Village
Amber Close
Amington
Tamworth
Staffordshire
B77 4RP
www.nasen.org.uk
welcome@nasen.org.uk
01827 311500

National Autistic Society (NAS)
Formed in 1962, the NAS is a UK-based charity for people with autism (including Asperger’s syndrome), their parents and carers. It champions the rights and interests of all people with autism and ensures that they and their families receive quality services appropriate to their needs. The Parent to Parent Line is a free, confidential telephone support service for parents of an adult or child with autism provided by volunteer parents of children with autism.
393 City Road
London EC1V 1NG
www.autism.org.uk
nas@nas.org.uk
Parent to Parent Line: 0808 800 4106
Autism helpline: 0808 8004104
020 78332299
National Blind Children’s Society
Helps support children who are blind and partially sighted, and their families. The society provides an educational advocacy service for families with children who are blind and partially sighted, and produces large-print books customised for individual children’s requirements.
Bradbury House
Market Street
Highbridge
Somerset
TA9 3BW
www.nbcs.org.uk
enquiries@nbcs.org.uk
Family support helpline: 01278 764770

National Childminding Association (NCMA)
Promotes quality registered childminding so that children, families and communities can benefit from the best in childcare and education. Its mission is to ensure that families in every community have access to high-quality, home-based childcare, play, learning and family support so they can help their children reach their full potential.
Royal Court
81 Tweedy Road
Bromley
Kent
BR1 1TG
www.ncma.org.uk
info@ncma.org.uk
0845 8800044

National Children’s Bureau (NCB)
Promotes the interest and well-being of all children and young people across every aspect of their lives. NCB advocates the participation of children and young people in all matters affecting them. They offer a Children and Young People HIV Network and host the Early Support website.
8 Wakley Street
London
EC1V 7QE
**National Consortium on Deaf-Blindness (NCDB)**
This US-based consortium is a national technical assistance and dissemination centre for children and young people who are deaf-blind. Its website offers a wide range of information, including articles, links, and bibliographies on a variety of subjects, and an online version of the journal *Deaf-blind perspectives*.

[www.nationaldb.org](http://www.nationaldb.org)

**The National Deaf Children’s Society (NDCS)**
The NDCS supports families with deaf children. It provides clear and balanced information on all aspects of childhood deafness, including temporary conditions such as glue ear. NDCS also campaigns on behalf of deaf children and their families.

15 Dufferin Street
London
EC1Y 8UR
[www.ndcs.org.uk](http://www.ndcs.org.uk)
[helpline@ndcs.org.uk](mailto:helpline@ndcs.org.uk)
Freephone helpline: 0808 8008880
020 74908656 (admin only) Minicom: 020 74908656

**The National Institute of Neurological Disorders and Stroke**
They support and performs basic, translational, and clinical neuroscience research through grants-in-aid, contracts, scientific meetings, and through research in its own laboratories, and clinics. They also fund and conduct research training and career development programs to increase basic, translational and clinical neuroscience expertise and ensure a vibrant, talented, and diverse work force.

NIH Neurological Institute
P.O. Box 5801
Bethesda,
MD 20824
Phone: (800) 352-9424 or (301) 496-5751

*NB: For access to free Telecommunications Relay Services (TRS) for people with hearing or speech impairments, dial 7-1-1 on your telephone.*
Natspec
A group of Specialist Colleges that give young people with a learning difficulty or disability the chance to become more independent and to learn in an exciting environment with personal support.
Derwen College, Oswestry, Shropshire, SY11 3JA
http://www.natspec.org.uk/
Parent/carer chair@natspec.org.uk
Skills Show & Competitions, caroline@carolinesmale.co.uk

NHS Direct
A 24-hour nurse advice and health information service, providing confidential information on what to do if you or a family member is feeling ill, have particular health conditions, or need local healthcare services or self-help and support organisations.
www.nhsdirect.nhs.uk
0845 4647
Textphone: 0845 6064647

The National Children’s Bureau
The National Children's Bureau (NCB) is a leading children's charity that for 50 years has been improving the lives of children and young people, especially the most vulnerable. They work with children, and for children, to reduce the devastating impact of childhood inequalities by being a strong independent advocate for children and young people ensuring that government policies and legislation have a positive impact on their lives being a voice for practitioners. They also work to achieve more by working in partnership involving children and young people so they are able to make a difference to their lives providing the evidence from research, analysis and practice to make the case for change.
8 Wakley Street, London
EC1V 7QE
http://ncb.org.uk/
enquiries@ncb.org.uk
The National Network of Parent Carer Forums (NNPCF)

The NNPCF is a network of local forums meeting in regional settings, working together to effect local and national service improvement through participation and co-production with parent carers. These Parent Carer Forum include parent carers with a full range of experiences in Health, Education and Social Care as their children have a wide range of conditions.

Contact a Family,
209-211 City Road,
London
EC1V 1JN
http://www.nnpcf.org.uk/
info@nnpcf.org.uk
0207 608 8708

National Portage Association (NPA)

A registered charity established in 1983 to offer support and information to parents and professionals involved in Portage, a home visiting educational service for preschool children with additional support needs and their families.

Kings Court
17 School Rd
Hall Green
Birmingham
B28 8JG
www.portage.org.uk
parents@portage.org.uk
0121 2441807


Specialises in child protection and the prevention of cruelty to children. In addition to its 24-hour helpline, the NSPCC runs campaigns, provides child protection training and advice, carries out research into the nature and effect of child abuse, and produces information leaflets.

Weston House
42 Curtain Road
Background information - Useful contacts and organisations

London EC2A 3NH
www.nspcc.org.uk
help@nspcc.org.uk
Helpline: 0808 800 5000 (24-hour)
Textphone helpline: 08001 0808 800 5000 (24-hour)
020 78252500

**Ofsted**
The Office for Standards in Education, Children’s Services and Skills inspects and regulates services that care for children and young people, and services providing education and skills for learners of all ages.
General enquiries
Piccadilly Gate
Store Street
Manchester
M1 2WD
General: 0300 123 1231 Schools: 0300 123 4234 Concerns: 0300 123 4666
Fax: 0300 123 3159
The helpline is open Monday to Friday from 8.00am to 6.00pm
https://www.gov.uk/government/organisations/ofsted
enquiries@ofsted.gov.uk

**Orphanet**
They are a reference portal for information on rare diseases and orphan drugs, for all audiences. Orphanet helps to improve the diagnosis, care and treatment of patients with rare diseases. They offer a range of freely accessible services such as an inventory of rare diseases and a classification of diseases elaborated using existing published expert classifications, an encyclopedia of rare diseases in English and French, progressively translated into the other languages of the website and an inventory of orphan drugs at all stages of development.
Orphanet / INSERM US14
Rare Disease Platform
96, rue Didot
75014 Paris,
France
http://www.orpha.net/
The Patients Association
The Patients Association Helpline helps thousands of patients and relatives every year, answering concerns and queries about any aspect of the Healthcare system. The Helpline is primarily a signposting service, which will either directly advise you on how to resolve your problem, or put you in contact with the organisation you need to speak to.

PO Box 935
Harrow
London
HA1 3YJ

www.patients-association.org.uk
helpline@patients-association.com

Helpline: 0845 608 4455
020 84239111

Preparing for Adulthood
The partnership brings together a wide range of expertise and experience of working with young people and families, at a local and national level and across government, to support young people into adulthood with paid employment, good health, independent living and friends, relationships and community inclusion.

National Development Team for Inclusion
First Floor
30-32 Westgate Buildings
Bath
BA1 1EF

info@preparingforadulthood.org.uk
http://www.preparingforadulthood.org.uk/
020 7843 6348

Pre-school Learning Alliance
A national educational charity and umbrella body linking 14,000 community-based preschools and 800,000 children and their families. Supports the active involvement of parents in their children’s early education and offers a range of training courses.

Fitzpatrick Building
188 York Way
London
N7 9AD
www.pre-school.org.uk
info@pre-school.org.uk
020 76972595

**RP Fighting Blindness**

Aims to raise funds for scientific research to provide treatments leading to a cure for Retinitis Pigmentosa (RP). It has branches throughout the UK and provides an information and support service for people with RP and their families.

PO Box 350
Buckingham MK18 1GZ
www.rpfightingblindness.org.uk
helpline@rpfightingblindness.org.uk
Helpline: 0845 1232354
01280 821334 (admin only)

**The Royal College of Psychiatrists**

They are a professional medical body responsible for supporting psychiatrists throughout their careers, from training through to retirement, and in setting and raising standards of psychiatry in the United Kingdom.

21 Prescot Street
London
E1 8BB
http://www.rcpsych.ac.uk/
General enquiries: reception@rcpsych.ac.uk
Membership enquiries: membership@rcpsych.ac.uk
Examinations - examinations@rcpsych.ac.uk
Press enquiries: eleicester@rcpsych.ac.uk or dhart@rcpsych.ac.uk
Switch board: 020 7235 2351 or 020 7977 6655 or
Fax: 0203 701 2761

**Royal College of Speech and Language Therapists (RCSLT)**

The RCSLT is the professional body for speech and language therapists in the UK; providing leadership and setting professional standards. They facilitate and promote research into the field of speech and language therapy, promote better education and training of speech and language therapists and provide information for our members and the public about speech and language therapy.

2 White Hart Yard
London
SE1 1NX
The Royal National Institute of Blind People (RNIB)
RNIB is the leading charity offering information, support and advice to almost two million people with sight loss. It has practical ways to help those living with sight loss, including advice about travelling, shopping, managing money and finances, and technology for blind and partially sighted people.
105 Judd Street
London
WC1H 9NE
www.rnib.org.uk
helpline@rnib.org.uk
Helpline: 0303 1239999

Scope
Scope is the UK’s leading disability charity. Its focus is on children, young people and adults with cerebral palsy and people living with other severe and complex impairments. Its vision is a world where disabled people have the same opportunities to fulfill their life ambitions as non-disabled people.
6 Market Road
London
N7 9PW
www.scope.org.uk
response@scope.org.uk
0808 8003333
Text: SCOPE plus message to 80039

Sense
The major UK voluntary organisation for children, young people and adults born with multi-sensory impairment (MSI) and their families. The website has information about the help and services available to people with MSI, their families and professionals.
101 Pentonville Road
London N1 9LG
www.sense.org.uk
info@sense.org.uk
0845 1270066
Textphone: 0845 1270066

Sibs
For brothers and sisters of children and people with additional needs, disability or chronic illness. Its purpose is to make a positive difference to the lives of siblings – to make growing up with someone with special needs a bit easier.
Meadowfield
Oxenhope
West Yorkshire
BD22 9JD
www.sibs.org.uk
info@sibs.org.uk
01535 645453

SOS!SEN
Offers free and independent advice on local education authorities’ legal duties to assess and provide for children with special educational needs, including how to appeal a SEN statement. The website offers tips and information sheets for parents.
Electroline House
15 Lion Road
Twickenham
Middlesex
TW1 4JH
www.sossen.org.uk
admin@sossen.org.uk
Helpline: 020 85383731

Tax Credit Helpline
Information about tax credits and applications for tax credits.
www.hmrc.gov.uk
0345 3003900
Textphone: 0345 3003909

Together for Short Lives
The leading UK charity for all children with life-threatening and life-limiting conditions, and all those who support, love and care for them. It supports families, professionals and services,
including children’s hospices. Its work helps to ensure that children can get the best possible care, wherever and whenever they need it.

Floor, Bridge House
48-52 Baldwin Street
Bristol
BS1 1QB

**www.togetherforshortlives.org.uk**

Helpline: 0845 1082201
General enquiries: 0345 3003900
Textphone: 0345 3003909

**Tourism for All**
Provides information about all types of holidays for people with additional needs.

7A Pixel Mill
44 Appleby Road
Kendal
Cumbria
LA9 6ES

**www.tourismforall.org.uk**

info@tourismforall.org.uk
0845 1249971

**Transition Information Network (TIN)**
The network is hosted by the Council for Disabled Children. The aim of the website is to provide information to parents and practitioners about disabled young people’s transition to adulthood. There is also a young people’s section with information, news and events.

c/o Council for Disabled Children
8 Wakley Street
London
EC1V 7QE

**www.transitioninfonetwork.org.uk**

tin@ncb.org.uk
020 78436006
**Treacher Collins Family Support Group**

Provides support, information and advice to families with Treacher Collins’ syndrome, First and Second Arch syndrome, atresia of the ear and any other condition combining conductive deafness with facial/head malformations.

114 Vincent Road
Norwich
Norfolk
NR1 4HH
[www.treachercollins.net](http://www.treachercollins.net)
[mail@treachercollins.net](mailto:mail@treachercollins.net)
01603 433736

**Turn2Us**

They help people in financial need gain access to welfare benefits, charitable grants and other financial help – online, by phone and face to face through our partner organisations.

Turn2us,
Unit 9,
Cefn Coed Parc,
Nantgarw,
Cardiff
CF15 7QQ.
[http://www.turn2us.org.uk/](http://www.turn2us.org.uk/)
[info@turn2us.org.uk](mailto:info@turn2us.org.uk)
Enquiries: 01443 827616
Helpline: 0808 802 2000 (9am-8pm Monday-Friday)

**Twin and Multiple Birth Association (TAMBA)**

TAMBA provides information and support networks for families of twins, triplets and more. It offers a range of publications and a telephone helpline for parents called Twinline. It has an additional needs group offering support to families.

Manor House, Churchill
Aldershot
Hampshire
GU12 4JU
[www.tamba.org.uk](http://www.tamba.org.uk)
[enquiries@tamba.org.uk](mailto:enquiries@tamba.org.uk)
Freephone helpline: 0800 1380509
Enquiries: 01252 332344
Whizz-Kidz
A national charity that raises money to provide disabled children and young people with mobility equipment not available through the NHS. The types of equipment available include powered and manual wheelchairs, tricycles and buggies. Whizz-Kidz also provides advice and information about the importance of independent mobility to young disabled people and their families, and campaigns to improve provision of equipment by statutory services.

4th Floor, Portland House
Bressenden Place
London
SW1E 5BH
www.whizz-kidz.org.uk
info@whizz-kidz.org.uk
020 72336600

Winston’s Wish
Works with children, young people and families on issues of death and bereavement.

3rd Floor
Cheltenham House
Clarence Street
Cheltenham
Gloucestershire
GL50 3JR
www.winstonswish.org.uk
info@winstonswish.org.uk
Helpline: 08452 030405
01242 515157

Working Families
Provides information and advice to working parents about parents’ rights, flexible working options, etc. It also has an established Waving not Drowning network of parents with disabled children who work or want to work.

1-3 Berry Street
London
EC1V 0AA
www.workingfamilies.org.uk
advice@workingfamilies.org.uk
Working Families helpline: 0300 0120312
Waving not Drowning helpline: 020 70170072
**YoungMinds**

One of the UK’s leading charities committed to improving the emotional well-being and mental health of children and young people, and empowering their parents and carers. Driven by its experiences, it campaigns, researches and influences policy and practice. It also provides expert knowledge to practitioners, parents and young people through the parent helpline, online resources, training and development, outreach work and publications.

Suite 11
Baden Place
Crosby Row
London
SE1 1YW

[www.youngminds.org.uk](http://www.youngminds.org.uk)
[parents@youngminds.org.uk](mailto:parents@youngminds.org.uk)

Parent Helpline: 0808 8025544
020 70895050

**YourLocalCinema.com**

Subtitled and audio-described cinema enables people with hearing or sight loss to enjoy films at the cinema with the aid of on-screen subtitles and a narrated soundtrack. Join the email list to receive full details of ‘accessible’ cinema shows in your area, every week.

[www.yourlocalcinema.com](http://www.yourlocalcinema.com)
[subtitles@yourlocalcinema.com](mailto:subtitles@yourlocalcinema.com)

Text/SMS: 0793 1341377
We acknowledge with thanks the contribution of the following organisations in the production of this resource:

www.ncb.org.uk/earlysupport

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