

A to Z of specific SEND conditions

Useful links to sources of support and information

Attention Deficit Disorder

- **ADDISS** – information and support: <http://www.addiss.co.uk>

Angelman Syndrome

- **Angelman Syndrome Support Education and Research Trust** – information, helpline, newsletter: <http://angelmanuk.org/>

Autism and Asperger syndrome

- **Ambitious about Autism** – services, awareness-raising, campaigns: <http://www.ambitiousaboutautism.org.uk/page/index.cfm>
- **Anna Kennedy Online** – offers information, training and advice, and supports families with autism: <http://www.annakennedyonline.com>
- **National Autistic Society** – information, support and schools: <http://www.nas.org.uk/>
- **Research Autism** – the only UK charity dedicated to research into interventions in autism: <http://researchautism.net/pages/welcome/home.ikml>
- **Talk about Autism** – a safe and friendly online community: <http://www.talkaboutautism.org.uk>
- **Caldwell Autism Foundation** – providing communication support to people on the autistic spectrum: <http://thecaldwellfoundation.org.uk/>
- **Royal College of General Practitioner** – childminders, parents and childcare staff may wish to hand this useful information about making the most of a visit to the GP to the parents of children with autism: <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~media/Files/CIRC/Autism/RCGP-Making-the-most-of-a-visit-to-your-GP-March-15.ashx>
- **Autism East midlands** – the largest specialist autism charity in the East Midlands: <http://www.norsaca.org.uk/about-us>
- **Autism East Anglia** – see for instance the A-Z factsheet of fundraising ideas: http://www.autism-anglia.org.uk/factsheets/a_-_z_of_fundraising
- **Autism West Midlands** – the leading charity in the West Midlands for people with autism: <http://www.autismwestmidlands.org.uk/>
- **Autism Connect** – an online social network for people with autism and their families: <https://autism-connect.org.uk/site/index>
- **The Autism directory** – find autism friendly resources in your local area and beyond. From CAMHS and coffee shops to SaLT's and special schools you can find them here. : <http://www.theautismdirectory.com/default.asp?contentID=1>
- **Child Autism UK** – Support, advice and services for children with autism See more at: <http://www.childautism.org.uk>

Brain injuries and conditions

- **Advance: The Institute for The Scotson Technique** - unique restorative science for children and young people with brain injuries: <http://www.scotsontechnique.com/>
- **BIBIC** (British Institute for Brain Injured Children)- offers families practical help <http://www.bibic.org.uk/>
- **Brainwave** – home-based programme for children with brain injuries/genetic conditions: <http://www.brainwave.org.uk/>
- **Cerebra** – support and information for families of children with brain-related conditions: <http://www.cerebra.org.uk/>
- **Child Brain Injury Trust** – provides information and support for the effects of 'traumatic' injury on a child's developing brain: <http://www.childbraininjurytrust.org.uk/>
- **Child Growth Foundation** – information about conditions causing growth problems: <http://www.childgrowthfoundation.org/>
- **Climb** – information for families of children living with inherited metabolic conditions: <http://www.climb.org.uk/>
- **Snowdrop** – provides neural developmental therapy for conditions including Cerebral Palsy, Autism, genetic conditions, developmental delay and brain injury: <http://www.snowdrop.cc/>

Cerebral palsy and Hemiplegia

- **Cerebral Palsy Guidance** – covers a wide range of topics, such as symptoms, causes, treatment and transitioning to adulthood: <https://www.cerebralpalsyguidance.com>
- **HemiHelp** – support for children and young people with hemiplegia (hemiparesis): <http://www.hemihelp.org.uk/>
- **Scope** – helpline and factsheets for parents: <http://www.scope.org.uk/>

Chromosome disorders

- **SOFT** – support for families affected by Patau's syndrome, Edwards syndrome, partial Trisomy, mosaicism and related disorders: <http://www.soft.org.uk/>
- **Unique** – information, networking and support for anyone affected by a rare chromosome disorder, their families and the professionals who work with them: <http://www.rarechromo.org/html/home.asp>
- **Genetic Alliance** – alliance of charities supporting children and families affected by genetic disorders: <http://www.geneticalliance.org.uk/>

Cockayne Syndrome

- **Amy and friends** – support and information for parents: <http://www.amyandfriends.org/>

Cystic fibrosis

- **Cystic Fibrosis Trust** – information, advice, support and funding: <http://www.cftrust.org.uk/>

Down's Syndrome

- **Down Heart Group** – information about associated heart conditions: <http://www.dhg.org.uk/>
- **Down's Syndrome Association** – information by life stages, support and helpline: <http://www.downs-syndrome.org.uk/>
- **Future of Down's** – online parenting support group: <http://www.futureofdowns.com/>

- **Downs Side Up** – links to resources and products that are useful for parents of children with Down Syndrome, as well as for practitioners: <http://www.downssideup.com/p/essential-websites.html>

Dyslexia and dyspraxia

- **Dyslexia-SpLD Trust (The)** – a collaboration of voluntary and community organisations funded by the Department for Education to help children with dyslexia/SpLD succeed in school: <http://www.thedyslexia-spldtrust.org.uk/>
- **Dyspraxia Foundation** – books, suggestions, teen newsletter, and adult support group: <http://www.dyspraxiafoundation.org.uk/>

Epilepsy

- **Daisy Garland Trust** – focuses on children (up to 12) with difficult-to-control epilepsy: <http://www.thedaisygarland.org.uk/>
- **Epilepsy Action**- information and support for children, adults and families: <http://www.epilepsy.org.uk/>
- **Young Epilepsy** – information and resources for young people: <http://youngepilepsy.org.uk/>
- **Klinefelter's Syndrome Association UK** – information and support: <http://www.ksa-uk.net/>
- **Rett UK** – information and support: <http://www.rettuk.org>
- **Sickle Cell Society** – information and counselling: <http://www.sicklecellsociety.org/>

Spina Bifida and Hydrocephalus

- **Shine** – information and advice, including a helpline: <http://www.shinecharity.org.uk/>

Hearing impairments

- **Elizabeth Foundation** – helping deaf preschool children learn to listen and talk: <http://www.elizabeth-foundation.org/>
- **National Deaf Children's Society** – help and support: <http://www.ndcs.org.uk/>
- **Heartline** – support and help for children with congenital heart conditions and their families

Learning difficulties/disabilities

- **Mencap** – support and information for families and carers of children with a learning disability: <https://www.mencap.org.uk/>
- **SCOPE** Online community full of tips and bright ideas from parents, carers, teachers and therapists
- **Easyhealth** - accessible health information for parents, supporters and carers of people with learning disabilities, and people with milder learning disabilities themselves.: <http://www.easyhealth.org.uk/>
- **Developmental delay**: Information for families Here's a useful new advice booklet [from](#) Contact a Family for parents with concerns about developmental delays in their children. Childcare providers may wish to pass this link to parents:

Limb conditions

- **REACH** – support and advice for children with hand or arm deficiencies, and their parents: <http://www.reach.org.uk/>

- **Steps** – support for parents of children affected by lower limb conditions: <http://www.steps-charity.org.uk/>

Speech and language impairments

- **Afasic** – supports children with speech, language and communication impairments: <http://www.afasic.org.uk/>
- **I CAN** – supports speech, language and communication development in children: <http://www.ican.org.uk/>

Tourette's syndrome

- **Tourettes Action** – information and support: <http://www.tourettes-action.org.uk>

Turner syndrome

- **Turner Syndrome Support Society** – information and support: <http://tss.org.uk>

Fragile X

- **Fragile X Society** – support, information and helplines for families, plus promotion of research: <http://fragilex.org.uk/>

Undiagnosed Conditions

- **SWAN UK** – offers support and information to families of children with undiagnosed genetic conditions: <http://undiagnosed.org.uk/>

Visual impairments

- **Calibre Audio Library** – provides audio books to those with sight impairment and dyslexia: <http://www.calibre.org.uk/>
- **Living Paintings** – a free library of Touch to See books bringing to life the visual world for blind or partially sighted people: <http://www.livingpaintings.org/>
- **Load2Learn** – accessible textbooks and images to support dyslexic, partially sighted or blind learners: <http://load2learn.org.uk/>
- **LOOK UK** – supporting parents and carers of children with a visual impairment: <http://www.look-uk.org/>
- **MISE** (Mobility and Independence Specialists in Education) – holds a register of specialist practitioners who will deliver habilitation training to visually impaired children and young people: <http://www.mise.org.uk/>
- **National Blind Children's Society** – help and info for children and young people with visual impairments, and their families: <http://www.nbcs.org.uk>
- **Talking Books for Children** – a free library of audio books for children, from the RNIB: <http://www.rnib.org.uk/talking-books-service>
- **VICTA Visually Impaired Children Taking Action** – support for blind and partially sighted children, young people and their families: <http://www.victa.org.uk/>

You may also wish to view the Contact a Family website for links about different conditions: <http://www.cafamily.org.uk/medical-information/conditions/>

Further information

Thank you to Hannah Postgate for originally compiling this list of useful links, and to all the settings that have since sent in suggestions. Please continue to let us know if any of the links above fail to work, or if you can suggest other more useful links: askLEX@family-action.org.uk

- Family Action is funded by the Department for Education (DfE) to support school-based childcare providers to develop high-quality and inclusive childcare for 0-5s with special educational needs and disabilities (SEND). Find out more about the project, and download a wide range of free resources from: www.learning-exchange.org.uk
- Our Learning Exchange Facebook page gives links to events, suppliers, equipment, training and venues that might be of interest to school-based childcare providers: www.facebook.com/pages/Learning-Exchange/904749822892733?sk=timeline

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