



**Wellspring**  
West Sussex

# Resource Booklet

**for parents and carers of children  
and young people with disabilities**

**2007**

## **WELLSPRING WEST SUSSEX**

Charity number 1100226

The main purpose of our organisation is to provide up-to-date and relevant information to children and young people with disabilities, and their parents and carers in West Sussex. We do this by providing a free, regular newsletter that has information about local and national support groups, local activities and events that are inclusive and new services and equipment. Information can also be found on our website at **[www.wellspringwestsussex.org.uk](http://www.wellspringwestsussex.org.uk)**. We also support annual Family Fun Days Out in Chichester and Horsham for families with disabled children and provide music, drama and circus skills workshops for groups of disabled youngsters.

We are very grateful to the following for their contributions to this Resource Booklet and we appreciate their continued support:

**Body Shop Foundation**

**Henry Smith Charity**

**ICIS: information for life**

**Mencap**

**Parent Partnership Service**

**West Sussex County Council**

Additional copies of this booklet are available. Please send 2 second class large letter stamps to:

26 Goldsmith Road

Worthing

BN14 8ER

Or email your request to **[info@wellspringwestsussex.org.uk](mailto:info@wellspringwestsussex.org.uk)**

# Contents

	<b>page</b>
Behavioural Difficulties	4
Carers Support Organisations	5
Children & Young People's Services	8
Computers	9
Educational Resources and Advice	10
Financial Advice and Services	12
Health Needs - Cancer	13
Health Needs - Epilepsy	13
Health Needs - General	14
Health Needs - Heart Conditions	17
Information Services & Advice	17
Learning Difficulties	19
Life Limiting & Life Threatening Illnesses	20
Physical Disability	22
Play and Leisure	24
Playschemes	27
Respite and Short Breaks	28
Sensory Impairments	30
Speech and Language	32
Transport and Mobility	33
Youth Clubs	36

## Behavioural Difficulties

### Challenging Behaviour Foundation

Tel: **01634 838739** Chairman of Trustees

Email: [info@thecbf.org.uk](mailto:info@thecbf.org.uk) [www.thecbf.org.uk](http://www.thecbf.org.uk)

Information and support to parents, carers and professionals.

### Child & Adolescent Mental Health Service (CAMHS)

Chichester & Bognor - Tel: **01243 815514**

Orchard House, 9 College Lane, Chichester, West Sussex PO19 6PQ

Patients are from 0-18 years. Referrals are by letter.

Worthing - Tel: **01903 286754/5**

Children's Centre, Worthing Hospital, Lyndhurst Road, Worthing, BN11 2DH

This service covers Adur, Chanctonbury, Littlehampton and Worthing. Provides assessment and help including family work and/or individual therapy. Referrals may be made via GP, other health professionals or Social Services.

### Hyperactive Childrens Support Group

Tel: **01243 539966** Open 10am-12pm Mon, Tues, Fri

Email: [hyperactive@hacsg.org.uk](mailto:hyperactive@hacsg.org.uk) [www.hacsg.org.uk](http://www.hacsg.org.uk)

Provides help, advice, information and support to parents of children who may be hyperactive and/or have ADD (Attention Deficit Disorder)

### The Learning Assessment & Neurocare Centre

Tel: **01403 240002** Email: [info@lanc.uk.com](mailto:info@lanc.uk.com) [www.lanc.uk.com](http://www.lanc.uk.com)

Specialises in helping children, adolescents and adults with neuro-biological conditions, especially ADHD and related conditions, Asperger and Tourette Syndrome, dyslexia, dyspraxia, etc. GP referral required.

### Sussex ADHD Support Group

Tel: **01293 428025**

Email: [info@sussexadhd.org.uk](mailto:info@sussexadhd.org.uk) [www.sussexadhd.org.uk](http://www.sussexadhd.org.uk)

Support group for people with or caring for someone with ADHD (Attention Deficit Hyperactivity Disorder). Drop-in session on the second Saturday of the month (except August) at Stepping Stones, 5 Perryfield Road, Southgate, Crawley, between 10am and 12.

### Sussex Downs AD/HD Support Group

Tel: **01273 709663** daytime Tel: **01273 411583** - after 7pm only

Support group with membership from Lewes, Brighton and Hove to Worthing, although support and information by telephone is available to anyone. Meetings take place in the Brighton & Hove area.

## **YoungMinds**

Tel: **0800 018 2138** Parents Info Service Tel: **020 7336 8445** Office

Email: **enquiries@youngminds.org.uk** **www.youngminds.org.uk**

A charity committed to improving the mental health of all babies, children and young people. The Parents' Information Service is for anyone with concerns about the mental health of a child or young person.

## **Carers Support Organisations**

### **Carers' Emergency Alert Card Scheme**

Tel: **01903 859929**

Email: **admin@icis-info4life.org.uk** **www.icis-info4life.org.uk**

A free scheme for people who look after an adult or child who depends on them because they are ill, have a disability or are frail.

### **Carers Liaison Project - Bognor Regis, Chichester and Rural**

Tel: **01243 782561** Helpline: **01243 537011**

Email: **rnorth@carersliaison.org.uk** **www.carersliaison.org.uk**

Information and support for carers in the Chichester District including Midhurst, Petworth, Arundel, Bognor and surrounding villages.

### **Carers Liaison Service - Worthing**

Tel: **01903 536378** **www.carerswsx.org.uk**

Support for people looking after someone who is ill, frail or has a disability in Adur, East Arun, Worthing and all of Chanctonbury.

### **Carers UK**

Tel: **0808 808 7777** Carers Line

Email: **info@carersuk.org** **www.carersuk.org**

East Grinstead - Sheila Dongray Tel: **07855 774703**

Horsham - Bernard See Tel: **01403 267111** or May Pope Tel: **01403 261265**

Mid Sussex - Mr John Candler Tel: **01444 232192**

A campaigning organisation providing information on all aspects of caring. The advice line offers free, confidential advice for carers.

### **Carers Support Service - North and Mid Sussex**

Tel: **01293 657040**

Email: **info@carerssupport.org.uk** **www.carerssupport.org.uk**

Support for carers in the Horsham, Crawley and Mid Sussex areas.

### **Circles Network West Sussex**

Tel: **01444 250552**

Email: **angela.butcher@circlesnetwork.org.uk** **www.circlesnetwork.org.uk**

Using circles of support and person centred planning tools and the values of inclusion, the project helps people to have control over and make changes in their lives.

### **Emotional Support for Carers - North & Mid Sussex**

Tel: **01293 657040** Email: **info@carerssupport.org.uk**

Free one-to-one counselling sessions and call-back service for carers in Horsham, Crawley and Mid Sussex areas.

### **Emotional Support for Carers - Southern Sussex**

Tel: **01903 528629** Email: **helen.florence@guildcare.org**

Offers free face to face confidential counselling service. The service covers Littlehampton to Southwick, and north to Chanctonbury.

### **Face to Face Sussex**

Springboard Project Tel: **01403 218888** Scheme Co-ordinator

Email: **facetoface@springboardproject.com**

**www.springboardproject.com/facetoface**

A one-to-one parent(s) befriending service covering West Sussex, Surrey, Brighton, Hove & Eastbourne, offering emotional support to parents discovering their child has a disability.

### **National Government Website for Carers**

**www.direct.gov.uk/carers**

### **Parent Carers Planning Group**

Tel: **01243 752158** Email: **jo.tyler@westsussex.gov.uk**

Group involving Children & Young People's Services, the local NHS and parent carers. Have regular discussions about services in the county.

## **Parent Carers Support Groups**

Crawley, Horsham and Mid Sussex Tel:**01293 657040**

**www.carerssupport.org.uk**

c/o The Orchard, 1-2 Gleneagles Court, Brighton Road, Crawley, RH10 6AD

Support for parents of children with special needs which meets every other month at The Orchard, except during the summer holidays.

East Grinstead - Tel: **01342 323567**

Offers support to parents of children with disabilities in the East Grinstead area.

PACSO, Chichester - Tel: **01243 533353** Email: **admin@pacso.org.uk**

**www.pacso.org.uk**

Registered charity providing support for parents and carers of children and young people with disabilities, living in the Chichester, Bognor and Midhurst area.

## **Parents Oasis**

Tel: **01903 879211** Contact after 5pm

Offers mutual support and information for parents and relatives of children with special needs. Support is via telephone, covers West Sussex.

## **Princess Royal Trust for Carers**

Tel: **020 7480 7788** Email:**help@carers.org** **www.carers.org**

The Trust provides quality information, advice and support services to carers.

## **Young Carers**

Tel: **01903 236562**

Young carers workshops 10-16yrs, full day activities during each school holiday.

Kids Aloud young carers group - St Wilfrid's School Youth Wing, Old Horsham Road, Southgate Crawley, West Sussex. Lin Smith. Tel: **01293 419996**

Mondays fortnightly, 7-9pm, 8-18yrs, 50p.

Young Carers Group - Wallis Centre, De La Warr Rd. East Grinstead, West Sussex. RH19 3BS. Jackie Cooper, Youth Worker. Tel: **01342 321585**.

Mondays fortnightly, 6.30-8pm, free.

Email: **wallis.youth.centre@westsussex.gov.uk**

Support for children and young people with caring responsibilities, up to age 19.

May be funding to help children with caring responsibilities take part in sports, drama clubs, guides and scouts or have family days out.

## **West Sussex Carers Website**

Tel: **01903 777615** Email: [projects@icis-info4life.org.uk](mailto:projects@icis-info4life.org.uk)

[www.westsussexcarers.org.uk](http://www.westsussexcarers.org.uk)

Website providing 24 hour information and help for carers and ex-carers in West Sussex. Information about caring and caring concerns, searchable database of local support and services, links to national services, young carers section, news pages, useful books, carers stories and more.

## **Children & Young People's Services**

### **Child Disability Teams**

Children and Young People's services teams set up to meet the needs of severely disabled children and their families.

North - Tel: **01403 246450** Email: [michelle.mead@westsussex.gov.uk](mailto:michelle.mead@westsussex.gov.uk)

South - Tel: **01243 642424** Email: [cdhds.ss@westsussex.gov.uk](mailto:cdhds.ss@westsussex.gov.uk)

### **Family Resource Team - County Team**

Tel: **01903 236562**

Works with children and young people aged 8-16, their families and carers who are having problems and at risk of family breakdown. Referrals via Children and Young People's Services and Joint Access Team only.

### **West Sussex County Council - Children and Young People's Services**

Organises and provides social care for children, young people and carers according to need in West Sussex. Ask for the Children's helpdesk.

Adur - Tel: **01273 268800**

Bognor Regis - Tel: **01243 642400**

Chichester - Tel: **01243 752644**

Crawley - Tel: **01293 895100**

Horsham - Tel: **01403 213100**

Littlehampton - Tel: **01903 738900**

Mid Sussex - Tel: **01444 446100**

Midhurst - Tel: **01243 752560**

Worthing - Tel: **01903 839100**

Out of hours Tel: **01903 694422**

## Computers

### AbilityNet

Freephone Advice: **0800 269545**

Email: [enquiries@abilitynet.org.uk](mailto:enquiries@abilitynet.org.uk) [www.abilitynet.org.uk](http://www.abilitynet.org.uk)

Helps disabled adults and children use computers and the internet by adapting and adjusting the information and communication technologies they use.

### Aidis Trust

Unit 7 & 8, 3 Gunthorpe Street LONDON E1 7RQ

Tel: **0207 426 2130** Email: [info@aidis.org](mailto:info@aidis.org) [www.aidis.org](http://www.aidis.org)

Helpline: **0845 120 3719**

Advise on computers and communication aids to individuals with physical or learning disabilities. Applications should be made in writing.

### donate a PC - website

Email: [info@donateapc.org.uk](mailto:info@donateapc.org.uk) [www.donateapc.org.uk](http://www.donateapc.org.uk)

This is a 'matchmaking' service for individuals and organisations to donate their un-needed computing hardware (computers, printers etc) to a UK charity. The service is primarily run for those who only have one or two items to donate.

### Gardener's Trust For The Blind

Tel: **020 7253 3757** Secretary

Boundary House, 117 Charter House Street, London EC1M 6PN

Offers grants to blind or partially sighted persons in England and Wales for computer equipment, courses, etc. Applications should be made in writing.

### IT Can Help - British Computer Society Disability Group, Sussex

Tel: **0800 269545**

Email: [info@itcanhelp.org.uk](mailto:info@itcanhelp.org.uk) [www.itcanhelp.org.uk](http://www.itcanhelp.org.uk)

Offers local computer assistance to individuals with disabilities, requests are handled by Abilitynet.

### The Roald Dahl Foundation

Tel: **01494 890465** Email: [admin@roaldahl.foundation.org](mailto:admin@roaldahl.foundation.org)

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

Gives grants and buys computers for children and young people who have suffered a head injury or with visual impairment. See website for specific conditions. Applications on behalf of individuals must be made through a social worker or health care professional.

## **Sequal Trust - Special Equipment & Aids for Living**

Tel: **0870 770 3272**

Email: [thesequaltrust@freeuk.com](mailto:thesequaltrust@freeuk.com) [www.the-sequal-trust.org.uk](http://www.the-sequal-trust.org.uk)

An independent, nationwide fundraising charity which aims to assist severely physically disabled people by providing communication equipment for all ages.

## **Educational Resources and Advice**

### **Advisory Centre For Education (ACE)**

Tel: **0808 800 5793** Advice Mon-Fri 2pm-5pm

Tel: **020 7704 9822** Info on exclusions [www.ace-ed.org.uk](http://www.ace-ed.org.uk)

Offers guidance to parents on all aspects of school education. Publishes a wide range of books and info sheets including: "Special Education Handbook" and "Children with Special Needs: Sources of Help".

### **Camelia Botnar Children's Centre**

Tel: **01903 504077**

A purpose-built, independent, pre-school play centre for children with special needs. Open 50 weeks of the year. Sessions are from 9am-12noon and 1pm-3.30pm, Monday to Thursday and 9am-12noon Friday.

### **Centre For Studies On Inclusive Education (CSIE)**

Tel: **0117 3284007** [www.csie.org.uk](http://www.csie.org.uk)

Help and support for children who have disabilities or learning difficulties who wish to remain in mainstream education.

### **CONNEXIONS VT Careers Management West Sussex**

1-2 The Chambers, Chapel Street, Chichester, West Sussex, PO19 1DL.

Tel: **01243 771666**. Email: [chichester.careers@vtplc.com](mailto:chichester.careers@vtplc.com)

[www.careers.co.uk](http://www.careers.co.uk)

Providing advice to young people on options available to them when they leave school. Provide information, support and advice for children with special educational needs.

### **Department for Education & Skills**

Tel: **0800 100900** Learn Direct Tel: **0845 602 2600** Publications

Tel: **0870 000 2288** Public Enquiry Line Email: [info@dfes.gsi.gov.uk](mailto:info@dfes.gsi.gov.uk)

[www.dfes.gov.uk](http://www.dfes.gov.uk) <http://inclusion.ngfl.gov.uk> - SEN & Disability Division

Produce various booklets: "Special Educational Needs a guide for parents" and "Guide to the Special Educational Needs Tribunal". DfES Inclusion website provides online educational materials for special needs teachers and learners.

### **Independent Panel for Special Education Advice (IPSEA)**

Tel: **0800 0184016** Advice Line Email: [ipsea.info@intamail.com](mailto:ipsea.info@intamail.com)

[www.ipsea.org.uk](http://www.ipsea.org.uk)

IPSEA offers free and independent advice and support to parents of children with special educational needs.

### **National Association For Special Educational Needs (NASEN)**

Tel: **01827 311500** Email: [welcome@nasen.org.uk](mailto:welcome@nasen.org.uk) [www.nasen.org.uk](http://www.nasen.org.uk)

NASEN exists to promote the development of children and young people with special educational needs and supports those who work with them,

### **Network 81 (Parents Group)**

Tel: **0870 770 3306** Helpline open Mon-Thurs, from 10am-2pm

Email: [network81@btconnect.com](mailto:network81@btconnect.com) [www.network81.org](http://www.network81.org)

Offers practical help and support to parents throughout all stages of educational assessment.

### **Opportunity Playgroups**

Crawley - Tel: **01293 546822** Mon-Frid 9.30am-12pm

Horsham - Tel: **01403 269548** 9am-12 noon

East Grinstead - Tel: **01342 323215** Mon, Wed, Frid 9.30am-12pm

Playgroups that provide a stimulating and caring environment for children under 5 with any kind of special need eg, physical, speech, learning or social problems. Offers support for parents.

### **Parent Partnership Service - West Sussex**

Tel: **0845 075 1008** Helpline 8.30am-5pm

Email: [parent.partnership@westsussex.gov.uk](mailto:parent.partnership@westsussex.gov.uk)

<http://wsgfl.westsussex.gov.uk/pp>

A service for parents and carers of children with special educational needs. Helpline provides advice and information on educational issues.

### **Portage Service**

A home visiting educational service for pre-school children with additional support needs and their families.

Chichester - Tel: **01243 536182**

Email: [chichester.ed.portage.service@westsussex.gov.uk](mailto:chichester.ed.portage.service@westsussex.gov.uk)

Crawley - Tel: **01293 615325** Email: [crawedp@westsussex.gov.uk](mailto:crawedp@westsussex.gov.uk)

Mid Sussex and Horsham - Tel: **01444 243150**

Email: [mid-sussex.ed.portage.service@westsussex.gov.uk](mailto:mid-sussex.ed.portage.service@westsussex.gov.uk)

Worthing - Tel: **01903 242558**

Email: [worthing.ed.portage.service@westsussex.gov.uk](mailto:worthing.ed.portage.service@westsussex.gov.uk)

## **Skill - National Bureau For Students With Disabilities**

Tel: **0800 328 5050** Info Line Tues 11.30am-1.30pm and Thurs 1.30pm-3.30pm.

Email: **info@skill.org.uk** **www.skill.org.uk**

Aims to develop opportunities for people with physical and sensory disabilities, learning and mental health difficulties, in post-16 education, training, employment and volunteering.

## **Financial Advice and Services**

### **Benefit Enquiry Line**

Tel: **0800 88 22 00** Email: **BEL-Customer-Services@dwp.gsi.gov.uk**

**www.dwp.gov.uk**

A national helpline giving general advice/information to people with disabilities and their carers. Opening times: weekdays 8.30am-6.30pm Sat 9am-1pm.

### **Disability Alliance**

Tel: **020 7247 8776** 10am-4pm Email: **office.da@dial.pipex.com**

**www.disabilityalliance.org**

Produces the Disability Rights Handbook and a self-help guide "Tell it like it is!" for readers to assess whether a child is eligible for DLA.

### **Jobcentre Plus**

Offers services previously delivered by jobcentres and social security offices.

Enquirers must know National Insurance number.

Tel: **0845 600 4254** Customer Contact Centre.

**www.jobcentreplus.gov.uk**

Bognor Regis - Tel: **01243 846300** General enquiries

Tel: **01243 845486** Disability Employment Adviser

Chichester - Tel: **01243 224162**

Tel: **01243 224103** Disability Employment Adviser

Haywards Heath - Tel: **01444 338000**

Horsham - Tel: **01403 355700** Disability Employment Adviser

Mon & Tues 9am-4.30pm Tel: **01403 355700**

Littlehampton - Tel: **01903 545540**

Disability Employment Adviser Tel: **01903 545555**

Worthing - Tel: **01903 286000** Disability Employment Adviser

## Health Needs - Cancer

### **CancerBACUP/ BACUP**

Tel: **0808 800 1234** Mon-Fri 9am-8pm

**www.cancerbacup.org.uk** **www.click4tic.org.uk**

Specialist cancer nurses provide information and emotional support to anyone affected by cancer, including patients, family and carers.

### **Christian Lewis Trust Children's Cancer Charity**

Tel: **01792 480500**

Email: **enquiries@christianlewis trust.org** **www.christianlewis trust.org**

Aims to improve the quality of life for children with cancer and provide emotional and practical support to their families.

### **Family Fund London and South East**

Tel: **01273 748362**

Email: **CLK@familyfund.org.uk** **www.familyfund.org.uk**

The Family Fund helps UK families caring at home for a severely disabled or seriously ill child, aged 16 and under by providing grants related to care of the child.

### **LEUCAN - Children with Leukaemia/Cancer Parents Support Group**

Tel: **01903 244515**

Email: **ian.camburn@btinternet.com** **www.naccpo.org.uk**

A self help/support group for parents of children with leukaemia or other forms of cancer. Covers area from Shoreham to Chichester.

### **Leukaemia Care Society**

Tel: **0800 169 6680** Helpline - 24hours, 7days

Email: **enquiries@leukaemiare.org.uk** **www.leukaemiare.org.uk**

Support and information for those with leukaemia and similar blood disorders via volunteers throughout the UK. May be able to provide limited financial assistance and holidays.

## Health Needs - Epilepsy

### **Epilepsy Action/ British Epilepsy Association**

Helpline: **0808 800 5050** Mon-Fri 9am-4.30pm (4pm on Fri).

Email: **helpline@epilepsy.org.uk** **www.epilepsy.org.uk**

Epilepsy Action helps its members through its services including the Advice and Information Centre, branch network and Accredited Volunteer scheme. Freephone Helpline is available.

## **Epilepsy Action - West Sussex/ British Epilepsy Association - West Sussex**

Tel:**01273 455537**

Has library of books, pamphlets and videos, information on consultants and hospitals specialising in the treatment of epilepsy, and regular meetings.

## **Epiweb**

Email: [postmaster@epiweb.org](mailto:postmaster@epiweb.org) [www.epiweb.org](http://www.epiweb.org)

Website of information for parents and carers of children who suffer from epilepsy run by parents.

## **National Centre For Young People With Epilepsy/ NCYPE**

Tel:**01342 832243** Marketing Manager

Email:[info@ncype.org.uk](mailto:info@ncype.org.uk) [www.ncype.org.uk](http://www.ncype.org.uk)

Provides specialist services, including education, care, support and information for young people with epilepsy, their families and carers, and professionals.

Includes St Piers School and Further Education College, National Assessment Centre and research and training facilities.

## **Health Needs - General**

### **Action For Sick Children/ National Association For The Welfare Of Children In Hospital (NAWCH)/ NAWCH Action for Sick Children**

Tel:**01663 763870**

Email:[enquiries@actionforsickchildren.org](mailto:enquiries@actionforsickchildren.org) [www.actionforsickchildren.org](http://www.actionforsickchildren.org)

Aims to promote a high quality of health care for children and young people in hospital and at home. Branch network for parent advice and support. Produce publications such as "Helping Children Cope with Pain" and "Teenagers in Hospital".

### **Association of Young People with ME/ AYME**

Helpline:**08451 232389** [www.ayme.org.uk](http://www.ayme.org.uk)

Organisation for children and young people from 5-26 years with ME. Helpline open 10am-2pm Mon-Fri and Wed evening 6-9pm. Provide information sheets, education and medical advice, friendship and support to the young people, their families and carers.

### **Asthma UK/ Asthma Society & Friends Of The Asthma Research Council**

Advice Line:**0845 701 0203** Mon-Fri, 9am-5pm

Publications line:**020 7786 5000**

Email:[info@asthma.org.uk](mailto:info@asthma.org.uk) [www.asthma.org.uk](http://www.asthma.org.uk)

Dedicated to improving the health and well-being of people in the UK whose lives are affected by asthma.

### **British Institute for Brain Injured Children (BIBIC)**

Tel:**01278 684060** Email:[info@bibic.org.uk](mailto:info@bibic.org.uk) [www.bibic.org.uk](http://www.bibic.org.uk)

Exists to help children reach their full potential and have a better quality of life. BIBIC's involvement also benefits families and carers too.

### **Cerebra, for Brain Injured Children and Young People/ Rescue - The Foundation For The Brain Injured Infant/ Parnet**

Helpline:**0800 328 1159** Counselling service:**0800 043 9385**

Parent support:**01267 244229**

Email:[info@cerebra.org.uk](mailto:info@cerebra.org.uk) [www.cerebra.org.uk](http://www.cerebra.org.uk)

Cerebra funds research in the UK which is linked to brain injury and neurological disorders affecting children. Also Parent Support.

### **Child Development Centres**

Centres for multi-disciplinary assessment and therapy of children with developmental problems and special needs.

Chichester - Tel:**01243 815218**

Crawley - Tel:**01293 600351** Centre Co-ordinator

Haywards Heath - Anytime:**01342 324713** Clinic:**01444 414100**

### **CLIMB - Children Living With Inherited Metabolic Diseases**

Freephone - families:**0800 6523181** Professionals etc: **0870 7700325**

Email:[info@climb.org.uk](mailto:info@climb.org.uk) [www.climb.org.uk](http://www.climb.org.uk)

Climb provides information and support on over 700 metabolic conditions. Network of parents who share experiences, a researcher, small grants to members, a young person's adviser, befriending network.

### **Contact A Family/CAF - Contact A Family/Rare Disorders Alliance UK**

Tel:**020 7608 8700** Helpline 10am-4pm:**0808 808 3555**

Email:[info@cafamily.org.uk](mailto:info@cafamily.org.uk)

Email:[rda@cafamily.org.uk](mailto:rda@cafamily.org.uk) (Rare Disorders Alliance) [www.cafamily.org.uk](http://www.cafamily.org.uk)

UK charity providing advice, information and support to families with disabled children. Services include: putting families in touch with support groups for specific medical conditions; linking individual families affected by rare disorders.

### **Continence Foundation**

Helpline:**0845 345 0165**

Email:[continence-help@dial.pipex.com](mailto:continence-help@dial.pipex.com) [www.continence-foundation.org.uk](http://www.continence-foundation.org.uk)

Provide confidential advice, information and help for bladder problems or other continence-related matters.

### **Cystic Fibrosis Trust - Sussex**

National office: **020 8464 7211** [www.cftrust.org.uk](http://www.cftrust.org.uk)

Sussex branch: **01444 230207** Email: [angee.holford@tesco.net](mailto:angee.holford@tesco.net)

Provides support and advice for people with Cystic Fibrosis, their families and carers.

### **Eczema Society/ National Eczema Society**

Information Line: **0870 241 3604** Mon-Fri. 8am-8pm Tel: **020 7281 3553**

Email: [helpline@eczema.org](mailto:helpline@eczema.org) [www.eczema.org](http://www.eczema.org)

To provide an improvement in the quality of life for the people with eczema and their families.

### **ERIC - Education and Resources for Improving Childhood Continence**

Helpline: **0845 370 8008** Mon-Fri, 10am-4pm. Tel: **0117 960 3060**

Email: [info@eric.org.uk](mailto:info@eric.org.uk)

[www.ericshop.org.uk](http://www.ericshop.org.uk) [www.trusteric.org](http://www.trusteric.org) [www.enuresis.org.uk](http://www.enuresis.org.uk)

Information and support to children, young people, parents and health professionals about childhood bedwetting, daytime wetting, constipation and soiling. Literature and leaflets offered.

### **Sickle Cell Society**

Tel: **020 8961 7795/4006**

Email: [info@sicklecellsociety.org](mailto:info@sicklecellsociety.org) [www.sicklecellsociety.org](http://www.sicklecellsociety.org)

To support families and individuals affected by sickle cell disorder, through financial support, counselling, talks, seminars, educational literature, children's holidays and respite care.

### **Syndromes Without a Name/ SWAN**

Tel/Fax: **01922 701234**

Email: [info@undiagnosed.org.uk](mailto:info@undiagnosed.org.uk) [www.undiagnosed.org.uk](http://www.undiagnosed.org.uk)

Help to find support for children and adults who have undiagnosed or unnamed conditions. Collect information about such conditions; put families in touch with others in similar situations. Publish a newsletter and information pack.

### **Unique - Rare Chromosome Disorder Support Group**

Helpline Tel: **01883 330766** Tel: **01293 525504**

Email: [info@rarechromo.org](mailto:info@rarechromo.org) [www.rarechromo.org](http://www.rarechromo.org)

A group run by and for parents of children with rare chromosome abnormalities diagnosed from ante-natal onwards. Puts parents in touch with each other and to support each other by the pooling of information etc, and to make the medical profession aware of the group so that families can be helped sooner.

## Health Needs - Heart conditions

### Downs Heart Group

Tel: **01424 830594** Email: [jaspall@aol.com](mailto:jaspall@aol.com)

Offers support, information and hospital visits to families whose child has Down's Syndrome and associated congenital heart problems.

### Heart Transplant Families Together (HTFT)

Tel: **01903 606826** Email: [htft@btopenworld.com](mailto:htft@btopenworld.com) [www.htft.org.uk](http://www.htft.org.uk)

A parent support group covering heart and heart/lung transplantation in children. The group aims to support families awaiting transplantation and families whose children have been through the procedure.

### Heartline Association

Tel: **01276 707636** Mon-Fri 10.00am-4.00pm

Email: [admin@heartline.co.uk](mailto:admin@heartline.co.uk) [www.heartline.org.uk](http://www.heartline.org.uk)

A voluntary organisation offering support to children with heart conditions, and their families. Facilitates contact between families through local support groups, social events and a quarterly newsletter.

## Information Services & Advice

### Asian Peoples Disability Alliance/ APDA

Tel: **020 8902 2113** Mon-Fri, 9.30am-5.30pm

Tel: **020 8902 2083**

Email: [apdmcha@aol.com](mailto:apdmcha@aol.com) [www.apda.org.uk](http://www.apda.org.uk)

Aims to provide appropriate services to Asian disabled people and their carers and families that mainstream service providers are unable to provide.

### Contact A Family/CAF - Contact A Family/Rare Disorders Alliance UK

- see Health Needs - General, page 16

### Council for Disabled Children

Tel: **020 7843 6000**

Email: [cdb@ncb.org.uk](mailto:cdb@ncb.org.uk) [www.ncb.org.uk/cdc](http://www.ncb.org.uk/cdc)

Promotes quality services and support for children and their families.

### **Disability Law Service**

Tel:**020 7791 9800** Mon-Fri, 10.30am-1pm and 2.30pm-5pm

Email:**advice@dls.org.uk** **www.dls.org.uk**

DLS offers confidential, free legal advice to disabled people, their families & carers. The advice is given by solicitors. Advice is available on employment, disability discrimination and community care, education, welfare benefits and consumer/contract.

### **Disabled Living Foundation**

Helpline:**0845 130 9177** Mon-Fri, 10am-4pm Textphone: **020 7432 8009**

Email:**info@dlf.org.uk** **www.dlf.org.uk**

Gives practical, up to date, unbiased information and advice on disability equipment and assistive technology. Equipment demonstration centre in London with over 600 items of equipment/assistive technology on display.

### **Early Childhood Service/ Children's Information Service/Sure Start**

Tel - Early Childhood Service:**01243 520813**

Children's Information Service:**01243 777807**

Email:**childrens.info.service@westsussex.gov.uk**

**www.surestart.gov.uk** **www.childcarelink.gov.uk**

**www.wsgfl.westsussex.gov.uk**

Early Childhood Service encourages the development of services for young children.

### **ICIS : information for life**

Enquiry Line:**0800 859929** Mon-Fri, 10am-12.30pm & 1.30pm-4pm, answerphone at all other times

Email:**enquiries@icis-info4life.org.uk** **www.icis-info4life.org.uk**

Confidential and impartial information resource for people of all ages in West Sussex with a difficulty, disability or illness. Helps people find services offering help on all aspects of daily living. Maintains the West Sussex Carers website.

Administers the West Sussex Carers Emergency Alert Card scheme.

### **Parent Partnership Service - West Sussex**

Tel: **0845 075 1008** Helpline 8.30am-5pm

Email: **parent.partnership@westsussex.gov.uk**

**http://wsgfl.westsussex.gov.uk/pp**

A service for parents and carers of children with special educational needs. Helpline provides advice and information on educational issues.

### **Signposts Mid Sussex**

Tel:**01444 241831** Email:**signpostsms@aol.com**

Mon, Tues, Thur, Frid 10-3.30pm, Wed & Sat 10-12.30pm

A free and confidential information service and meeting place for people with learning difficulties, their carers and their friends.

### **Wellspring West Sussex**

Tel:**01903 859929** Email:**info@wellspringwestsussex.org.uk**

**www.wellspringwestsussex.org.uk**

This registered charity is an organisation for children and young people with disabilities and special needs, and their parents and carers in West Sussex.

### **West Sussex County Council/ WSCC**

24 hr helpline:**0845 7581232** **www.westsussex.gov.uk**

Information on any matter concerning County Council, District or Town Councils throughout West Sussex.

## **Learning Difficulties**

### **Autism & Asperger Action**

Tel:**01903 211725** Tel:**01903 244209**

Email:**aaaction@ukf.net** **www.aaaction.ukf.net**

An active group of parents, carers, professionals and people with ASD working towards improved support for affected young people (14+) and adults in West Sussex.

### **Down's Syndrome Association**

Switchboard:**020 8682 4001** Tel:**0845 230 0372**

Email:**info@downs-syndrome.org.uk** **www.downs-syndrome.org.uk**

Provides advice, information and support to people with Down's Syndrome, their families and professionals.

Chichester - Tel:**01243 782686**

Horsham & Crawley - **01403 225134**

Worthing - Tel:**01903 203317**

### **National Autistic Society/ NAS Advice Line**

Tel:**020 7833 2299**

Autism Helpline:**0845 070 4004** 10am-4pm

Autism Alert Card:**0845 070 4004**

Parent to Parent support:**0800 952 0520**

Advocacy for Education Service:**0845 070 4002**

Email:**nas@nas.org.uk** **www.autism.org.uk**

Information, advice and services for children and adults with Autism and Asperger Syndrome.

## **Sussex Autistic Society**

Head Office - Tel:**01903 882666**

Email:**admin@sussexautisticsociety.org** **www.sussexautisticsociety.org**

For support, membership advice and information about autism for families in East and West Sussex.

Southdowns Family Centre, Rustington - Tel:**01903 882666**

Provides a friendly and welcoming place for families to meet, where support and advice is offered. Covers all of Sussex.

## **Life Limiting & Life Threatening Illnesses**

### **Association for Children with Life-Threatening or Terminal Conditions and Their Families (ACT)**

Tel:**0845 108 3201** Information:**0117 922 1556**

Email:**info@act.org.uk** **www.act.org.uk** **www.act4families.org.uk**

Provides information on support services available for families whose children have life-threatening or terminal conditions.

### **CHASE Hospice Care for Children**

Tel:**01483 230960** Email: **bridget.turner@chasecare.org.uk**

**www.chasecare.org.uk**

CHASE Hospice Care for Children charity provides practical and emotional care and support to life-limited children, young people and their families. The service is for families in South West London, Surrey and West Sussex.

### **The Cherries**

Tel:**01243 778103**

A purpose-built, five bedroomed bungalow providing a respite care facility for children in Chichester aged 0-19 years with severe to profound learning difficulties, life threatening illnesses and associated healthcare needs.

### **Chestnut Tree House Children's Hospice**

Tel:**0845 450 5820** Head of Care Email:**admin@chestnut-tree-house.org.uk**

**www.chestnut-tree-house.org.uk**

Children's hospice for young people aged 0-19 with progressive life-limiting and life threatening illnesses. Respite and end of life care onsite. Community service: respite, activity days and teenager programme.

### **Dreams Come True Charity**

Tel:**01730 815000** Freephone:**0800 0186013**

Email:**info@dctc.org.uk** **www.dctc.org.uk**

A nationwide charity, making the most treasured dreams of terminally and seriously ill children (aged 2 - 21 years inclusively) come true.

## **Family Fund London and South East**

- see Health Needs - Cancer, page 14

## **Make-A-Wish Foundation UK**

Tel:**01276 24127**

Email:**info@make-a-wish.org.uk** **www.make-a-wish.org.uk**

Grants the wishes of children aged 3-17 years who live with life-threatening illnesses.

## **The Nigel Clare Network Trust**

Tel:**020 8769 0941**

Email:**postmaster@nigelclare.org.uk** **www.nigelclare.org**

Aims to enhance the quality of life for families caring for children and young people with conditions which limit their lives by length, quality, or both.

## **Rainbow House**

Tel:**01372 453309**

Email:**pat.keown@rainbowtrust.org.uk** **www.rainbowtrust.org.uk**

Rainbow House is a home where families of children with life-threatening and terminal illness come for short stays. Offers practical and emotional support.

## **REACT (React, Rapid, Effective Assistance for Children with potentially Terminal Illness)**

Tel:**020 8940 2575**

Email:**react@reactcharity.org** **www.reactcharity.org**

Provides individual financial assistance where possible. For equipment/facilities to help with care and treatment, funeral expenses and mobile home holidays.

## **Sussex Snowdrop Trust/ Snowdrop Trust**

Tel:**01243 815273** Email:**jenny.bush@wsx-pct.nhs.uk**

A charity which supports children with life-threatening illnesses and their families. Provides equipment and general support to the families by sending out nurses or specially screened volunteers. Covers area east of Emsworth to Littlehampton and north to Midhurst.

## **When You Wish Upon A Star**

Tel:**0115 979 1720**

Email:**whenyowish1@aol.com** **www.whenyowishuponastar.org.uk**

Aims to fulfill wishes for any child aged 2-16yrs who has a life threatening or terminal illness. Also have holiday homes and caravans in Britain, Spain and Florida.

## Physical Disability

### **Arthritis Care / Young Arthritis Care**

Tel: **0808 800 4050** Helpline Tel: **0808 808 2000** Helpline Young People

Email: [helplines@arthritiscare.org.uk](mailto:helplines@arthritiscare.org.uk) [www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

Provides information and support on a range of issues related to living with arthritis, including self-management programmes to help people to cope with their condition.

### **ASBAH - Association for Spina Bifida & Hydrocephalus**

Tel: **01733 555988** Helpline: **0845 4507755**

Email: [helpline@asbah.org](mailto:helpline@asbah.org) [www.asbah.org.uk](http://www.asbah.org.uk)

Advice and information on all aspects of spina bifida and hydrocephalus including education, continence, mobility etc.

### **CHOICES for Families of Children with Arthritis**

Tel: **01273 430219**

Email: [info@kidswitharthritis.org](mailto:info@kidswitharthritis.org)

[www.kidswitharthritis.org](http://www.kidswitharthritis.org) [www.kidsunlimited.info](http://www.kidsunlimited.info)

A registered charity led by parents providing impartial advice for families, a free comprehensive handbook, training and workshops

### **Contact A Family/CAF - Contact A Family/Rare Disorders Alliance UK**

- see Health needs - General, page 16

### **HemiHelp (Hemiplegia Support Group)**

Tel: **0845 123 2372**

Email: [support@hemihelp.org.uk](mailto:support@hemihelp.org.uk) [www.hemihelp.org.uk](http://www.hemihelp.org.uk)

Provides support and information to children and young people with hemiplegia and their families; quarterly newsletters, workshops, activity days.

### **Independent Living Association - West Sussex**

Tel: **01903 219482** [www.ilawestsussex.org](http://www.ilawestsussex.org)

A joint initiative by the Independent Living Association (ILA) and West Sussex County Council to implement the Council's Direct Payments policy for disabled people over the age of 16, parents of disabled children and carers. Direct Payments is a cash payment to people who need social services to live independently. The payment enables people to arrange and pay for personal assistant services as an alternative to services provided by West Sussex County Council. Also provides information, advice and support to people interested in managing their own personal assistant arrangements. An advocacy service (Advocacy for Independence) is provided by the ILA.

### **Independent Living Funds**

Tel: **0845 601 8815** Email: [funds@ilf.org.uk](mailto:funds@ilf.org.uk) [www.ilf.org.uk](http://www.ilf.org.uk)

Government funded trust to help severely disabled people live independently in the community. Contact or look at website for details of criteria for application.

### **Jennifer Trust for Spinal Muscular Atrophy**

Tel: **0800 975 3100** Freephone Helpline

Email: [jennifer@jtsma.org.uk](mailto:jennifer@jtsma.org.uk) [www.jtsma.org.uk](http://www.jtsma.org.uk)

Support group for children and adults who have Spinal Muscular Atrophy and their families. Quarterly newsletter and annual conference weekend. Grants available towards specialist equipment. Network of contact volunteers offering local support and advice.

### **Muscular Dystrophy Campaign/ MD Group**

Tel: **020 7720 8055** Information and Advice Line

Email: [info@muscular-dystrophy.org](mailto:info@muscular-dystrophy.org) [www.muscular-dystrophy.org](http://www.muscular-dystrophy.org)

A national charity which researches into treatments and cures for people affected by any of the conditions known as muscular dystrophy or by a related neuromuscular disorder. Provides expert medical care at Muscle Centres; information; advice; a team of Care Advisers and financial assistance with essential equipment.

### **Phab - England**

Tel: **020 8667 9443**

Email: [info@phabengland.org.uk](mailto:info@phabengland.org.uk) [www.phabengland.org.uk](http://www.phabengland.org.uk)

Sussex - Tel: **01273 821789** Email: [hugh.sussexphab@fsmail.net](mailto:hugh.sussexphab@fsmail.net) Organisation aiming to integrate people with and without physical disabilities through some 250 clubs in England. Activities include social meetings, sports, outings and holidays. Some groups are specifically for younger people up to the age of 25.

### **Reach - The Association For Children With Hand Or Arm Deficiency**

Tel: **0845 130 6225** Email: [reach@reach.org.uk](mailto:reach@reach.org.uk) [www.reach.org.uk](http://www.reach.org.uk)

Parent support group, providing contact with other families with similar problems. Produce a quarterly newsletter, various informative factsheets and a video.

## **REMAP (Rehabilitation Engineering Movement Advisory Panels)**

D9 Chaucer Business Park, Kemsing, Sevenoaks, Kent, TN15 6YU.

Tel: **0845 1300456**

Email: **info@remap.org.uk** **www.remap.org.uk**

London and South East - Geoff Meekums. Tel: **01732 866105**

Each Remap panel has member engineers, who apply technology and basic skills to the design and production of aids and the adaption of existing aids to meet the needs of people with disabilities, where such aids are not commercially available. There is no charge to the client to whom the aid or device is given.

## **SASBAH - Sussex Association For Spina Bifida & Hydrocephalus**

Tel: **01903 507000** Main Office      Tel: **01825 722112** SASBAH Clinic

Tel: **01903 723278** SASBAH Advisers

Email: **sasbahoffice@tiscali.co.uk** **www.sasbah.co.uk**

Provides support for people with spina bifida and/or hydrocephalus in East and West Sussex. May be able to provide welfare grants. Field workers offer advice, support and friendship.

## **SCOPE Response**

Tel: **0808 800 3333** Email: **response@scope.org.uk** **www.scope.org.uk**

Helpline provides information on cerebral palsy, disability issues and the work of Scope. The team of experienced counsellors can provide initial counselling and support and can refer to Scope or external services as appropriate.

South East and Southern Community - Tel: **01959 564686**

Email: **southeast@scope.org.uk**

## **Play and Leisure**

### **Bikes, Trikes and Toys**

There are many different companies which manufacture specially adapted bikes, trikes and other toys. Contacting ICIS:information for life or the Disabled Living Foundation (contact details on page 19 & 20) will enable you to obtain a list of suppliers for specific products.

## **National Association of Toy & Leisure Libraries**

Tel: **020 7255 4600** Email: [admin@playmatters.co.uk](mailto:admin@playmatters.co.uk) [www.natll.org.uk](http://www.natll.org.uk)

National body for toy and leisure libraries in the UK. Toy Libraries lend good quality, carefully chosen toys to families with young children, including children with special needs. Publishes the annual 'Good Toy Guide'.

Local Toy Libraries.

Bognor Regis - Tel: **01243 821692**

Burgess Hill & District - Tel: **01444 245793**

Chichester - Tel: **01243 520817**

Crawley - Tel: **01293 518656**

East Grinstead - Tel: **01342 301396**

Haywards Heath - Tel: **01444 452310**

Horsham - Tel: **01403 218888**

Littlehampton - Tel: **01903 736626**

Worthing - Tel: **01903 229250**

## **National Play Information Service**

Based at the National Children's Bureau, 8 Wakley Street, London, EC1V 7QE.

Tel: **020 7843 6000** Email: [library@ncb.org.uk](mailto:library@ncb.org.uk) [www.ncb.org.uk](http://www.ncb.org.uk)

Has a large specialist reference library and information service on the subject of play. Commercial play information and grants for play.

## **RE:PLAY**

Southeast Regional Play Association, 33 Melrose Gardens, Hersham, Surrey, KT12 5HF.

Hannah Boyce. Tel: **01932 883 213**. Email: [hannah@playwork.org.uk](mailto:hannah@playwork.org.uk)

[www.playworksoutheast.org.uk](http://www.playworksoutheast.org.uk) [www.serps.org.uk](http://www.serps.org.uk)

Promotes play as part of child's development through advice, information and lobbying government.

## **The Cinema Exhibitors' Association Card**

Tel: **0845 123 1296** Email: [info@ceacard.co.uk](mailto:info@ceacard.co.uk) [www.ceacard.co.uk](http://www.ceacard.co.uk)

A national card that can be used to verify that the holder is entitled to one free ticket for a person accompanying them to the cinema. To apply you will need to be in receipt of the disability living allowance. Application forms are available from cinemas across the UK or a form can be downloaded from the website.

## **Clubs and Activities (see also section on Youth Clubs)**

West Sussex hosts many different clubs, groups and activities for children and young people with and without disabilities. A selection of activities are listed below, but for a more comprehensive list of activities, tailor made to the needs of your child or young person, please contact ICIS: information for life (contact details on page 19)

### **Crawley Community Arts Workshops for Young People**

Tel: **01293 552941** Email:[community.arts@crawley.gov.uk](mailto:community.arts@crawley.gov.uk)

Activities for young people in the Crawley area.

### **Footloose Dance Theatre Group**

Tel: **01293 438156** Community Arts Officer Email:[jo.joseph@crawley.gov.uk](mailto:jo.joseph@crawley.gov.uk)

Dance theatre group for children and young people aged 6 - 19 years with learning disabilities. Wednesdays 5.30pm-6.30pm Manor Green Primary School.

### **Shine Theatre Group**

Tel: **01273 832855** Director

Email:[mel@upton23.freeseve.co.uk](mailto:mel@upton23.freeseve.co.uk) [www.shinetheatregroup.co.uk](http://www.shinetheatregroup.co.uk)

An inclusive theatre group, catering for people with physical disabilities, learning disabilities, able bodied and socially disadvantaged. Pupils aged 5- 19 years participate in dance, drama, singing and performance.

### **Special Needs Discos**

Held at various venues across the county.

Horsham District Council, Horsham Leisure Link, Park House Lodge, North Street, Horsham. RH12 1RL.

Contact Nick Jenkins. Tel: **01403 215216**

Email: [nick.jenkins@horsham.gov.uk](mailto:nick.jenkins@horsham.gov.uk)

For children and adults and young people with special needs to perform dance, be a member of a rock band or a DJ and help run the events themselves.

### **Springboard Project - Horsham**

Tel: **01403 257699** Activities only

Email:[info@springboardproject.com](mailto:info@springboardproject.com) [www.springboardproject.com](http://www.springboardproject.com)

A charitable play and recreation centre for all children including those with disabilities or additional support needs, including a toy library, soft play room, sensory room, lounge area, kitchen, creative activities playroom and large outdoor Jubilee Leisure Garden.

### **Step-by-Step Dance Group**

Tel: **01403 864255** Group Leader

Email: [info@springboardproject.com](mailto:info@springboardproject.com) [www.springboardproject.com](http://www.springboardproject.com)

Dance Group for children and youngsters with additional needs aged 8-18.

Meets Mondays term time only at St Peter's School Cowfold From 5.30pm - 6.30pm £3 per session.

## Playschemes

### **Adur Special Needs Project**

Shoreham-by-Sea Tel/Fax: **01273 441866**

**www.adurspecialneedsproject.co.uk**

ASP is for up to 40 children and young people aged 5-23 with special needs in West & East Sussex. Runs a 3 week summer playscheme and Respite Project every second and fourth weekend.

### **Ashdown Club for Children with Special Needs - Guild Care**

Worthing Tel: **01903 528607** Answerphone **www.guildcare.org**

Ashdown Club offers a safe and stimulating environment for children with a wide range of special needs, both physical and behavioural.

### **Bunnyhoppers/Grasshoppers/Outburst**

Horsham Tel: **01403 257699** Activities Co-ordinator

Email:**activities@springboardproject.com** **www.springboardproject.com**

Activity Schemes for children with additional needs and disabilities: Bunny Hoppers (0-5) one Sunday a month. Grasshoppers (5-13) on Saturdays and Outburst (13-18) during school holidays. Book in advance.

### **Butterflies Playscheme**

Ifield, Crawley Tel: **07887 511593** Runs from 9.30am-3.30pm in holidays.

Play/activity scheme for children aged 5-18 years old with severe and profound learning difficulties. Primarily for children from Manor Green Primary and Manor Green College, Crawley but may take children from elsewhere in Crawley. Referral direct to Butterflies playscheme.

### **Chanctonbury Community Playscheme**

Tarring, Worthing Tel: **01903 203253** Organiser

A four week summer playscheme for children with special needs, aged 5-19, based for 2 weeks at Rydon School, Storrington and 2 weeks at Davison High School in Worthing. Places must be booked by the beginning of May.

### **Kangaroos Playscheme**

Cuckfield and Haywards Heath Tel: **01444 255120** Administrator

Email:**jenni-kangaroos@freeola.com** **www.kangaroos.org.uk**

Runs Saturday clubs and holiday playschemes for children aged 5-19 with learning difficulties living in Mid-Sussex. Sessions must be booked in advance.

### **Millpond Integrated Adventure Playground**

Crawley Tel: **01293 542174** Email: [nikke.gladwin@crawley.gov.uk](mailto:nikke.gladwin@crawley.gov.uk)

Open access facility for children aged 5-16yrs, open term time from Tuesdays-Fridays 3pm - 6.30pm, plus Saturdays and school holidays from 10.30am - 6pm. This facility has been specially designed for children with disabilities.

### **Parent Carers Support Group (PACSO)**

Chichester - see Carers Support Organisations, page 7

### **Sussex Autistic Society - Southdowns Family Centre**

Rustington - see Learning Disabilities, page 22

## **Respite and Short Breaks**

### **Crossroads Caring for Carers**

Provides respite support for carers in their own home, by sending in trained attendants to take over the caring role.

[www.caringforcarers.org.uk](http://www.caringforcarers.org.uk)

Chichester and Bognor - Tel: **01243 864600**

Mid Downs - Tel: **01403 249090**

Email: [middowns.crossroads@virgin.net](mailto:middowns.crossroads@virgin.net)

Worthing - Tel: **01903 216678**

Email: [worthingcrossroads@hotmail.com](mailto:worthingcrossroads@hotmail.com)

### **Direct Payments Scheme**

Tel: **01903 219482**

Email: [directpayments@ilawestsussex.org](mailto:directpayments@ilawestsussex.org) [www.ilawestsussex.org](http://www.ilawestsussex.org)

Direct Payments is a cash payment to people who need Children and Young People's Services (CYPS) to live independently. The payment enables people to arrange and pay for personal assistant services as an alternative to services provided CYPS.

### **Family Placement Disabilities Team**

North of County - Tel: **01403 246400** South of County - Tel: **01243 642444**

[www.westsussex.gov.uk](http://www.westsussex.gov.uk)

Scheme which recruits and assesses individuals and families to provide short breaks for children and young people with disabilities aged 0 -18 years. Accessed via Child Disability Teams (see page 8).

### **Finches**

Tel: **01444 245117**

Fully accessible bungalow run by Chailey Heritage offering respite care and an outreach in the child's own home, for children with complex health needs aged 0-16 years. 24 hour nurse care provided.

## **Holly Lodge**

Tel: **01403 255880**

West Sussex Primary Care Trust run residential home offering respite care for children 0 -19 years old with profound learning difficulties. Referral by social worker, community nurse, paediatrician, doctor.

## **Home Start**

A voluntary organisation promoting the welfare of families with at least one child under 5 years of age. Volunteers offer regular support, friendship and practical help to families with difficulties in their own homes, helping to prevent family crisis and breakdown.

Arun - Tel: **01243 869611**

Email:[arunhomestart@ukonline.co.uk](mailto:arunhomestart@ukonline.co.uk)

Crawley and Horsham - Tel: **01293 416327**

Email:[candhhomestart@wwmail.co.uk](mailto:candhhomestart@wwmail.co.uk)

[www.home-startcrawleyandhorsham.com](http://www.home-startcrawleyandhorsham.com)

Mid Sussex - Tel: **01444 250557**

Email:[home-start@midsussex.freerve.co.uk](mailto:home-start@midsussex.freerve.co.uk)

[www.homestart-midsussex.co.uk](http://www.homestart-midsussex.co.uk)

Worthing and Adur - Tel: **01903 236916**

Email:[wa@homestart0903.fsnet.co.uk](mailto:wa@homestart0903.fsnet.co.uk)

## **Residential Short Breaks - Respite**

Three homes run by Children and Young People's Services for children with severe learning disabilities. Access via Child Disability Teams (see page 8).

Cissbury Lodge - Worthing Tel: **01903 700888**

Lancing Close - Crawley Tel: **01293 526501**

Orchard House - Cuckfield Tel: **01444 454226**

## **Sitting Service - West Sussex**

A sitting service for children with disabilities in their own home, providing a break for parents and carers. Referral to the service is via the Children and Young People's services following an assessment of need.

Arun and Chichester - Tel :**01243 642462**

Crawley, Horsham & Mid-Sussex - Tel: **01403 246450**

Worthing and Adur - Tel: **01243 642318**

## **Tourism for All UK**

Tel: **0845 124 9971** Information

Email:[info@tourismforall.org.uk](mailto:info@tourismforall.org.uk) [www.tourismforall.org.uk](http://www.tourismforall.org.uk)

Information and advice on all aspects of holidays for disabled people.

## Sensory Impairments

### Sensory Services Team - West Sussex

Tel: **01903 745331** Email: **DeafServicesTeam.SS@westsussex.gov.uk**

Email: **roviteous.SS@westsussex.gov.uk**

Central office for provision of services for adults and children with sensory impairments in West Sussex. Referrals via Children & Young People's Services (see page 8) Services for deaf children 0-18 are provided by the Social Worker with Deaf Children, based at the Child Disability Team North (see page 8).

### Sensory Support Team In Education

Tel: **01903 746739**

Team of specialist advisory teachers and learning support assistants, who work with children who have a hearing and/or a visual impairment. Referrals taken from schools. Also work with pre-school children.

## Deafness and Hard of Hearing

### National Deaf Children's Society (NDCS)

Tel: **0808 800 8880** Freephone Helpline

Email: **helpline@ndcs.org.uk** **www.ndcs.org.uk**

Provides advice and information on all aspects of childhood deafness, including education, benefits, technology and equipment. Support with benefit claims, Disability Appeal Tribunals and special educational needs tribunals/appeals.

### National Deaf Children's Society - Southern England

Tel/Fax: **01296 620666** Textphone: **01296 620665** **www.ndcs.org.uk**

Support and social activities for deaf children (0-25 years) and their families from East and West Sussex, Hampshire, Kent and the Isle of Wight.

### RNID (Royal National Institute for Deaf People)

Tel: **0808 808 0123** Information Email: **informationline@rnid.org.uk**

Tel: **0808 808 6666** Tinnitus Help Email: **tinnitushelpline@rnid.org.uk**

**www.rnid.org.uk**

Offers a range of services, including information, awareness training, campaigning, residential care, communication services, employment services, telephone relay service (Typetalk), Tinnitus Helpline.

### Springboard - Crawley

Tel: **07980 351913**

Support group for pre-school deaf children and their parents which meets on the second and fourth Friday of month at NSPCC, Broadfield Park, Crawley from 9.30am-11.30am.

### **Sussex Deaf Association - West Sussex**

Tel/Fax: **01903 506416** Community Worker Tel: **01273 671899** Head Office

Email: [sda.worthing@freezone.co.uk](mailto:sda.worthing@freezone.co.uk) [www.sussexdeaf.co.uk](http://www.sussexdeaf.co.uk)

Provides communication support, advocacy, assistance with benefit forms, Deaf Awareness Training, British Sign Language courses, social groups and outings.

### **West Sussex Deaf & Hard of Hearing Association - Haywards Heath**

Tel: **01444 415582** Minicom: **01444 415593**

Email: [wsdeaf@wsdeaf.org.uk](mailto:wsdeaf@wsdeaf.org.uk) [www.wsdeaf.org.uk](http://www.wsdeaf.org.uk)

Helps people to express their views, sets up sign language and lip reading classes, provides information and advice, equipment, helps with improving and developing services.

## **Blindness and Visual Impairment**

### **Action for Blind People**

Tel: **0800 915 4666** Helpline Email: [info@actionforblindpeople.org.uk](mailto:info@actionforblindpeople.org.uk)

[www.actionforblindpeople.org.uk](http://www.actionforblindpeople.org.uk)

National charity for blind and visually impaired people providing supported housing, holiday hotels, employment support, information and advice, financial help and welfare rights service. Provides sporting activities for children.

### **Blatchington Court Trust**

Tel: **01273 727222**

Email: [enquiries@blatchington-court.co.uk](mailto:enquiries@blatchington-court.co.uk) [www.blatchington-court.co.uk](http://www.blatchington-court.co.uk)

Promotes the education (including social and physical training) and employment of visually impaired young people under 30 from Sussex.

### **LOOK - Sussex**

Tel: **01273 832267**

Email: [wendy@looksussex.co.uk](mailto:wendy@looksussex.co.uk) [www.looksussex.co.uk](http://www.looksussex.co.uk)

Charity providing information and support for families in East and West Sussex who have a child or young adult with a visual impairment.

### **RNIB - Royal National Institute of the Blind**

Tel: **08457 669 999** Helpline - prefix phone number with **18001** to use typetalk

Email: [helpline@rnib.org.uk](mailto:helpline@rnib.org.uk) [www.rnib.org.uk](http://www.rnib.org.uk)

Practical support, information and advice to people of all ages with a sight problem. Provides talking books, schools, colleges, computer training and rehabilitation training, and hotel guide. Vacation scheme for children and young people.

## Dual Sensory Impairment

### Deafblind UK/ National Centre for Deafblindness

Tel: **0800 132320** Helpline

Email: [info@deafblind.co.uk](mailto:info@deafblind.co.uk) [www.deafblind.org.uk](http://www.deafblind.org.uk)

Information and advice on dual sensory loss, 24 hour helpline, counselling.

Teaches touch-based communication systems. Visits the deafblind.

### Sense/ National Deaf Blind & Rubella Association

Tel: **0845 127 0060** Text: **0845 1270062**

Email: [info@sense.org.uk](mailto:info@sense.org.uk) [www.sense.org.uk](http://www.sense.org.uk)

South East - Tel: **0845 127 0076** Email: [info@sense.org.uk](mailto:info@sense.org.uk)

Charity working with deafblind children and adults offering individually tailored education programmes; residential and community supported living services; respite provision including specialist holidays, day services and employment services; outreach training and consultancy and intervenor services, providing one-to-one support to enable deafblind people to access community services and live as independently as possible.

## Speech and Language

### 1 Voice

Tel: **0845 330 7862** Email: [info@1voice.info](mailto:info@1voice.info) [www.1voice.info](http://www.1voice.info)

1 Voice - communicating together; recognises that a communication disability can be isolating for children and their families. Offers a network for families.

### Aidis Trust

- see Computers, page 9

### Afasic - Unlocking Speech & Language

Helpline: **0845 355 5577**

Email: [info@afasic.org.uk](mailto:info@afasic.org.uk) [www.afasic.org.uk](http://www.afasic.org.uk)

Advice, information and support, including a telephone helpline, newsletters; seminars/workshops for parents and professionals; self-help groups throughout the country.

### I CAN

Tel: **0845 225 4071**

Email: [info@ican.org.uk](mailto:info@ican.org.uk) [www.ican.org.uk](http://www.ican.org.uk) [www.talkingpoint.org.uk](http://www.talkingpoint.org.uk)

Special focus on children with communication disability. Provides a combination of specialist therapy and education for children, information for parents, and training and advice for teachers and other professionals.

## **The Speech Centre**

Tel: **01892 661116**

Specialists in speech technology for both the professional and disabled user market.

## **Triangle**

Tel:**01273 413141** Email:**info@triangle-services.co.uk**

**www.triangle-services.co.uk**

Provides individual outreach and therapeutic support for children and young people up to age 12 presenting severely challenging behaviour. Caters for children with additional physical, sensory, learning and communication difficulties, as well as challenging behaviour. UK wide training and consultancy for communicating and consulting with disabled children. Fully accessible training and groupwork venue in Hove. Currently outreach provided in East Sussex, Brighton and Hove, West Sussex, Surrey and some London boroughs.

## **Transport, Mobility & Wheelchairs**

### **Action for Kids Charitable Trust**

Tel: **0845 300 0237** Helpline

Email:**info@actionforkids.org** **www.actionforkids.org**

Aims to combat the problems facing severely disabled children and their families. Provides mobility aids not available on the NHS for young people with any disability aged 0-26 in the UK.

### **Association Of Wheelchair Children**

Tel: **0870 121 0050**

Email:**headoffice@wheelchairchildren.org.uk**

**www.wheelchairchildren.org.uk**

Aim to aid and support children who use wheelchairs and their families. Try to ensure that children have the right equipment and run training courses for children using wheelchairs for outdoor mobility.

### **Banstead Mobility Centre/ Queen Elizabeth's Foundation Mobility Centre**

Tel: **020 8770 1151**

Email: **info@mobility-qe.org** **www.qefd.org.uk/mobilitycentre/**

Information and assessment service on all aspects of outdoor mobility. Driving ability, car adaptations and electric wheelchair assessments and training for disabled people including residential driving tuition. Register of driving instructors for disabled people.

### **Children Today Charitable Trust**

Tel: **01244 335622**

Email: **info@children-today.org.uk** **www.children-today.org.uk**

A charity providing financial help to purchase specialised equipment for children and young people with disabilities. Equipment includes, but is not limited to: trikes, wheelchairs, walking aids and communication aids.

### **Disabled Living Foundation (DLF)**

see Information Services & Advice, page 20

### **Easy Riders Wheelchair Programmes**

Tel: **020 7428 8100**

Email: **wheelchairs@varietyclub.org.uk** **www.varietyclub.org.uk**

Provide funding for custom designed wheelchairs for children with disabilities

### **Family Fund London and South East**

- see Health needs - cancer, page 14

### **GBL Wheelchair Services Ltd - Littlehampton**

Tel: **01903 733528**

Email: **littlehampton@wheelchairwarehouse.com**

**www.wheelchair-warehouse.com**

Sells powered and manual wheelchairs and scooters, both new and secondhand. Also hires out manual wheelchairs. Can supply sports chairs and handbikes, walking aids and ramps.

### **Get Kids Going**

Tel: **020 7481 8110**

Email: **info@getkidsgoing.com** **www.getkidsgoing.com**

Aims to provide disabled children and youngsters up to age 26 with the opportunity of participating in various sports by providing specially built sports wheelchairs. Also by giving disabled athletes sports grants for training, travel to competitions, equipment etc.

### **J C Robinson Trust No.3**

Southend Farm, Wooton Under Edge, Gloucester GL12 7PB

Tel: **01453 842243**

One off grants of up to £1,000 to people in need with a preference for those living in Sussex, Bristol and South Gloucester. Includes wheelchairs and washing machines. Applicants please apply by letter with the backing of a professional who knows the situation such as a doctor or social worker.

### **KidsOut**

Tel: **01525 385232**

Email: **kidsout@kidsout.org.uk** [www.kidsout.org.uk](http://www.kidsout.org.uk)

National charity providing fun for disadvantaged children and special needs children throughout the UK. Operates a Funds for Fun scheme, which gives small financial grants to individuals, families, schools and groups for the purchase of special play equipment, toys, holidays, respite care and outings.

### **League of the Helping Hand**

Tel: **01273 493551**

Email: **secretary@lhh.org.uk** [www.lhh.org.uk](http://www.lhh.org.uk)

Provides grants for people who are in financial need due to illness or disability. Applications via professional person who knows details of finances and personal circumstances.

### **Lifeline 4 Kids**

Tel: **020 7794 1661**

Email: **rda@lifeline4kids.org** [www.lifeline4kids.org](http://www.lifeline4kids.org)

To assist disabled children, mentally, physically or otherwise deprived, with equipment, clothing, etc. (Do not give monetary grants).

### **Mavis - Mobility Advice & Vehicle Information Service**

Tel: **01344 661000** Email: **mavis@dft.gsi.gov.uk**

**[www.dft.gov.uk/access/mavis](http://www.dft.gov.uk/access/mavis)**

Helps disabled and older motorists make informed choices about driving, vehicle adaptation and suitable vehicle types for both drivers and passengers.

### **Melanie Braysher Trust**

Tel: **01428 651461**

Supply and loan mobility equipment for children and young people (generally up to 20 years old, but this can be flexible) within an approximate 25 mile radius of Haslemere.

### **Motability**

Tel: **0845 456 4566** Car Schemes Tel: **01264 384480** Wheelchair/Scooters

**[www.motability.co.uk](http://www.motability.co.uk)**

Provides affordable convenient, and trouble-free motoring. Also offers financial assistance for mobility solutions in certain circumstances.

## **RADAR/ Royal Association for Disability & Rehabilitation**

Tel: **020 7250 3222**

Email: [radar@radar.org.uk](mailto:radar@radar.org.uk) [www.radarsearch.org](http://www.radarsearch.org) [www.radar.org.uk](http://www.radar.org.uk)

National disability organisation campaigning for disabled people's rights and full integration into society. Provides the National Key Scheme (NKS) and guide to accessible toilets

## **Transport Co-ordination Group**

Tel: **01243 756603**

Jo Brocken - Tel: **01243 777391** Email: [jo.brocken@westsussex.gov.uk](mailto:jo.brocken@westsussex.gov.uk)  
[www.westsussex.gov.uk](http://www.westsussex.gov.uk)

Provides advice and support to community groups to begin and operate transport schemes. Annually updated community transport directory.

## **Wheelchair Service – West Sussex**

Crawley & Horsham - Tel: **01403 227000 ext 7160**

Western Sussex PCT - Tel: **01243 531268** Email: [anne.ennis@wsx-pct-nhs.uk](mailto:anne.ennis@wsx-pct-nhs.uk)

Worthing - Tel: **01903 846500** Email: [wheelchairservice@aaw.nhs.uk](mailto:wheelchairservice@aaw.nhs.uk)

Provides and maintains wheelchairs on loan to Health Authority residents with long term mobility problems. Short term loans available from British Red Cross or Home Loans - NRS Direct Care Equipment Loan Service. Initial referral is via either GP, OT, physiotherapist, consultant or senior house doctor.

## **Whizz-Kidz - The Movement For Non-Mobile Children**

Tel: **020 7233 6600**

Email: [info@whizz-kidz.org.uk](mailto:info@whizz-kidz.org.uk) [www.whizz-kidz.org.uk](http://www.whizz-kidz.org.uk)

Raises money to provide disabled children and young people with customised mobility equipment that is not available through the NHS. Equipment provided includes powered and manual wheelchairs, trikes, buggies and walking aids.

## **Youth Clubs**

### **Adur Special Needs Project - Youth Club**

Tel: **01903 754901** Part-time Youth Worker

An evening youth club for disabled, 8 -18 year olds on Tuesdays at the Youth Centre, Penhill Road, Lancing, offering a range of activities.

### **Ashdown Club for Children with Special Needs**

6-8 Ashdowne Road, Worthing Tel: **01903 528607** Answering Service

Email: [jill.lancaster@guildcare.org](mailto:jill.lancaster@guildcare.org) [www.guildcare.org](http://www.guildcare.org)

Situated in a purpose-adapted building, there is a youth club for young people with special needs aged 12 - 18 on Wednesday evenings.

### **Friday Zone**

Pagham & Rose Green Youth Centre, Hawkins Close, Bognor Regis.

Tel: **01243 264439** Youth Leader's Office

Youth club for young people with special needs and/or autistic spectrum disorder, aged 11-19 years. One Friday a month.

### **Junior Gateway Youth Club**

12-18 yrs. The Wallis Centre, De La Warr Rd. East Grinstead, Mondays from 6.30pm-8pm.

Tel: **01342 321585** Youth Worker

Email: [wallis.youth.centre@westsussex.gov.uk](mailto:wallis.youth.centre@westsussex.gov.uk)

### **M8S Youth Club - Horsham**

Horsham Youth Centre, Hurst Road, Horsham

Tel: **01403 210388**

Email: [horsham.youth.centre@westsussex.gov.uk](mailto:horsham.youth.centre@westsussex.gov.uk)

A youth club for young people aged 13-19 years, with additional needs and disabilities held Wednesdays 7pm-9pm.

### **Manor Green College Youth Club**

Crawley Tel: **01293 520351**

Youth Wing, Thomas Bennett School, Ashdowne Drive, Mondays 6-9pm

### **PHAB Club - Crawley (junior)**

Dormans Youth Arts Centre, Dormans, Crawley

Tel: **01293 526388** Email: [DYAC@westsussex.gov.uk](mailto:DYAC@westsussex.gov.uk)

Club for physically disabled and able-bodied young people, aged 11-19 years on Fridays from 5pm-7pm.

### **Salvation Army - Worthing**

11, Crescent Rd, Worthing on Thursday 7-9.30pm

Tel: **01903 234497**

Email: [welcome\\_in@btconnect.com](mailto:welcome_in@btconnect.com) [www.salvationarmy.org.uk/worthing](http://www.salvationarmy.org.uk/worthing)

Runs a Youth Club for young people with Learning Difficulties aged 15 and over.

### **Signposts Mid Sussex**

Frenz! Saturday, 10-12pm, 16-25 years at Delmon House, 38, Church Road, Burgess Hill. See also Information Services & Advice, page 20

### **Springboard Buddy Scheme - “Buddies”**

Tel: **01403 257699** Buddies Co-ordinator

Email: **buddies@springboardproject.com** **www.springboardproject.com**

A friendship group for teenagers with disabilities and additional needs to access their local recreation and leisure facilities on a flexible basis with volunteers of their own age group. Based in Crawley, Horsham, East Grinstead and Mid Sussex.

### **STARS Youth Club at Millpond Integrated Adventure Playground**

Crawley Tel: **01293 542174** Community Services Manager

Email: **nikke.gladwin@crawley.gov.uk**

Runs from 7pm - 9pm on the first Tuesday of each month and every Tuesday during school holidays for children with special needs and disabilities.

### **The Weald Youth Wing Youth Club**

Weald School, Station Road, Billingshurst

Zohra Lichioui Tel: **01403 782539** Mobile: **07767 433314**

On Tuesday 7-9pm aged 13-20yrs. No charge For young people with additional needs.

### **Youth Club -Steining Special Task Force**

Tel: **01903 815515** Youth Worker

Youth club for young people aged 11-25 years, with or without disabilities. Meet on the first and third Saturdays of the month from 2.30pm-5pm at the Cuthman Centre, Shooting Field, Steining.





Wellspring West Sussex acknowledges with thanks the work of ICIS : information for life in developing, maintaining and providing the information about the services listed in the Directory. The information was correct to the best of their knowledge when this Directory was printed.

**Typeset and Design by Lizzie Baily**  
**[lizzie@wellspringwestsussex.org.uk](mailto:lizzie@wellspringwestsussex.org.uk)**

Printed by Shanks Printers and Finishers  
01903 716442