### Support Groups and Learning Disabilities - January 2012

There are many support groups working in the field of learning disability and this page of the web portal is in development. If you know of any missing support groups please contact us. Email : <u>Sandra.Wilson@nes.scot.nhs.uk</u>

The list below was gathered from research for the Learning Disabilities Managed Knowledge Network. Support Groups here are arranged with Scotland first, umbrella groups, and then subject specific. General support groups in disabilities and caring are also included, plus links to International Support Groups where relevant.

See also the **NHS Support Service Directory for learning disability support groups.** <u>http://www.nhsinform.co.uk/support-services.aspx</u> Other general database providers in Scotland include **Update** <u>http://www.update.org.uk</u>, **Inclusion Scotland** <u>http://inclusionscotland.org.uk</u> and **GCVS** <u>http://www.gcvs.org.uk</u>

# Scotland

### **Umbrella Groups**

**SCLD** (Scottish Consortium on Learning Disability) A partnership of 12 organisations offering advice, consultancy and awareness raising. <u>http://www.scld.org.uk</u>

#### Learning Disability Alliance Scotland http://www.ldascotland.org/

**CCPS - Coalition of Care and Support Providers in Scotland**. <u>http://www.ccpscotand.org</u> Its mission is to identify, represent, promote and safeguard the interests of third sector and not-for-profit social care and support providers in Scotland, so that they can maximise the impact they have on meeting social need. **Members List** <u>http://www.ccpscotland.org/aboutccps/members-list</u>

### General

**Enable Scotland** lead charity in learning disability in Scotland. http://www.enable.org.uk/index.php

**Quarriers** Through person centred support, Quarriers assists people with learning disabilities, autism, acquired brain injury and complex physical disabilities towards achieving their aspirations and ambitions, however challenging these may be. Whilst mainly supporting people living in their own homes, services may also be delivered in small group living environments, in family settings, and through residential short breaks. http://www.quarriers.org.uk/

**KEY Community Supports -** <u>http://www.keycommunitysupports.org/index.asp</u> Provides individual support to people with learning disabilities.(mostly in West of Scotland)

#### ARC Scotland (Association for Real Change) http://www.arcuk.org.uk/scotland

Information, support and networking for providers of services to people with a learning disability.(mostly in East of Scotland)

#### The Richmond Fellowship Scotland <a href="http://www.trfs.org.uk/">http://www.trfs.org.uk/</a>

Provides high-quality community-based services for people who require support in their lives. All of their services work in person-centred ways to offer choice, promote inclusion and maximise ability.

#### Real-Life Options <u>http://reallifeoptions.org</u>

UK wide with offices in Scotland offering support to people with learning disabilities to make their own choices and live their own lives.

### UK

### **Umbrella Groups**

Learning Disability Coalition <u>http://www.learningdisabilitycoalition.org.uk/</u>

The Learning Disability Coalition has 15 member organisations and over 160 supporting organisations who have come together to ensure that there is enough public funding for people with a learning disability to have the same chances and choices as everyone else. The member organisations are : Association for Real Change (ARC), BILD (British Institute of Learning Disabilities), The Down's Syndrome Association, Foundation for People with Learning Disabilities, the Hesley Group, Mencap, National Autistic Society, People First, Real Life Options, Sense, The National Forum of People with Learning Difficulties, National Family Carer Network, Turning Point, United Response and Vogage..

### General

BILD - British Institute of Learning Disabilities http://www.bild.org.uk

**Mencap** - National organisation that fights for equal rights and greater opportunities for people with learning disabilities. <u>http://www.mencap.org.uk/</u>

#### Ask Mencap

Provides lots of downloadable information on issues relevant to people with learning disabilities and their carers, including health. <u>http://www.askmencap.org.uk</u>

#### Foundation for People with Learning Disabilities

National organisation that promotes the rights, quality of life and opportunities for people with learning disabilities through research, development and influencing policy. Free resources to download and purchase. <u>http://www.learningdisabilities.org.uk</u>

Paradigm <u>http://www.paradigm-uk.org</u>

Leonard Cheshire http://www.lcdisability.org/ email: scotlandoffice@LCDisability.org

#### The Salvation Army http://www1.salvationarmy.org.uk/uki/www\_uki.nsf

**Common Knowledge** – Provides online learning, accessible information and social networking for people with learning difficulties. <u>http://www.ckuk.org.uk</u>

#### **The Rix Centre**

Charitable research & development organisation committed to realising the benefits of new media technology to transform the lives of people who have learning disabilities. <u>http://www.rixcentre.org/</u>

#### Real-Life Options <a href="http://reallifeoptions.org">http://reallifeoptions.org</a>

UK wide with offices in Scotland offering support to people with learning disabilities to make their own choices and live their own lives.

Voyage <u>http://www.voyagecare.com/</u>

Has been supporting people who have learning disabilities, autism, head and spinal injuries and other complex disabilities for over 20 years.

**Equal Futures** <u>http://equalfutures.org.uk</u> supports families to develop personal future plans for a loved one with a disability including housing options, advocacy and establishing a loving and caring circle of support. Working in most of the central belt of Scotland, reaching from Blairgowrie to Peebles and from Troon to Haddington.

#### **Local Groups**

Health and Happiness (Highlands) - http://www.healthandhappiness.org.uk

**Unity Enterprise** is a Scottish inter-church charity founded in 1989 with a 'person-centred approach' working in Central Scotland. Develops innovative programmes designed to promote the development of people as individuals and within their community including those with learning disabilities. <u>http://www.unity-enterprise.com/</u>

### International

**Inclusion International** – set up by Mencap and a German charity. (Special interest research networks in ageing, Down's Syndrome, autism, PMLD. Co-Chairs with Groningen University. Also have round table specific meetings on themes. Working with WHO on ageing. http://www.inclusion-international.org/

**The National Center for Learning Disabilities (NCLD)** – The National Center for Learning Disabilities works to ensure that the nation's 15 million children, adolescents and adults with learning disabilities have every opportunity to succeed in school, work, and life. http://www.ncld.org/

**Best Buddies** – support group dedicated to establishing a global volunteer movement that creates opportunities for one-to-one friendships, integrated employment and leadership

development for people with intellectual and developmental disability. <u>http://www.bestbuddies.org/</u>

## **Subject specific**

### **Accessible Information**

Information Alternatives http://www.informationalternatives.co.uk/why\_accessible\_info.htm

**Elfrida Society** <u>http://www.elfrida.com</u> The Elfrida Society researches better ways of supporting people with learning disabilities and provides a wide range of accessible information on health issues.

**Glasgow Good Information Group** <u>http://ggig.org.uk</u> a community group supported by Service Organisations in the Glasgow area with membership open to people who use services and are interested in making information easier to understand, support organisations working to help people live more independently and other individuals and organisations interested in good information.

### Advocacy

**People First (Scotland)** It is the independent self-advocacy organisation in Scotland. We are run by and for people with learning difficulties. <u>http://www.peoplefirstscotland.org/</u>

Scottish Independent Advocacy Alliance (SIAA) http://www.siaa.org.uk/

**Ceartas** - professional advocacy to adult community groups in East Dunbartonshire. http://www.ceartas.org.uk/

Drumchapel Advocacy Project http://www.mokaweb.com/waverley/advocacy.htm

**Partners in Advocacy** provides advocacy to adults using learning disability services and to children and young people using mental health services or with any additional support needs, in Edinburgh, East & Mid Lothian, East Renfrewshire, Glasgow & Dundee. http://www.partnersinadvocacy.org.uk/

### **Autism Spectrum**

National Autistic Society http://www.autism.org.uk/

#### Scottish Autism - http://www.scottishautism.org/

Scottish charity committed to working for the rights and quality of life of people with autism. Offers a range of support for people with autism including education, day care, supported living, vocational opportunities, respite and outreach.

Autism Initiatives http://www.autisminitiatives.org/

National Centre for Autism Studies (University of Strathclyde) http://scottishautismnetwork.org.uk/

### **Carers Groups in Scotland**

#### **Umbrella Groups**

Carers Scotland - http://www.carersuk.org/scotland

Carersnet - website of the Coalition of Carers in Scotland - http://www.carersnet.org/

Coalition of Care and Support Providers in Scotland (CCPS) -

http://www.ccpscotland.org/

List of members http://www.ccpscotland.org/about-ccps/members-list

#### Scotland

Princess Royal Trust for Carers - At the heart of The Trust is a unique network of 144

independently-managed Carers' Centres. See map for Scottish Centres. <u>http://www.carers.org/ http://professionals.carers.org/young-</u> <u>carers/health,3065,PP.html</u>

Crossroads Caring Scotland - http://www.crossroads-scotland.co.uk/

Ycnet - website of the Scottish Young Carers Alliance http://www.youngcarers.net/

**Shared Care Scotland.** (includes a database of respite care and accessible holiday accommodation) <u>http://www.sharedcarescotland.org.uk/</u>

#### **Local Carers Groups**

Carers Link (East Dunbartonshire) - http://www.carerslink.org.uk/

CarersNET (Edinburgh & Lothian)- run by Vocal http://www.vocal.org.uk

### **Behaviour that Challenges and Positive Behavioural Support**

#### **Challenging Behaviour Foundation**

Provides guidance and information on supporting people with challenging behaviour, including fact sheets to download. <u>http://www.thecbf.org.uk</u>

#### Positive Behavioural Support - British Institute of Learning Disabilities

http://www.bild.org.uk/behavioursupport.htm

#### Care and Treatment of Offenders with Learning Disabilities

Provides information on people with learning disabilities who have or are at risk of committing offences. <u>http://www.ldoffenders.co.uk</u>

### **Cerebral Palsy**

#### Scope

Promotes equal rights and improved quality of life for disabled people, especially those with cerebral palsy. <u>http://www.scope.org.uk</u>

### **Down's Syndrome**

Down's Syndrome Scotland <u>http://www.dsscotland.org.uk/</u>

**Down Syndrome Association** England http://www.downs-syndrome.org.uk/resources/links/medical/62.html

Down's Heart Group http://www.dhg.org.uk

### **Children/Young People**

#### Kindred (formerly SNIP) http://www.kindred-scotland.org/home

A voluntary organisation based within the Royal Hospital for Sick Children supporting families of children and young people with additional needs. Kindred is run by a committee of parents of children/young people with additional support needs and professionals working in the field. Most of the Kindred staff have experience of parenting children/young people with additional support needs.

**Contact a Family** Provides information on the health needs and syndromes associated with children with disabilities. <u>http://www.cafamily.org.uk/index.html</u>

### Communication

The Communication People <u>http://www.communicationpeople.co.uk/</u> Communication Forum Scotland "Talk for Scotland Toolkit" http://www.communicationforumscotland.org.uk/

### **Disability – general**

Update http://www.update.org.uk Scotland's national disability information provider

Disability Help Scotland http://www.disabilityhelp-scotland.co.uk/index.html

The Thistle Foundation charity supporting people with disabilities and long term health conditions. <u>http://www.thistle.org.uk/</u>

Inclusion Scotland http://www.inclusionscotland.org/

### **Education**

**Lead** (specialists in linking education and disability) is a voluntary organisation set up to widen access to learning for disabled young people and adults and carers across Scotland. http://www.lead.org.uk/

### Epilepsy

**Epilepsy Action** National organisation that aims to improve the quality of life and promote the interests of people living with epilepsy. It provides free information and materials to purchase. - <u>http://www.epilepsy.org.uk/</u>

Epilepsy Scotland http://www.epilepsyscotland.org.uk

### **Fetal Alcohol Syndrome**

#### (Awaiting information on new group in Scotland)

#### FAS Aware UK

www.fasaware.co.uk

This website has been designed to raise awareness, give informed choice, provide information and support for people affected by / interested in FAS. National Organisation on Fetal Alcohol Syndrome (NOFAS-UK)

http://www.nofas-uk.org

NOFAS-UK promotes public awareness about the risks of alcohol consumption during pregnancy with the goal to reduce the number of babies being born with FASD. It further acts as a source of information to the general public, press and to medical professionals.

#### National Organisation on Fetal Alcohol Syndrome (NOFAS-USA)

http://www.nofas.org

#### **FASD Connections**

#### www.fasdconnections.ca/index.htm

FASD Connections is committed to building a community in which adolescents and adults with FASD are included and encouraged and where their desire and potential is supported; where the experience of families is understood, acknowledged, and accepted; and where systems are equipped to respond in an informed, compassionate and responsible way.

### **PMLD** (Profound and Multiple Learning Disability)

#### PAMIS (Scotland) http://www.pamis.org.uk/index.php

**Mencap** - UK organisation that fights for equal rights and greater opportunities for people with learning disabilities. <u>http://www.mencap.org.uk/</u>

### **Prader-Willi Syndrome**

Prader-Willi Syndrome Association (UK): <u>www.pwsa.co.uk/</u>

International Prader-Willi Syndrome Organisation <u>www.ipwso.org/</u>

### **Sensory Impairment**

**Sense Scotland** working with people who have impairments to vision and hearing with or without other disabilities <u>http://www.sensescotland.org.uk/</u>

Look Up <u>http://www.lookupinfo.org</u>

Hayfield Support Services with Deaf People (including those with a learning disability.Based in Glasgow but take UK referrals)<a href="http://www.hayfield.org.uk">http://www.hayfield.org.uk</a>

### **Social Inclusion**

#### **Umbrella groups in Scotland**

Altrum <u>http://www.altrum.org.uk/index.asp</u> Altrum is an umbrella group or organisation of organisations and individual people committed to fostering creativity, community and citizenship for all. ee) Full List of Members <u>http://www.altrum.org.uk/members.asp</u> **EDG** – **Edinburgh Development Group** Committed to the principles of inclusion and equality and working with people who have learning difficulties and their families. <u>http://www.edg-sco.org/index.html?pid=1</u>

FAIR Deal - http://www.fair-deal.org/

People First (Scotland) <u>http://www.peoplefirstscotland.org/</u>

**Cornerstone** - is one of Scotland's largest charities and a leading provider of services for people with learning disabilities and others with support needs.

http://www.cornerstone.org.uk/

**Keys to Inclusion** – Edinburgh based charity promoting the inclusion of children with disabilities for the benefit of the children, their families and their communities. <u>http://www.keystoinclusion.co.uk/</u>

**Self Directed Support Scotland (SDSS)** - The forum for Disabled People's Self Directed Support Organisations Scotland wide, working together to promote better and effective outcomes for all. SDSS is an umbrella organisation of Disabled People's Organisations and as a membership organisation, SDSS has a wealth of experience and knowledge of Personalisation, Self Directed Support and its related tools, such as Direct Payments, to call upon. <u>http://www.sdsscotland.org.uk</u>

### Home Care and Supported Living

carr gomm - supporting people and communities <a href="http://www.carr-gommscotland.org.uk/">http://www.carr-gommscotland.org.uk/</a>

**Support for Ordinary Living** deliver services to men and women with learning disabilities in Lanarkshire. Services are designed to ensure that people are supported to live life to the full within their own homes, families and the community. Each person has dedicated support or live-in support workers who work in a person centred way to deliver the right amount and type of support required by each individual. <u>http://www.forliving.org</u>

**Loretto Care** established in 2002 and provides a range of care and support services to people in need including those with learning disabilities and works closely with Loretto Housing. Currently working in Glasgow, Renfrewshire, North Lanarkshire, and South Lanarkshire <u>http://www.lorettoha.co.uk/care-about</u>

### Housing

**Shelter Scotland** <u>http://scotland.shelter.org.uk</u> works to alleviate the distress caused by homelessness and bad housing.

Housing Support Enabling Unit (part of CCPS) <u>http://www.ccpscotland.org/hseu/about-us</u>

### **Visual Arts**

**Project ability** <u>http://www.project-ability.co.uk/</u> Project Ability is a Glasgow-based visual arts organisation which creates opportunities for people with disabilities and people with mental health issues to express themselves and achieve artistic excellence.