

# INFORMATION SHEET



making a difference  
to the lives of people with  
severe learning disabilities

## Further Information for Parents

This list is not comprehensive but gives details of some organisations, books and leaflets which parents may find useful. Contact a Family (contact details on page 2) can provide details of support groups for specific syndromes not mentioned in this information sheet.

### FURTHER INFORMATION ON CHALLENGING BEHAVIOUR

*The Challenging Behaviour Foundation produces information packs and DVDs on various aspects of challenging behaviour. References to further sources of information are provided in the majority of information sheets. Please see our resource order form or website for full details.*

#### **British Institute of Learning Disabilities (BILD)**

UK wide charity which campaigns to improve the lives of people with a learning disability.

Publications include:

*Easy Guide to Being Held Safely (2004) BILD*

ISBN: 1 90408271 8 £7.00

*Easy Guide to Physical Intervention (2002) BILD*

ISBN: 1 90251997 3 £7.00

*Carers' Guide to Physical Interventions and the Law: information and advice for parents, carers and care workers supporting children, young people and adults with learning disabilities (2005)*

Lyon, C & Pimor, A.

ISBN: 1 90408281 5 £12.00

BILD publications: 0845 370 0067

Website: [www.bild.org.uk](http://www.bild.org.uk)

#### **National Autistic Society (NAS)**

UK wide charity which provides individuals with autism and their families with information, support and details of services that they can access. Publications include:

*Understanding Behaviour (2005) May, F*

ISBN 978 1 89928 0674 £6.00

*Challenging Behaviour and Autism: Making sense – Making Progress.* Whitaker, P

ISBN: 1 89928051 3 £14.00

Helpline: 0845 070 4004

Website: [www.nas.org.uk](http://www.nas.org.uk)

#### **Scope**

Charity in England and Wales for people with cerebral palsy, their families and carers.

Publications include Scope booklet: *Challenging Behaviour and Cerebral Palsy* (2007)

Helpline: 0808 800 3333

Website: [www.scope.org.uk](http://www.scope.org.uk)

#### **Tuberous Sclerosis Association**

Charity supporting people with Tuberous Sclerosis and their parents and carers. Information booklets include:

*Behaviour and Autism – adolescence and adulthood management of challenging behaviour*

General enquiries: 0121 445 6970

Website: [www.tuberous-sclerosis.org](http://www.tuberous-sclerosis.org)

## PARENTS PERSPECTIVES

### Gregory, J

*Bringing up a challenging child at home. When love is not enough* (2000).

The author describes her life with her daughter who has a learning disability and challenging behaviour. She describes her struggle to cope with the behaviour, the effects on the rest of the family and explains how she got the right support.

Jessica Kingsley

ISBN: 1 85302874 8

£13.95

### Telfer, J

*Christopher's Story. The Child Within the Man* (2006).

Christopher has autism and severe challenging behaviour. Christopher's mother tells of her determination to remain together as a family, when the only alternative offered was residential care.

Chipmunkpublishing.

ISBN 978 1 84747 309 7

E-book £5.00

Paperback £12.00

## GENERAL INFORMATION FOR CARERS

### Carers UK

UK wide charity providing information and advice to carers about their rights and how to get support. Campaigns for equality for carers. Fact sheets include: *How do I get help? Carer's assessments made clear; Direct payments for carers; Carer's Allowance and the Carer Premium.* A selection of fact sheets can be downloaded from the Carers UK website or Tel: 0845 241 0963. One copy of each fact sheet free to carers.

CarersLine: 0808 808 7777

Website: [www.carersuk.org](http://www.carersuk.org)

### Contact a Family

UK wide charity providing advice, information and support to the parents of all disabled children. Services include a family linking scheme and a number of useful free publications including: "A Guide to Assessments / Services" and "A guide to claiming Disability Living Allowance for children"

Helpline: 0808 808 3555.

Website: [www.cafamily.org.uk](http://www.cafamily.org.uk)

### The Nuffield Foundation

Publications include: *Care Matters. A guide to the Carers (Equal Opportunities) Act 2004.*

*Russel, P. (2007)* and *A guide to support for adult learners caring for disabled children or other family members.* Russel, P. (2005).

Limited hard copies available: 020 7631 0566. Free to download: [www.nuffieldfoundation.org](http://www.nuffieldfoundation.org)

## CARE OPTIONS

### Department for Children, Schools & Families

*A Parent's guide to direct payments* (2006)

ISBN: 1-84478-682-X.

Explains the steps a parent needs to take in order to set up direct payments. One copy free to parents.

Tel: 0845 60 222 60

Website: [www.everychildmatters.gov.uk](http://www.everychildmatters.gov.uk)

### **Disabilities Care Register**

Offer a free information service for people searching for a care home or independent housing options for disabled adults aged 16-64.

Helpline: 0800 38 92 077

Website: [www.carechoices.co.uk](http://www.carechoices.co.uk)

## **EDUCATION**

### **Advisory Centre for Education**

*Special Education Handbook 9<sup>th</sup> Edition (2005).*

Describes how parents should go about getting extra help for their child and explains their rights and their role within the whole 'statementing' process.

ACE ISBN: 1 87067231 3 £17.99

### **Gabbitas Educational Consultants**

*Schools for Special Needs. 13<sup>th</sup> Edition (2007-2008).*

Information on a variety of education related topics, plus a directory of special schools. Updated annually.

Kogan Page ISBN: 0 7494 4987 X £23.99

### **Independent Panel for Special Education Advice (IPSEA) (England & Wales)**

Charity offering free and independent advice to parents of children with special educational needs in England and Wales on: local authorities' legal duties to assess and provide for children with special educational needs; exclusions of children with special needs/disabilities; actions or inaction by local authorities and/or schools which discriminate against children with disabilities.

Helpline: 0800 0184016

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

### **ISEA (Scotland)**

A charity established by parents to provide free, independent advice, information and support to parents who have a child/young person with special educational needs in Scotland.

Tel: 0131 454 0096

Website: [www.isea.org.uk](http://www.isea.org.uk)

### **Morris, J**

*The right place? A parents' guide to choosing a residential special school (2003).*

Written with input from parents whose children attend a residential special school. Includes a chapter on what to look for and ask about.

Joseph Rowntree Foundation ISBN 1 85935 149 2 (or free pdf available at [www.jrf.org.uk](http://www.jrf.org.uk))

### **Special Educational Needs Advice Centre (SENAC) (Northern Ireland)**

A charity providing information for parents who have a child/young person with special educational needs in Northern Ireland.

Tel: 028 9079 5779

Website: [www.senac.co.uk](http://www.senac.co.uk)

## **RIGHTS**

### **Disability Law Service**

UK charity providing free advice on community care, disability discrimination, education, employment, welfare and benefits. Free fact sheets available to download from website include: “*An Introduction and Overview of Community Care*” and “*English Social Services Complaint Procedure*”

Advice line: 020 7791 9800

Website: [www.dls.org.uk](http://www.dls.org.uk)

### **Mental Capacity Implementation Programme**

*Making decisions. A guide for family, friends and other unpaid carers. Helping people who are unable to make some decisions for themselves (2006).* Explains the Mental Capacity Act which is relevant to anyone supporting an individual aged 16 or over who maybe unable to make some decisions for themselves.

Tel: 020 7210 0025

Email: [makingdecisions@dca.gsi.gov.uk](mailto:makingdecisions@dca.gsi.gov.uk)

## **SLEEP**

### **Durand, VM**

*Sleep Better! A Guide to Improving Sleep for Children with Special Needs (1998).* Step by step instructions to help children with disabilities get the rest they need.

Jessica Kingsley

ISBN:1 55766315 7

£15.95

## **TOILET TRAINING**

### **Wheeler, M**

*Toilet Training for Individuals with Autism and Related Disorders. A comprehensive guide for Parents and Teachers (1999).*

Easy to read explanation of effective strategies for teaching toileting skills.

Jessica Kingsley

ISBN:1 885477 45 3

£13.95

### **White, M & Rogers, J**

*We can do it! Helping children who have learning disabilities with bowel and bladder movement: a guide for parents (2002).*

Practical guide to support parents who have a child with learning disabilities.

ERIC (Education Resources for Improving Childhood Continence) ISBN: 1 903444195 £3.95

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