

# INFORMATION SHEET



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

## Further Information for Family Carers

The Challenging Behaviour Foundation is a small charity specialising in challenging behaviour associated with severe learning disabilities. We have a wide range of information sheets and DVDs that are free of charge to family carers. Our resources mainly focus on challenging behaviour but we are aware that families may also need information in a range of other topics including benefits, rights and care options.

This list is just a small selection of organisations, books, blogs, websites and information sheets that family carers may find useful. Contact a Family (contact details on page 3) can provide details of support groups for specific syndromes not mentioned within this information sheet.

***All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need, when you need it.***

***The CBF relies on the support of our friends and colleagues to continue to provide free resources to families.***

***Please see below for details of how to support us.***

***Please note that the Challenging Behaviour Foundation is not recommending the organisations on this list.***

To make the information easier to use, we have grouped the resources into 17 different categories and you can find the page numbers in the contents list below:

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## **CHALLENGING BEHAVIOUR**

Organisation	Resources available	Examples of topics covered
<p><b>The Challenging Behaviour Foundation</b>            Family Support Service: 0845 602 7885 until  <b>05/01/2015. After this date our number is            changing to 0300 666 0126)</b>            Information sheet requests: 01634 838739            Website: <a href="http://www.challengingbehaviour.org.uk">www.challengingbehaviour.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Information sheets</li> <li>• DVDs</li> <li>• Telephone /email support service</li> <li>• Family linking scheme</li> <li>• Email networks</li> </ul>	<ul style="list-style-type: none"> <li>• Challenging behaviour</li> <li>• Health and challenging behaviour</li> <li>• Communication and challenging behaviour</li> <li>• Specific Behaviours (e.g. difficult sexual behaviour, pica)</li> </ul>
<p><b>British Institute of Learning Disabilities (BILD)</b>            Website: <a href="http://www.bild.org.uk">www.bild.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Information sheets (some easy-read)</li> <li>• List of approved companies that provide physical intervention training                Go to: our services &gt; PAIS &gt; PAIS organisations</li> </ul>	<ul style="list-style-type: none"> <li>• Time out and seclusion</li> <li>• Intensive Interaction</li> <li>• De-escalation and deaf people</li> <li>• Chemical restraint</li> <li>• Physical interventions</li> <li>• Self-injurious behaviour</li> </ul>
<p><b>National Autistic Society (NAS)</b>            Autism Helpline: 0808 800 4104            Website: <a href="http://www.autism.org.uk">www.autism.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Information pages on many aspects of autism and Asperger's</li> <li>• Advice and Support Helpline (Autism)</li> </ul>	<ul style="list-style-type: none"> <li>• The sensory world of autism</li> <li>• Obsessions, repetitive behaviour and routines</li> <li>• Anxiety in adults with an autism spectrum disorder</li> <li>• Preparing a person with autism for change</li> <li>• Coping with Christmas</li> </ul>
<p><b>Social Care Institute for Excellence (SCIE)</b>            Website: <a href="http://www.scie.org.uk">www.scie.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Information pages on learning disabilities and challenging behaviour.                Go to: All topics &gt; People &gt; People with learning disabilities</li> </ul>	<ul style="list-style-type: none"> <li>• Getting the right support for adults /teenagers /children who display challenging behaviour</li> </ul>

## **GENERAL INFORMATION FOR FAMILY CARERS**

Organisation	Resources available	Examples of topics covered
<p><b>Carers Trust</b> Tel: 0844 800 4361 Website: <a href="http://www.carers.org">www.carers.org</a></p>	<ul style="list-style-type: none"> <li>• Discussion boards</li> <li>• Carers blogs</li> <li>• Information pages</li> <li>• Local Carers' Centre search page Go to: Local Support &gt; What is a Carers' Centre? &gt; Find your local carers' centre here</li> <li>• Crossroads Care scheme (flexible breaks) Go to: Local Support &gt; What is a Crossroads Care Scheme?</li> </ul>	<ul style="list-style-type: none"> <li>• Young carers</li> <li>• Tax credits and benefits</li> <li>• Local support (respite)</li> <li>• Transport and mobility</li> </ul>
<p><b>Carers UK</b> Carers Line: 0808 808 7777 Website: <a href="http://www.carersuk.org">www.carersuk.org</a></p>	<ul style="list-style-type: none"> <li>• Factsheets</li> <li>• Telephone advice line</li> <li>• Listening service run by trained volunteers</li> <li>• Online forum</li> </ul>	<ul style="list-style-type: none"> <li>• Finances and benefits</li> <li>• Assessments</li> <li>• Carers' rights</li> <li>• Carers' education, work and career development</li> <li>• Respite for carers</li> </ul>
<p><b>Contact a Family</b> (supports families of individuals up to the age of 25) Helpline: 0808 808 3555 Websites: <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a> <a href="http://www.makingcontact.org">www.makingcontact.org</a></p>	<ul style="list-style-type: none"> <li>• Email and telephone helpline</li> <li>• Resource library</li> <li>• 'Making Contact' - family linking</li> <li>• Local workshops and information sessions</li> <li>• Local support groups</li> <li>• Helpline</li> </ul>	<ul style="list-style-type: none"> <li>• Getting social care services when your child has additional needs</li> <li>• A guide to claiming Disability Living Allowance for children</li> <li>• Specific medical information e.g. genetics and an A-Z of medical conditions</li> </ul>

## **GENERAL INFORMATION FOR FAMILY CARERS (Continued)**

Organisation	Resources available	Examples of topics covered
<p><b>Foundation for People with Learning Disabilities</b>            Contact number for publications: 0207 803 1100            Website: <a href="http://www.learningdisabilities.org.uk">www.learningdisabilities.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Free publications are available to download online or can be ordered by telephone</li> <li>• Online forums</li> </ul>	<ul style="list-style-type: none"> <li>• ‘My kind of a future’: A workbook to help young people with learning disabilities prepare for the future</li> <li>• What do I need to know about NHS Continuing Healthcare?</li> </ul>
<p><b>HFT</b>            Tel: 0117 906 1751            Website: <a href="http://www.hft.org.uk">www.hft.org.uk</a>            Email: <a href="mailto:familycarersupport@hft.org.uk">familycarersupport@hft.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Workshops (free for family carers)</li> <li>• Family Carer Support Service</li> <li>• Family Carer News Digest (includes news about issues that may affect family carers) Go to: Supporting people &gt; Family carers &gt; Family carers support service &gt; Resources &gt; Family carer news digest</li> </ul>	<ul style="list-style-type: none"> <li>• Carers’ rights and issues</li> <li>• Fulfilling lives (relationships, work, meaningful activities)</li> <li>• Health</li> <li>• Housing and support options</li> <li>• Money matters (benefits, charging, wills, trusts)</li> <li>• Personal and individual budgets, support planning and self-directed support</li> </ul>
<p><b>Mencap</b>            Helpline: 0808 808 1111            (England, Ireland and Wales)            Website: <a href="http://www.mencap.org.uk">www.mencap.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Telephone helpline</li> <li>• Language line translation service</li> <li>• Information pages</li> <li>• Reports</li> <li>• Factsheets</li> </ul>	<ul style="list-style-type: none"> <li>• Direct payments</li> <li>• Providing for the future (wills and trusts)</li> <li>• Friendships and relationships</li> <li>• Accessing services</li> <li>• Telling people about your child’s disability</li> <li>• Brothers, sisters and the family</li> </ul>
<p><b>Young Carers Trust</b>            Tel: 0844 800 4361            Website: <a href="http://www.youngcarers.net/">www.youngcarers.net/</a></p>	<ul style="list-style-type: none"> <li>• Online forums</li> <li>• Blog pages</li> <li>• Safe chat room</li> <li>• “Agony Aunt” advice service</li> <li>• Online youth worker advice service</li> </ul>	<ul style="list-style-type: none"> <li>• Coping with school</li> <li>• Dealing with feelings</li> <li>• Child-friendly information about illnesses and disabilities</li> </ul>

## **FAMILY PERSPECTIVES**

Resource	Description	Examples of topics covered
<p><b>Blog: <i>Do you speak Autism?</i></b> www.doyouspeakautism.wordpress.com</p>	<p>This blog is written by a mother of two children, one of whom has been diagnosed with Autism</p>	<ul style="list-style-type: none"> <li>• Sleep</li> <li>• Toilet raining</li> <li>• Behaviour management</li> <li>• Travel</li> </ul>
<p><b>Book: <i>Andrew Give Us A Kiss (2006)</i></b> by Gordon, L, Trafford Publishing RRP £8.95</p>	<p>This book is written from the perspective of Andrew. Throughout this book, he describes growing up with a developmental disability and the challenges he and his parents frequently experience.</p>	<ul style="list-style-type: none"> <li>• Autism</li> <li>• Family life</li> </ul>
<p><b>Blog: <i>Sharing Stories</i></b> www.jgregorysharingsstories.blogspot.co.uk</p>	<p>A mother of three shares stories about her life, including her own experiences caring for her daughter with severe learning disabilities and complex needs. Her blog features real life accounts of how she manages to deal with her daughter's challenging behaviour and how she handles the barriers she is frequently confronted with.</p>	<ul style="list-style-type: none"> <li>• Family life</li> <li>• Autism</li> <li>• Severe learning disabilities</li> <li>• Social housing</li> <li>• Challenging behaviour</li> <li>• Caring for an adult daughter</li> </ul>
<p><b>Book series:</b> - <i>Christopher's Story (2006)</i> - <i>Christopher's Story Part II: The Child within the Man (2007)</i> - <i>Christopher's Story Part III: The Child Within the Man: The Conclusion (2008)</i> By Telfer, J, Chipmunk Publishing RRP £10 each (£5.15 on Kindle)</p>	<p>Christopher has autism and severe challenging behaviour. In her three books book, Christopher's mother tells of her fight to secure schooling, accommodation and social services support for her son, and tells of her determination to remain together as a family, when the only alternative offered was residential care.</p>	<ul style="list-style-type: none"> <li>• Autism</li> <li>• Challenging behaviour</li> <li>• Schooling</li> <li>• Accommodation</li> <li>• Family life</li> </ul>

## **FAMILY PERSPECTIVES (Continued)**

Resource	Description	Examples of topics covered
<b>Special Needs Jungle</b> Website: <a href="http://www.specialneedsjungle.com">www.specialneedsjungle.com</a> Facebook Page: <a href="http://www.facebook.com/SpecialNeedsJungle">www.facebook.com/SpecialNeedsJungle</a>	Parent-led information, resources and informed opinion about children and young people with SEN, Special Needs, Disabilities, Health Conditions and Rare Diseases. Family carers can contribute as guest-posters	<ul style="list-style-type: none"> <li>• SEND Reforms</li> <li>• Health</li> </ul>

## **PERSON CENTRED PLANNING**

Resource	Resources Available	Examples of topics covered
<b>Helen Sanderson Associates</b> Website: <a href="http://www.helensandersonassociates.co.uk">www.helensandersonassociates.co.uk</a>	<ul style="list-style-type: none"> <li>• Free downloadable resources on person centred planning</li> <li>• Go to: Reading Room &gt; How &gt; Person Centred Planning</li> </ul>	<ul style="list-style-type: none"> <li>• 'What is person centred planning?'</li> <li>• 'The impact of person centred planning'</li> <li>• 'Health Action Planning'</li> <li>• 'It's my meeting': Finding ways to involve people with high support needs in person centred planning'</li> <li>• MAPs (a planning style for children and adults)</li> <li>• PATH (a planning style that works well when a person has a group of people around them that are committed to making things happen)</li> </ul>

## **CARE, HEALTHCARE AND EDUCATION INSPECTORATES – BY COUNTRY**

Country	Organisation	Resources available
<b><u>England</u></b>	<b>Care Quality Commission (CQC)</b> Tel: 03000 616161 Website: <a href="http://www.cqc.org.uk">www.cqc.org.uk</a>	<ul style="list-style-type: none"> <li>• Inspection reports for health and social care services in England available to download; hard copies available on request</li> <li>• Information on what to do if you have a complaint about health or social care</li> <li>• Tips on choosing social care</li> </ul>
	<b>Ofsted</b> Tel: 0300 123 1231 Website: <a href="http://www.ofsted.gov.uk">www.ofsted.gov.uk</a>	<ul style="list-style-type: none"> <li>• Inspection reports for schools and colleges in England</li> <li>• Information on best practices such as nurture groups and music therapy</li> <li>• Information on what to do if you have a complaint about your child's school</li> </ul>
<b><u>Scotland</u></b>	<b>Care Inspectorate (Scotland)</b> Website: <a href="http://www.scswis.com">www.scswis.com</a> Tel: 0845 600 9527	<ul style="list-style-type: none"> <li>• Inspection reports for care services in Scotland</li> <li>• Advice on choosing services</li> <li>• Lists of care services available in Scotland</li> <li>• Advice on what to do if you have a complaint</li> <li>• Some resources are available in easy read format</li> </ul>
	<b>Education Scotland</b> Website: <a href="http://www.educationscotland.gov.uk">www.educationscotland.gov.uk</a>	<ul style="list-style-type: none"> <li>• Inspection reports for schools and colleges in Scotland</li> <li>• Curriculum information</li> <li>• Information about additional educational support available in Scotland</li> </ul>
	<b>Healthcare improvement Scotland</b> Website: <a href="http://www.healthcareimprovementscotland.org">www.healthcareimprovementscotland.org</a>	<ul style="list-style-type: none"> <li>• Inspection reports for healthcare providers in Scotland</li> </ul>

## **CARE, HEALTHCARE AND EDUCATION INSPECTORATES – BY COUNTRY (Continued)**

Country	Organisation	Resources available
<b><u>Wales</u></b>	<b>Care and Social Services Inspectorate Wales (CSSIW)</b> Tel: 0300 7900 126 Website: <a href="http://www.cssiw.org.uk">www.cssiw.org.uk</a>	<ul style="list-style-type: none"> <li>• Inspection reports for social care services in Wales</li> <li>• Directory of registered care services in Wales</li> <li>• Information on how to make a comment or complaint about the social services you receive in Wales</li> </ul>
	<b>Estyn - Her Majesty's Chief Inspector of Education and Training in Wales</b> Tel: 029 2044 6446 Website: <a href="http://www.estyn.gov.uk">www.estyn.gov.uk</a>	<ul style="list-style-type: none"> <li>• Inspection reports for education services in Wales</li> <li>• Information on best practice in education</li> </ul>
	<b>Healthcare Inspectorate Wales</b> Website: <a href="http://www.hiw.org.uk">www.hiw.org.uk</a>	<ul style="list-style-type: none"> <li>• Inspection reports for healthcare services in Wales</li> <li>• Directory of healthcare services in Wales</li> <li>• Information on how to raise a concern about a healthcare service in Wales</li> </ul>
<b><u>Northern Ireland</u></b>	<b>The Regulation and Quality Improvement Authority (RQIA)</b> Tel: 028 9051 7500 Website: <a href="http://www.rqia.org.uk">www.rqia.org.uk</a>	<ul style="list-style-type: none"> <li>• Inspection reports for healthcare and social care providers in Northern Ireland</li> <li>• Advice on how to make a complaint about healthcare or social care providers in Northern Ireland</li> </ul>
	<b>Education Training Inspectorate (ETI)</b> Telephone: 028 9127 9726 Email: <a href="mailto:inspectionsservices@deni.gov.uk">inspectionsservices@deni.gov.uk</a> Website: <a href="http://www.etini.gov.uk">www.etini.gov.uk</a>	<ul style="list-style-type: none"> <li>• Inspection reports for schools and colleges in Northern Ireland</li> <li>• Information on good practice</li> </ul>



## **CARE OPTIONS**

Organisation	Resources available	Examples of topics covered
<p><b>Care Choices</b>            Helpline: 0800 389 2077            Website: <a href="http://www.carechoices.co.uk">www.carechoices.co.uk</a></p>	<ul style="list-style-type: none"> <li>• Information pages</li> <li>• Directory of care providers                Go to: Publications &gt; Regional Care Services Directories</li> <li>• Care home and home care checklists that are useful when choosing services                Go to: Advice &gt; Checklists</li> </ul>	<ul style="list-style-type: none"> <li>• Types of care that are available</li> <li>• Funding</li> </ul>
<p><b>Housing and Support Alliance</b>            Tel: 0845 4561497 / 0300 2010455            Website: <a href="http://www.housingandsupport.org.uk">www.housingandsupport.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Telephone advice service</li> <li>• Free downloadable information sheets (some easy-read)</li> </ul>	<ul style="list-style-type: none"> <li>• Housing options</li> <li>• Financing</li> <li>• Rights</li> <li>• Assistive technology</li> <li>• Good practice</li> </ul>
<p><b>InControl</b>            Tel: 01564 821 650            Website: <a href="http://www.in-control.org.uk">www.in-control.org.uk</a></p>	<p>All with a focus on self-directed support :</p> <ul style="list-style-type: none"> <li>• Factsheets (some easy-read)</li> <li>• Events and courses</li> <li>• Live webchats and webcasts</li> </ul>	<ul style="list-style-type: none"> <li>• Self-directed support</li> <li>• Support brokerage</li> <li>• Support planning</li> <li>• Training and choosing your own staff</li> </ul>

## **EDUCATION**

Organisation	Resources available	Examples of topics covered
<p><b>Independent Panel for Special Education Advice (IPSEA) (England)</b>            Helpline: 0800 018 4016            Website: <a href="http://www.ipsea.org.uk">www.ipsea.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Free helpline for parents of children with special educational needs in England</li> <li>• Downloadable information sheets</li> </ul>	<ul style="list-style-type: none"> <li>• Getting the right educational support</li> <li>• Disability discrimination</li> <li>• Transport</li> <li>• Tribunals</li> <li>• Transition</li> <li>• Education reform in England</li> </ul>
<p><b>Special Educational Needs Advice Centre (SENAC) (Northern Ireland)</b>            Tel: 028 9079 5779            Website: <a href="http://www.senac.co.uk">www.senac.co.uk</a></p>	<ul style="list-style-type: none"> <li>• Downloadable factsheets and information packs for families living in Northern Ireland</li> <li>• Independent advocacy</li> <li>• Telephone advice line</li> </ul>	<ul style="list-style-type: none"> <li>• Introduction to the Special Educational Needs System in Northern Ireland</li> <li>• Department of Education for Northern Ireland Code of Practice</li> <li>• Education reform in Northern Ireland</li> </ul>
<p><b>SNAP Cymru (Wales)</b>            Helpline 0845 120 3730            Helpline from mobile 0345 120 3730            Email: <a href="mailto:enquiries@snapcymru.org">enquiries@snapcymru.org</a>            Website: <a href="http://www.snapcymru.org">www.snapcymru.org</a></p>	<ul style="list-style-type: none"> <li>• Independent support and information to families living in Wales</li> <li>• Information leaflets and webpages</li> <li>• Advocacy</li> <li>• Disagreement resolution</li> </ul>	<ul style="list-style-type: none"> <li>• Choosing a school</li> <li>• Transition</li> <li>• Education reform in Wales</li> </ul>
<p><b>Enquire (Scotland)</b>            Helpline: 0845 123 2303            Website: <a href="http://www.enquire.org.uk">www.enquire.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Free helpline</li> <li>• Information pages and downloadable publications</li> <li>• Lists of local authorities</li> <li>• Podcasts</li> <li>• Online 'Find a service' search facility</li> </ul>	<ul style="list-style-type: none"> <li>• The parent's guide to additional support for learning (comprehensive guide to the additional support for learning system in Scotland)            Go to: Publications &gt; The parents' guide to additional support for learning</li> </ul>

## **EDUCATION (Continued)**

Organisation	Resources available	Examples of topics covered
<p><b>Contact a Family</b> Helpline: 0808 808 3555 Website: <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Telephone Advice Line (Education Specialist Advisors)</li> <li>• Information pages Go to Advice and support &gt; Education</li> </ul>	<ul style="list-style-type: none"> <li>• Transport to school and college</li> <li>• Exclusions</li> <li>• Education, Health and Care Plans (EHC plans)</li> <li>• Home Education</li> </ul>
<p><b>Joseph Rowntree Foundation</b> Website: <a href="http://www.jrf.org.uk">www.jrf.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Booklet by Morris, J: <i>The right place? A parents' guide to choosing a residential special school (2003)</i> Search for the guide using the search function on the website</li> </ul>	<ul style="list-style-type: none"> <li>• How to find out what residential special schools there are</li> <li>• What to look for and ask about when deciding on a school</li> <li>• What should ring alarm bells for you when looking at a school</li> </ul>
<p><b>Coram Children's Legal Centre</b> Free education legal adviceline for those eligible for Legal Aid: 0845 345 4345 Website: <a href="http://www.childrenslegalcentre.com">www.childrenslegalcentre.com</a></p>	<ul style="list-style-type: none"> <li>• Telephone advice line</li> <li>• Downloadable factsheets Go to: Free legal advice &gt; Free legal advice factsheets &gt; Schools and education</li> </ul>	<ul style="list-style-type: none"> <li>• Disability discrimination in education</li> <li>• Special educational needs</li> </ul>
<p><b>Schools for Special Needs</b> Website: <a href="http://www.schoolsforspecialneeds.co.uk">www.schoolsforspecialneeds.co.uk</a></p>	<ul style="list-style-type: none"> <li>• Book by Gabbitas Educational Consultants <i>Schools for Special Needs</i>. RRP £29.50 Updated annually</li> </ul>	<ul style="list-style-type: none"> <li>• Assessment and identification of needs, new education, health and care plans, suitable provision and school choice</li> <li>• Where to seek help, parents' rights and the role of the local authority</li> <li>• Directories of special schools and colleges</li> </ul>
<p><b>Ace Education</b> Tel: 0300 0115 142 Website: <a href="http://www.ace-ed.org.uk">www.ace-ed.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Telephone advice line</li> <li>• Downloadable booklets (£2 each)</li> </ul>	<ul style="list-style-type: none"> <li>• Exclusions</li> <li>• Needs assessments</li> </ul>

## **HEALTH**

Organisation	Resources available	Examples of topics covered
<b>Easyhealth</b> Website: <a href="http://www.easyhealth.org.uk">www.easyhealth.org.uk</a>	<ul style="list-style-type: none"> <li>• Easy read leaflets</li> <li>• Downloadable templates for resources, e.g. health action plans and hospital passports</li> </ul>	<ul style="list-style-type: none"> <li>• Easy read information on specific illnesses e.g. diabetes</li> <li>• Leaflets, e.g. <i>'Going to the chemist'</i></li> </ul>
<b>Improving Health and Lives Learning Disabilities Observatory</b> <a href="http://www.improvinghealthandlives.org.uk">www.improvinghealthandlives.org.uk</a>	<ul style="list-style-type: none"> <li>• Reports on the health and healthcare of people with learning disabilities</li> <li>• Map showing the location and contact details of Acute Liaison Nurses in England Go to: <a href="http://www.improvinghealthandlives.org.uk/aln">www.improvinghealthandlives.org.uk/aln</a></li> </ul>	<ul style="list-style-type: none"> <li>• Making reasonable adjustments to primary care services</li> <li>• Improving the health and wellbeing of people with learning disabilities</li> </ul>
<b>MIND</b> Helpline: 0300 123 3393 Website: <a href="http://www.mind.org.uk">www.mind.org.uk</a>	<ul style="list-style-type: none"> <li>• Telephone helpline for anyone experiencing or affected by a mental health problem</li> <li>• Information pages</li> <li>• Local MIND services</li> </ul>	<ul style="list-style-type: none"> <li>• Types of mental health problems</li> <li>• Legal rights and mental health legislation</li> <li>• Drugs and treatments</li> <li>• Guides to support and services</li> </ul>
<b>Rethink</b> Advice line: 0300 5000 927 Website: <a href="http://www.rethink.org">www.rethink.org</a>	<ul style="list-style-type: none"> <li>• Advice line for anyone affected by mental illness</li> <li>• Directory of local groups and advocacy services</li> <li>• Siblings support service</li> <li>• Downloadable information factsheets</li> </ul>	<ul style="list-style-type: none"> <li>• Information on specific mental health problems e.g. schizophrenia</li> <li>• Medications</li> <li>• Treatment and support</li> <li>• Early intervention</li> <li>• Looking after yourself</li> </ul>
<b>YoungMinds</b> Parents' Helpline: 0808 802 5544 Website: <a href="http://www.youngminds.org.uk">www.youngminds.org.uk</a>	<ul style="list-style-type: none"> <li>• Telephone helpline for parents of children with mental health problems</li> <li>• Information webpages on mental health and where to get help</li> </ul>	<ul style="list-style-type: none"> <li>• Obsessions and compulsions</li> <li>• Autism and Asperger's</li> <li>• Parents survival guide for parents and carers</li> <li>• Looking after yourself</li> </ul>

## **SIGHT AND HEARING IMPAIRMENTS**

Organisation	Resources available	Examples of topics covered
<b>HALD</b> (Hearing and Learning Disabilities) Website: <a href="http://www.hald.org.uk">www.hald.org.uk</a>	<ul style="list-style-type: none"> <li>Information pages and downloadable information sheets</li> <li>Photos of objects to do with hearing (e.g. hearing aids)</li> <li>HALD Speech Discrimination Test. Go to: Recourses &gt; Assessment and Treatment &gt; HALD Speech discrimination Test</li> </ul>	<ul style="list-style-type: none"> <li>Communicating with someone with a hearing impairment (information for carers)</li> <li>Using a hearing aid</li> <li>Audiology appointments</li> </ul>
<b>National Deaf Children's Society</b> Website: <a href="http://www.ndcs.org.uk">www.ndcs.org.uk</a> Tel: 0808 800 8880	<ul style="list-style-type: none"> <li>Information for parents of deaf children with additional and complex needs Go to: Family support &gt; additional and complex needs</li> <li>Online forum for parents of deaf children with additional needs</li> <li>List of local support groups</li> </ul>	<ul style="list-style-type: none"> <li>Technology to aid communication</li> <li>Autism and hearing difficulties</li> <li>Booklet: '<i>Deaf Children with Additional Needs</i>' Go to: Family support &gt; additional and complex needs&gt; view our publications &gt; Deaf Children with additional needs</li> </ul>
<b>RNIB</b> (Royal National Institute of Blind People) Website: <a href="http://www.rnib.org.uk">www.rnib.org.uk</a> Tel: 0141 772 5588 email: <a href="mailto:learningdisability@rnib.org.uk">learningdisability@rnib.org.uk</a>	<ul style="list-style-type: none"> <li>Free information service for people with sight difficulties and learning disabilities and other complex needs (telephone and email support) Go to: Services we offer &gt; Learning disability service &gt; Information services</li> </ul>	<ul style="list-style-type: none"> <li>Information on leisure activities</li> <li>Details of optometrists who can give eye exams to people in residential care</li> <li>How to register someone as blind</li> </ul>
<b>SENSE</b> for deafblind people Website: <a href="http://www.sense.org.uk">www.sense.org.uk</a> Tel: 0300 330 9256	<ul style="list-style-type: none"> <li>Free information and advice service for deafblind people and their families</li> <li>Information pages. Go to: About deafblindness</li> </ul>	<ul style="list-style-type: none"> <li>Communicating with deafblind people</li> <li>Clinical assessments</li> <li>Technology</li> </ul>
<b>SEEABILITY</b> Website: <a href="http://www.seeability.org">www.seeability.org</a>	<ul style="list-style-type: none"> <li>Information pages on vision and eye care for people with sight loss and other disabilities.</li> <li>Database of Optometry practices which provide appropriate facilities and eye tests for people with learning disabilities Go to: Our services &gt; advisory services &gt; Eye care services near you</li> </ul>	<ul style="list-style-type: none"> <li>Having an eye test</li> <li>Eye care for people with Downs Syndrome</li> <li>Functional Vision Assessments</li> <li>Wearing glasses</li> </ul>

## **HOLIDAYS**

Organisation	Resources available
<p><b>Contact a Family</b> Tel: 0808 808 3555 Website: <a href="http://www.cafamily.org.uk">www.cafamily.org.uk</a></p>	<ul style="list-style-type: none"> <li>Downloadable booklet on play and leisure for disabled children, how to get help with funds, and where to find more information about taking a holiday. Also includes information about arranging holidays and organisations which give grants for them. Go to Advice and Support &gt; Resource Library &gt; Subject: Leisure &gt; <i>Parent Guide: Holidays, play and leisure</i></li> </ul>
<p><b>Enable Scotland</b> Tel: 0300 0200 101 Website: <a href="http://www.enable.org.uk">www.enable.org.uk</a></p>	<ul style="list-style-type: none"> <li>List of accessible UK holiday destinations for people with learning disabilities Go to: ENABLE direct &gt; Publications &gt; Resource List &gt; <i>Holiday Resource List 2013</i></li> </ul>
<p><b>Holidays for All</b> Tel: 0845 1249971 Website: <a href="http://www.holidaysforall.org.uk">www.holidaysforall.org.uk</a></p>	<ul style="list-style-type: none"> <li>Directory of accessible holiday providers</li> </ul>
<p><b>HFT</b> Tel: 0117 906 1700 Website: <a href="http://www.hft.org.uk">www.hft.org.uk</a></p>	<ul style="list-style-type: none"> <li>Downloadable guide containing useful and in depth information about taking individuals with learning disabilities on holiday that includes lists of service providers. Go to: Supporting people &gt; Family carers &gt; Resources &gt; <i>2014 holiday information guide</i></li> </ul>
<p><b>Tourism for All</b> Tel: 0845 124 9971 Website: <a href="http://www.tourismforall.org.uk">www.tourismforall.org.uk</a></p>	<ul style="list-style-type: none"> <li>Free directory of accessible holiday destinations Go to: TFA Directory &gt; <i>Learning Disability Holidays</i></li> </ul>

## **MONEY**

Organisation	Resources available	Examples of topics covered
<b>Turn 2 Us</b> Helpline: 0808 802 2000 Website: <a href="http://www.turn2us.org.uk">www.turn2us.org.uk</a>	<ul style="list-style-type: none"> <li>• Online benefits calculator</li> <li>• Online grants search</li> <li>• Information pages</li> <li>• Jargon buster</li> <li>• Helpline for people who are unable to use the internet</li> </ul>	<ul style="list-style-type: none"> <li>• How to gain access to grants, welfare benefits and other financial assistance</li> </ul>
<b>Family Fund</b> Tel: 01904 621115 Website: <a href="http://www.familyfund.org.uk">www.familyfund.org.uk</a>	<ul style="list-style-type: none"> <li>• Grants for essential items such as washing machines, clothing and specialist equipment</li> <li>• Discount vouchers</li> </ul>	n/a
<b>Citizens Advice Bureau</b> Tel (Wales): 03444 77 20 20 Tel (England): 03444 111 444 Website: <a href="http://www.citizensadvice.org.uk">www.citizensadvice.org.uk</a>	<ul style="list-style-type: none"> <li>• Telephone advice line</li> <li>• List of local Citizen's Advice Bureaux</li> </ul>	<ul style="list-style-type: none"> <li>• Welfare benefits</li> <li>• Debt relief</li> </ul>
<b>Money Advice Service</b> Tel: 0300 500 5000 Website: <a href="http://www.moneyadviceservice.org.uk">www.moneyadviceservice.org.uk</a>	<ul style="list-style-type: none"> <li>• Advice and guides to help improve your finances</li> <li>• Tools and calculators to help you keep track and plan ahead</li> <li>• Support in person, over the phone and online</li> </ul>	<ul style="list-style-type: none"> <li>• Debt and borrowing</li> <li>• Insurance</li> <li>• Care and disability</li> <li>• Benefits</li> <li>• Budgeting and managing money</li> </ul>

## **EMPLOYMENT FOR PEOPLE WITH LEARNING DISABILITIES**

Organisation	Resources available
<p><b>Sustainable Hub of Innovative Employment for People with Complex Needs (SHIEC)</b>            Website: <a href="http://www.shiec.co.uk">www.shiec.co.uk</a></p>	<ul style="list-style-type: none"> <li>• Personal stories of how people with learning disabilities have found work experience and paid employment (including individuals with severe learning disabilities and very limited communication whose behaviour is described as challenging)                Go to: <a href="#">Stories</a></li> <li>• Downloadable booklet for family carers that offers information on paid, voluntary and self-employment. It includes step-by-step advice on: Helping your family member decide if they would like to work; thinking about the kinds of work they would like to do; how to get work experience, and finding the right job for them.                Go to: <a href="#">Link &gt; Getting a Job</a></li> </ul>
<p><b>Remploy</b>            Tel: 0300 456 8110            Website: <a href="http://www.remploy.co.uk">www.remploy.co.uk</a></p>	<ul style="list-style-type: none"> <li>• Employment service for disabled people</li> <li>• Online CV builder</li> <li>• Job search page</li> <li>• Career advisors</li> </ul>



## **RIGHTS**

Organisation	Resources available	Examples of topics covered
<p><b>The Scottish Government</b> (for families whose relative lives in Scotland) Website: <a href="http://www.scotland.gov.uk">www.scotland.gov.uk</a></p>	<ul style="list-style-type: none"> <li>Downloadable guide: <i>Adults with Incapacity (Scotland) Act 2000. Guardianship and Intervention Orders – making an application. A Guide for Carers</i> Search for the guide using the ‘search this site’ box</li> </ul>	<ul style="list-style-type: none"> <li>How the Adults with Incapacity Act aims to help people in Scotland aged sixteen or over who lack capacity to make some or all decisions for themselves</li> <li>How the act allows carers/guardians whose relative lives in Scotland make decisions on a person’s behalf</li> </ul>
<p><b>Office of the Public Guardian</b> (for family carers whose relative lives in England and Wales) Website: <a href="http://www.justice.gov.uk">www.justice.gov.uk</a></p>	<ul style="list-style-type: none"> <li>Downloadable information sheet: <i>Making decisions: A guide for family, friends and other unpaid carers (Mental Capacity Act)</i> Go to: I am a... &gt; Member of the Public &gt; Mental Capacity Act: Powers of Attorney &gt; Mental Capacity Act Booklets &gt; A Guide for Family, Friends and Other Unpaid Carers</li> </ul>	<ul style="list-style-type: none"> <li>What is mental capacity?</li> <li>Who decides whether someone has capacity in England and Wales?</li> <li>What happens if a person lacks capacity in England and Wales?</li> <li>What is the role of a Deputy in England and Wales?</li> <li>Challenging decisions in England and Wales</li> </ul>
<p><b>see also...</b> Webpage: <a href="http://www.gov.uk/government/organisations/office-of-the-public-guardian">www.gov.uk/government/organisations/office-of-the-public-guardian</a> Tel: 0300 456 0300</p>	<p><b>for...</b></p> <ul style="list-style-type: none"> <li>Information pages</li> <li>Application forms to become a person’s deputy</li> </ul>	<p><b>for information on...</b></p> <ul style="list-style-type: none"> <li>Making decisions on behalf of someone else</li> <li>Deputies: Act on behalf of someone who lacks capacity</li> <li>Report a concern about an attorney or deputy</li> </ul>

## **RIGHTS (Continued)**

Organisation	Resources available	Examples of topics covered
<b>HFT</b> <b>Website: <a href="http://www.hft.org.uk">www.hft.org.uk</a></b>	<ul style="list-style-type: none"> <li>Free downloadable guide: <i>Using the mental capacity act: A resource for families and friends of people with learning disabilities</i> Go to: Supporting People &gt; Family Carers &gt; Resources &gt; Using The Mental Capacity Act</li> <li>The above guide is supported by a series of film clips</li> </ul>	<ul style="list-style-type: none"> <li>Assessing Capacity</li> <li>Best Interest Decisions</li> <li>Challenging a Decision</li> <li>Health</li> <li>Involving Family Carers</li> <li>Managing Finances</li> <li>Moving Home</li> <li>Transition</li> </ul>
<b>Every Disabled Child Matters</b> <b>Website: <a href="http://www.edcm.org.uk">www.edcm.org.uk</a></b>	<ul style="list-style-type: none"> <li>Downloadable information sheets</li> </ul>	<ul style="list-style-type: none"> <li><i>Using the Law to Fight the Cuts to Disabled Children's Services</i></li> <li><i>My Rights, Your Responsibility – Your Child's Right to be Included</i></li> <li><i>Disabled Children: A Legal Handbook</i> Go to: Resources &gt; Resources for Disabled Children</li> </ul>
<b>Blog: <i>The Small Places</i></b> <b>Website: <a href="http://www.thesmallsplaces.wordpress.com">www.thesmallsplaces.wordpress.com</a></b>	<ul style="list-style-type: none"> <li>Blog about legal capacity and human rights, especially in the healthcare and social services</li> </ul>	<ul style="list-style-type: none"> <li>Mental Capacity Act (2005)</li> <li>Care Act (2014)</li> <li>Blog post: <i>Spread the Word: You DON'T need mental capacity to vote</i></li> </ul>
<b>Luke Clements (solicitor and Professor of Law at Cardiff University)</b> <b>Website: <a href="http://www.lukeclements.co.uk">www.lukeclements.co.uk</a></b>	<ul style="list-style-type: none"> <li>Downloadable papers and articles about the rights of individuals who experience social exclusion (including people with learning disabilities)</li> </ul>	<ul style="list-style-type: none"> <li>Carers rights</li> <li>Human rights</li> </ul>

## **RIGHTS (Continued)**

Organisation	Resources Available	Examples of topics covered
<p><b>Irwin Mitchell Solicitors</b>  <b>Website: <a href="http://www.irwinmitchell.com">www.irwinmitchell.com</a></b></p>	<ul style="list-style-type: none"> <li>• Free information sheets on legal rights</li> <li>• Template letters            Go to: Personal Legal Services &gt; Protecting your rights &gt; Human rights &gt; Health and social care law &gt;</li> <li>• These include:               <ul style="list-style-type: none"> <li>- Continuing healthcare appeals</li> <li>- Formal complaint letter – cuts to services</li> <li>- Request to consider eligibility for community care support</li> <li>- Request for S47 assessment of needs</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• Court of protection</li> <li>• <i>Deprivation of Liberty Safeguards</i>            Go to: Personal Legal Services &gt; Protecting your rights &gt; Human rights &gt; Deprivation of Liberty Safeguards</li> <li>• <i>Challenging a refusal to assess your disabled child for specialist services</i>            Go to: Personal Legal Services &gt; Protecting your rights &gt; Human rights &gt; Health and social care law &gt; Challenging A Refusal To Assess Your Disabled Child For Specialist Services</li> </ul>
<p><b>Disability Rights UK            Equality Advisory / Support            Service: 0808 800 0082            Disabled Students Helpline:            0800 328 5050            Website:  <a href="http://www.disabilityrightsuk.org">www.disabilityrightsuk.org</a></b></p>	<ul style="list-style-type: none"> <li>• Downloadable factsheets</li> <li>• Helpline services (see left)</li> </ul>	<ul style="list-style-type: none"> <li>• Access to work and apprenticeships for disabled people</li> <li>• Welfare benefits and tax credits</li> <li>• Rights for disabled students</li> <li>• Appeals advice</li> </ul>
<p><b>Disability Law Service            Advice line: 020 7791 9800            Website: <a href="http://www.dls.org.uk">www.dls.org.uk</a></b></p>	<ul style="list-style-type: none"> <li>• Telephone appointment advice service</li> <li>• Online advice request service</li> <li>• Factsheets (downloadable or by post on request)            Go to: Advice &gt; Factsheets</li> </ul>	<ul style="list-style-type: none"> <li>• Community care</li> <li>• Education</li> <li>• Discrimination</li> <li>• Welfare benefits</li> <li>• Human rights</li> </ul>

## DIFFICULT TOPICS

Organisation	Resources Available	Examples of topics covered
<p><b>Books Beyond Words</b>            Website: <a href="http://www.booksbeyondwords.co.uk">www.booksbeyondwords.co.uk</a>            RRP £10 / £4.95 eBook            Free to borrow on request from your local library</p>	<ul style="list-style-type: none"> <li>• Picture books designed to help people with learning disabilities communicate more easily and explore their own experiences</li> </ul>	<ul style="list-style-type: none"> <li>• Depression</li> <li>• Personal hygiene</li> <li>• Romantic relationships</li> <li>• Puberty</li> <li>• Death and grief</li> </ul>

## SLEEP

Organisation	Resources Available	Examples of topics covered
<p><b>Cerebra</b>            Helpline: 0800 328 1159            Website: <a href="http://www.cerebra.org.uk">www.cerebra.org.uk</a></p>	<ul style="list-style-type: none"> <li>• Sleep practitioner support service</li> <li>• Online information videos                Go to: get help &gt; sleep service</li> </ul>	<ul style="list-style-type: none"> <li>• Night waking</li> <li>• Sleep routine</li> <li>• Early rising</li> <li>• Encouraging your child to sleep alone</li> </ul>
<p><b>Handsel Trust</b>            Tel: 01497 831550            Website: <a href="http://www.handsseltrust.org">www.handsseltrust.org</a></p>	<ul style="list-style-type: none"> <li>• Online, downloadable publications                Go to: Sleep &gt; Sleep Resources</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Sleep? What's that?</i>                (Impact of sleep problems in families of disabled children)</li> <li>• <i>The Early Support Network Guide for Parents</i>                (Understanding sleep, What causes sleep problems, How to help your child get a good night's sleep)</li> </ul>
<p><b>Sleep Scotland</b>            (supporting children up to 18 years)            Tel: 0131 651 1392            Website: <a href="http://www.sleepscotland.org">www.sleepscotland.org</a></p>	<ul style="list-style-type: none"> <li>• Sleep support line (Scotland only)</li> <li>• Sleep counselling (Scotland only)</li> <li>• Information on sleep services in other parts of the UK</li> </ul>	<ul style="list-style-type: none"> <li>• Sleep awareness and education</li> <li>• Bedtime routine</li> <li>• Sleep hygiene</li> <li>• Creating a good sleeping environment</li> </ul>

## **TOILETING**

Organisation	Resources available	Examples of topics covered
<p><b>ERIC (Education and Resources for Improving Childhood Continence)</b>            Helpline: 0845 370 8008 / info@eric.org.uk            Website: www.eric.org.uk</p>	<ul style="list-style-type: none"> <li>• Helpline (telephone and email)</li> <li>• Online community message board peer support</li> <li>• Free downloadable information sheets</li> </ul>	<ul style="list-style-type: none"> <li>• Daytime wetting</li> <li>• Bedwetting</li> <li>• Constipation</li> <li>• Soiling</li> <li>• Toilet training</li> </ul>
<p><b>Book: <i>Toilet Training for Individuals with Autism and Related Disorders. A comprehensive guide for Parents and Teachers (2007).</i></b>            by Wheeler, M., Future Horizons            RRP: £14.95</p>	<ul style="list-style-type: none"> <li>• An easy to read book that offers strategies for teaching toileting skills to children with developmental disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>• How to gauge 'readiness'</li> <li>• Overcoming fear of the bathroom</li> <li>• How to teach someone with autism to use toilet paper, flush the toilet and wash their hands</li> <li>• Toileting in unfamiliar environments</li> </ul>

***Please note that the Challenging Behaviour Foundation is not recommending the organisations on this list.***

**Last updated December 2014**

### **The Challenging Behaviour Foundation**

We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email [info@thecbf.org.uk](mailto:info@thecbf.org.uk), or visit our website: [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

If you have found this information useful, please consider making a donation.

You can show your support at [www.challengingbehaviour.org.uk](http://www.challengingbehaviour.org.uk)

Make a £5 donation by texting Cbfd05£5 to 70070

Or email us to get involved at [support\\_us@thecbf.org.uk](mailto:support_us@thecbf.org.uk)