Patient Information Forum
For Professionals Working in Consumer Health Information

Learning Disabilities Resource List

December 2013

Compiled By Sian Finn

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About this resource

PiF's Learning Disabilities Resource List collates research, guidance, best practice and further contact details. It is intended to support the development of high quality patient information for people with learning disabilities. **Please note, the websites referenced in this resource we last accessed by PiF in October 2013**. If you have any feedback about the resource please contact admin@pifonline.org.uk.

About the author

Sian Finn has worked for 30 years in the NHS in roles such as health promotion specialist, clinical governance manager and self care programmes manager. She has a nursing and information background and has always been passionate about promoting patient empowerment through supporting self-management, patient information and shared decision making.

Sian is currently taking some time out of the formal working environment to explore new career options and learning opportunities. Her main interests at present are exploring the potential of social media in relation to promoting the patient empowerment agenda (@SianFinn), participating in a number of MOOCs with Coursera and Future Learn, and volunteering at the Stroke Association's Life after Stroke Centre.

About Patient Information Forum

The Patient Information Forum (PiF) is the organisation for people working in consumer health information and support. PiF campaigns to ensure consumer health information is central to high-quality, patient-centred care. We help providers develop high quality information and support for their patients and the public. To find out more about our work and join our organisation visit www.pifonline.org.uk.

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Contents

1.   Definition of learning disabilities

- *Improving Health and Lives* is the name of the Learning Disabilities Observatory together with its sister project the Confidential Enquiry into the Deaths of People with Learning Disabilities. Since April 1st 2013 it has been operated by Public Health England. The working definition of learning disabilities that informs their work can be found on the link below:

  www.ihal.org.uk/about/definition/detail

- For an explanation of learning disabilities see NHS choices website or learning disability websites

  http://www.nhs.uk/livewell/childrenwithalearningdisability/pages/whatislearningdisability.aspx

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2.   Key learning disability organisations & websites (general)

- British Institute for Learning Disabilities   www.bild.org.uk

- CHANGE   www.changepeople.co.uk

- Foundation for People with Learning   http://www.learningdisabilities.org.uk/about-us/
  Disabilities

- Hft   http://www.hft.org.uk/

- Learning Disabilities Observatory   www.ihal.org.uk

- Learning Disability UK   http://www.learningdisability.co.uk

- Mencap   www.mencap.org.uk

- Profound and Multiple Learning   www.pmldnetwork.org
  Disabilities Network (PMLD)

## 3.	Key learning disability organisations & websites (specific conditions)

- Autism in Mind			www.autism-in-mind.co.uk

- Autism Independent UK			www.autismuk.com

- Down's Syndrome Association			http://www.downs-syndrome.org.uk/

- Klinefelter's Syndrome			http://www.ksa-uk.net/

- Prada Willi Association (UK)			http://www.pwsa.co.uk/

- Rett UK			www.rettuk.org

- The Fragile X Society			www.fragilex.org.uk

- The National Autistic Society (UK)			http://www.autism.org.uk/

- Turner's Syndrome Support Society (UK)	www.tss.org.uk

- Williams Syndrome Foundation			www.williams-syndrome.org.uk

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## 4.	Collections of health service information

- NICE Evidence Services			https://www.evidence.nhs.uk/

- Reasonable adjustments database of examples			http://www.improvinghealthandlives.org.uk/adjustments/

- NHS Choices information for the public			http://www.nhs.uk/livewell/childrenwithalearningdisability/pages/whatislearningdisability.aspx

5.   Key reports about learning disabilities and health

5.1   Facts and Figures

- Eric Emerson et al (2012) People with Learning Disabilities in England 2011. Improving Health All Lives. Learning Disabilities Observatory
- Local area data: www.ihal.org.uk/numbers/howmany/laestimates
- Other useful links can be found on the BILD site: www.bild.org.uk/information/figures

5.2   Health Information Needs Assessments/ Audits

- Equality Commission for Northern Ireland (2013) Review of the Formal Investigation into the Accessibility of Health Information for people with a Learning Disability in NI (Easy Read and audio versions available)

  http://www.equalityni.org/sections/default.asp?secid=8&cms=Publications_Disability_investigation+reports&cmsid=7_33_574&id=574

- Equality Commission for Northern Ireland (2008) Formal Investigation - The Accessibility of Health Information in Northern Ireland for People with a Learning Disability June 2006 to December 2007

  http://www.equalityni.org/archive/pdf/FormalInvestDisability(Full).pdf

- Ptolomey, J (2008) Learning Disabilities Audit Project Greater Glasgow and Clyde NHS Board

  http://www.phru.net/learningdisabilities/Learning%20Disabilitites%20Final%20Report/Final%20report%20learningdisabilitiesaudit_march2008_final.pdf

- Public Health Resource Unit, NHS Greater Glasgow and Clyde

  http://www.phru.net/learningdisabilities/default.aspx

- McConkey, R (February, 2006) Accessibility of healthcare information for people with a learning disability. *A Review and Discussion Paper,* University of Ulster

  www.equalityni.org/archive/tempdocs/LiteratureRev(f)I.doc

- King, S (2011) Clear information can cut inequalities in learning disabilities Nursing Times 01.02.11 / Vol 107 No 4 / www.nursingtimes.net

  http://www.nursingtimes.net/Journals/2013/01/18/n/p/h/010211Clear-information-can-cut-inequalities-in-learning-disabilities.pdf

5.3 Health and Healthcare

- DH (July, 2013) Six Lives: Progress Report on Health for People with Learning Disabilities. London, DH
- DH (December, 2012) Winterbourne View Review Concordat: Programme of Action
- Hoghton, M., Turner, S and Hall, I (October 2012) Improving the Health and Wellbeing of People with Learning Disabilities. An Evidence Based Commissioning Guide for Clinical Commissioning Groups (CCGs) Learning Disabilities Observatory, RCGP, Royal College of Psychiatrists
- Learning Disability Services Inspection programme: National Overview (June, 2012). CQC
- Emerson, E et al (2012) Health Inequalities & People with Learning Disabilities in the UK: 2012
- Turner, S and Robinson, C (2011) Health Inequalities and People with Learning Disabilities in the UK: 2011. Implications and actions for commissioners. Evidence into Practice Report No 1 (revised) Learning Disabilities Observatory
- Parliamentary and Health Service Ombudsman (March 2009) Six Lives
- DH (2009) Valuing People Now: a new three year strategy for people with learning disabilities. London, DH
- DH (2009) Improving the health and wellbeing of people with learning disabilities. Best Practice Guidance. London, DH
- CQC (2009) Position statement and action plan for learning disability 2010-2015. CQC London
- Michael, J. (2008). Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Healthcare for All
- Mencap (2007) Death by Indifference
- Mencap (2004) Treat me right! Best healthcare for people with a learning disability
- NPSA (2004) Understanding Patient Safety Issues for people with learning disabilities
- NHS Scotland (2004) Health Needs Assessment Report People with Learning Disabilities in Scotland.
- Department of Health (2001) Valuing People: A New Strategy for Learning Disability for the 21st Century. London, DH
- The Joseph Rowntree Foundation has a number of reports relating to learning disabilities and health

http://www.jrf.org.uk/publications/browse/category/I

5.4   Reasonable Adjustments

- Turner, S and Robinson, C (2011) Reasonable adjustments for people with Learning Disabilities Implications and Actions for Commissioners and Providers of Healthcare. Evidence into Practice Report No 3. Learning Disabilities Observatory
- Reasonable adjustments database of examples:

  http://www.improvinghealthandlives.org.uk/adjustments/

5.5   Health Checks

- Hoghton, M and the RCGP Learning Disabilities Group (2010) A step by step guide for GP Practices. Annual Health checks for people with a learning disability. RCGP
- Health Check Resources from Learning Disability Observatory:

  http://www.improvinghealthandlives.org.uk/projects/annualhealthchecks

- Steps for primary care staff to complete LD checks:

  http://www.oxleas.nhs.uk/gps-referrers/learning-disability-services/health-check-resources/

6.   Professional guidance

- RCGP Learning Resources:

  http://www.rcgp.org.uk/clinical-and-research/clinical-resources/learning-disabilities.aspx

- GMC Learning Resources:

  http://www.gmc-uk.org/learningdisabilities/

- RCN (2011) Meeting the health needs of people of people with learning disabilities. RCN Guidance for Nursing Staff
- RCN (2010) Dignity in health care for people with Learning Disabilities. RCN Guidance
- RCN (2010) Mental health nursing of adults with learning disabilities
- Help the Hospices (2013) Towards excellence in Hospice care. Widening access to palliative care for people with learning disabilities. Help the Hospices, London

7. Communicating with people with learning disabilities

7.1 General Guidance

- BILD factsheet on Communication

  http://www.bild.org.uk/information/factsheets/

- Communication Matters is a UK-wide organisation committed to supporting people of all ages who find communication difficult because they have little or no clear speech

  www.communicationmatters.org.uk

- Makaton

  www.makaton.org

- Signalong

  www.signalong.org.uk

7.2 Communication and People with the most Complex Needs

- People with the most complex needs are often referred to in the literature as having Profound and Multiple Learning Disabilities (PMLD).

  http://www.pmldnetwork.org/

- Goldbart, J (2010) Communication and people with the most complex needs: What works and why this is essential. It is available in standard and Easy Read versions from the Mencap website.

  http://www.mencap.org.uk/all-about-learning-disability/information-professionals/communication

8.   Making information accessible

- CHANGE provides a free guide 'How to make information accessible' on their website:

  http://www.changepeople.org/free-resources/

- The UK Association for Accessible Formats (UKAAF) was founded in 2009 by the merger of three former industry associations: COTIS (Confederation of Transcribed Information Services), UKABP (UK Association of Braille Producers), and BAUK (the Braille Authority of the UK).

  http://www.ukaaf.org/

- Office for Disability Issues (Nov, 2008) Producing Better Information for Disabled People. A Toolkit for Local Authorities. HM Government

  http://odi.dwp.gov.uk/docs/wor/imp/toolkit.pdf

- Information on producing accessible information, including for electronic communication Scottish Accessible Information Forum (SAIF)

  http://www.saifscotland.org.uk/

- Website with accessible information features and tools to make your own accessible information. It includes a photographic database and guidelines about sensory timetables. Funded by Portsmouth Partnership Board for People with Learning Disabilities and Solent NHS Trust:

  http://www.accessibleinfo.co.uk/

- Photographs/ Pictures

  www.photosymbols.com

- Change picture bank

  www.changepeople.co.uk

- Widgets

  http://www.widgetbox.com/tag/learning%20disability

- Other communication aids

  http://www.talkingmats.com/

8.1 How to Write Easy Read Material/Principles of Easy Read

- DH (Nov, 2010) Making written information easier to understand for people with learning disabilities. Guidance for people who commission or produce Easy Read information –Revised Edition 2010:

  http://odi.dwp.gov.uk/docs/iod/easy-read-guidance.pdf

- Mencap : 'Make it Clear – a guide to easy read information'

  http://www.mencap.org.uk/what-we-do/resources-and-training

- Disability Rights Commission (2006) How to use easy words and pictures (easy read version):

  http://www.equalityhumanrights.com/uploaded_files/how_to_use_easy_words_and_pictures.pdf

8.2 Website Design, ICT and Assistive Technology

- Guidance on making websites accessible: The World Wide Web Consortium (W3C) not only develops technical standards for the web, but, since the UN Convention on the Rights of Persons with Disabilities, has sought to make the benefits of the web available to people with disabilities

  http://www.w3.org/WAI/intro/accessibility.php

- Working together: Computers and people with learning disabilities. Providing access to technology. DO IT (Disabilities, Opportunities, Internetworking and Technology. (2013) University of Washington

  http://www.washington.edu/doit/

- Learning Disability Wales conference examined how the person-centred use of Assistive Technology can support independence and safety for people with a learning disability and their families and care

  http://www.learningdisabilitywales.org.uk/independence-through-personalised-technology.php

8.3   Communication Passports

- Information about communication passports for people who cannot speak for themselves:

  http://www.communicationpassports.org.uk/Home/

- SCOPE (2010) Communication Passport Template. A SCOPE guide to making communication passports

  http://www.scope.org.uk/help-and-information/publications/communication-passport

8.4   Health Passport/Healthcare Passport

- Some organisations are creating specific health related passports for people with learning disabilities. Examples are given on the link below:

  http://www.gmc-uk.org/learningdisabilities/333.aspx

- Daniel Marsden (March 2012) Implementing and Evaluation 'My Health Passport' in Practice for People with Learning Disabilities

  http://fons.org/programmes/report-details.aspx?nstid=19857&page=123&from=2

9. Useful websites for health information for people with learning disabilities

Organisation	Background Information	Website
• 'A Picture of Health'	The range of Easy Read information on the 'A Picture of Health' website has been developed; locally, nationally or from other NHS areas. This website was originally produced by NHS Southwest.	http://www.apictureofhealth.southwest.nhs.uk/
• Beyond Words	Small not-for profit social enterprise set up in 2011. It originated in St George's, University of London.	http://www.booksbeyondwords.co.uk/home
• Easy Health	Website which is part sponsored by Mencap. It was also originally part sponsored by Wandsworth PCT. There are over 500 leaflets, made by many different organisations.	www.easyhealth.org.uk
• FAIR (Family Advice and Information Resource)	An information and advice service for people with learning disabilities, parents, carers and people who work with them in Edinburgh.	www.fairadvice.org.uk
• General Medical Council	Resources web pages	http://www.gmc-uk.org/learningdisabilities/333.aspx

Organisation	Background Information	Website
• NHS Inform	Provides a coordinated approach and a single source of quality assured health information for the public in Scotland. There is an easy info section with 3 categories: Health, wellbeing, tests and treatments	http://www.nhsinform.co.uk/Easy-Info
• North Essex Partnership NHS Foundation Trust	Gives examples of leaflets such as an explanation of the Care Programme Approach and medication leaflets in Easy read format	http://www.nepft.nhs.uk/for-families-and-friends/learning-disabilities/leaflets-and-information-learning-disability/
• Nottsinfoscript	This website is part of a collection of websites which provide personalised Health and Social care information to the people of Nottinghamshire. These websites are funded and managed by the Nottinghamshire NHS and Nottingham County Council.	http://nottsinfoscript.co.uk/
• Patient .co.uk	Links to easy read material on a wide range of websites including: Change portfolio, easyhealth, easy info zone, Great Ormond Street, Elfrida Society	http://www.patient.co.uk/health/accessible-leaflets
• Pavilion Publishing	Publishing company providing books and training packs to buy	http://www.pavpub.com/c-22-learning-disability.aspx
• Royal College of Psychiatrists	Health Advice section with leaflets for people with learning disabilities on mental health issues and common medication	http://www.rcpsych.ac.uk/mentalhealthinfo/problems/learningdisabilities.aspx

Organisation	Background Information	Website
• Royal National Institute for the Blind	Accessible literature both in specialist formats such as braille and mainstream formats such as printed material and web pages	www.rnib.org.uk/access
• Signpost Sheffield	About the Joint Learning Disabilities Service in Sheffield, which has access to a range of leaflets:	https://www.signpostsheffield.org.uk/
• Social Care Institute for Excellence (SCIE)	A few easy read resources including personalisation	http://www.scie.org.uk/topic/careneeds/learningdisabilities/adultswithlearningdisabilities
• The Elfrida Society	Publishes materials by people with learning difficulties, for people with learning difficulties and for people who work with them. There is a charge for these publications	http://www.elfrida.com/publications.html
• The Friendly Resource Company	Social Enterprise run by and for people with learning disabilities. There is a catalogue of DVDs and other accessible resources available to buy:	http://www.friendlyresources.org.uk/
• The Learning Disabilities Foundation	Worked with Easy Health to produce a range of guides produced on key medical conditions in an Easy Read format for people with learning disabilities. These are downloadable free from the website.	http://www.learningdisabilities.org.uk/our-work/health-well-being/easy-read-guides-health-conditions/?view=Standard

10.   Involving people with learning disabilities in producing material

- Mencap Involve Me Project: a practical guide has been launched along with an independent evaluation of the project. The guide refers to real-life examples as well as video clips, downloadable resources and the Involve Me film, which are all available on an interactive DVD

  http://www.mencap.org.uk/involveMe

- Chapter 4 'Involving people with learning disabilities' DH (Nov, 2010) Making written information easier to understand for people with learning disabilities. Guidance for people who commission or produce Easy Read information –Revised Edition 2010

- Office for Disability Issues (Nov, 2008) Producing Better Information for Disabled People. A Toolkit for Local Authorities. HM Government

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11.   External companies & organisations that design and produce accessible material

- SpeakUp works with 2 social enterprises The Friendly Resource Group and The Friendly Information company . It can make information accessible in print, on film and using Makaton or BSL

  www.speakup.org.uk

- Fair (Family Advice and Information Resource) provide a design, copy-writing and illustration service for organisations who want their publications to be made more accessible

  www.fairadvice.org.uk

- Communication People are a small company who specialise in the design of easy read material and picture communication books:

  www.communicationpeople.co.uk

- Dorset People First is an organisation providing an Easy Read Design service for people with learning difficulties:

  http://peoplefirstdorset.org.uk/our-services/

- Inspired is a company run by a team of directors with and without learning disabilities who specialise in designing and producing material for people with learning disabilities. They offer a range of products to help you make your own material more accessible too.

  http://www.inspiredservices.org.uk/

- Easy Read is a company specialising in developing accessible websites:

  www.easy-read-online.co.uk

12.   Networks for people with learning disabilities

- Netbuddy pools the expertise of parents, carers and learning disability professionals. It offers practical solutions to everyday issues

  http://www.netbuddy.org.uk/

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13.   Apps

- "Friendship Circle of Michigan is a non-profit organization that provides programs and support to the families of individuals with special needs. Since Friendship Circle of Michigan was founded in 1994 Friendship Circle has spread to over 80 cities worldwide.

  www.friendshipcircle.org/about

- With over a thousand apps now available to help individuals with special needs it has become increasingly difficult to find and choose the right special needs app. The Friendship Circle App Review gives you the ability to find the perfect special needs app for your child"

  http://www.friendshipcircle.org/blog/2013/08/02/8-special-needs-apps-you-should-know-about/

  http://www.friendshipcircle.org/apps/

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