

Learning Disabilities Audit Project
Greater Glasgow and Clyde NHS Board
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Author: Joanna Ptolomey

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Executive Summary

Greater Glasgow and Clyde NHS Board are required to provide information on health and lifestyle for all groups of their population. This commitment includes supporting groups of people who cannot read or have low literacy skills. People with learning disabilities not only have issues around literacy but also specific health needs. As part of their response to these issues Greater Glasgow and Clyde NHS Board commissioned an audit to identify health information resources in the learning disabilities area. Furthermore the health information resources should be suitable for three target groups

- People with learning disabilities
- Health professionals working with people with learning disabilities
- Families/carers of people with learning disabilities

Health information resources were searched for over a wide variety of health topics published in the last ten years. The search was limited to the United Kingdom.

The greatest numbers of resources were found to be concentrated in sexual health and mental health across the three target groups.

The search process for resources, specifically for people with learning disabilities, used a set of quality preferable criteria. Only around 20% of all these resources met most of the preferable criteria. The main criteria that most resources fell down on were that they had not been tested or developed by the client group.

This report and the corresponding databases, available at www.phru.net/learningdisabilities are part of the response by Greater Glasgow and Clyde NHS Board to the health needs assessment report "People with learning disabilities in Scotland" (1) for accessible targeted health resources for people with learning disabilities and those caring and working for them.

Section 1: Introduction and Background

Greater Glasgow and Clyde NHS Board is required to ensure that people who have a learning disability and people who don't read, (e.g. deaf communities, non English speakers, and those with low literacy), have access to information on health and lifestyle the same as other members of the population. The commitment to this is through the NHS Greater Glasgow and Clyde Equality Scheme and Draft Communication Support and Language Plan (2).

It is well recognised, and there is much evidence to support (18), that people with a learning disability have greater health needs than other populations and often these health needs are unmet or unrecognised. These health needs are threefold. Firstly, their health needs are the same as everybody else, secondly their health needs are met specific to the nature of the learning disability, and thirdly due to societal factors compounding ill health due to inequality of health/social provision. A recent Health Needs Assessment report (19), People with Learning Disabilities in Scotland, clearly evidences the health inequality experienced by people with a learning disability. It suggests that family and paid carers, and health and social care professionals should have access to resources for use with people with a learning disability. In addition there should also be available accessible targeted resources on specific health needs of the learning disability population.

With these points in mind Greater Glasgow and Clyde NHS Board commissioned an audit to identify what health information resources are available specifically for people with learning disabilities. The health information resources should be in suitable formats for not only people with learning disabilities but also people and professionals who work and care for them.

Section 2: Definition of a Learning Disability

The term “learning disability” is generally accepted in the health and social care setting as appropriate terminology for describing a person who has an overall impairment of intellect or function. It is used in much of the recent literature on the subject (20). There are some that consider this term a label and convenient for some purposes but that the person should always be considered first.

At the initial stages there was discussion by the project team on the definition of learning disability in the context of this audit. The project team, comprising health professionals involved in health inequalities, a learning disability health professional, a health promotion professional and an information professional discussed the criteria and considered widely reported evidence, experts opinion and professional practice at this time. For the purposes of this audit the definition of learning disabilities concerns the following points

- The disability has been present before the age of 18 years old (usually early onset)
- Previous normal functioning in a person older than 18, who has had a brain injury is not considered to be learning disabled
- People with specific learning difficulties such as dyslexia or ADHD should not be considered
- A reduced ability to understand new or complex information
- A reduced ability to learn new skills
- A reduced ability to cope independently

Section 3: Audit Methodology

3.1: Health Topic Scope

The People with Learning Disabilities report (21) considered the specific health needs of people with learning disabilities and based on this evidence a range of ten health topics were considered for inclusion into the audit.

- Children
- Lifestyle
- Health Rights
- Men's Health
- Mental Health
- Nutrition
- Safety
- Sexual Health
- Respiratory
- Women's Health

With the expertise of health professionals at Greater Glasgow and Clyde NHS Board these broad subject headings were scoped out to produce specific definitions of these health topics. Appendix 1 lists the complete scope of the individual health topics. The health topics in the directory have been updated to incorporate a number of resources which did not fit into the original topics. The Lifestyle topic has been changed to Health and Wellbeing and Parenting has also been included.

3.2: Search Processes

The search for resources was confined mainly to the United Kingdom over the last ten years and considered formats including (but not limited to) leaflets, booklets, books, reports, posters, audiocassettes, videos/DVDs, CD's, work books, teaching packs, presentations, conference proceedings, and web-based multimedia formats.

To ensure a comprehensive approach, the search focussed on two broad areas of sources

- Specialist sources for the learning disabilities area
- Specialist sources for health topic areas

Appendix 2 lists the complete sources for the search process.

3.3: Target Groups

Three target groups were considered for the audit.

- Health professionals working with people with a learning disability
- Families/carers of people with a learning disability
- People with learning disabilities

3.4: Criteria for Resources

The target group (people with learning disabilities) have a unique set of criteria that needed to be considered when looking for suitable health information resources. This criterion was discussed at length at the initial project meeting for the audit and based on experience and expertise of using resources within the learning disabilities client group a key set of best practice was defined.

Information resources that are suitable for people with learning disabilities are generally considered to be in an “easy read” format. The project team considered what does “easy read” mean? A very simplistic view would be that the words used are easy, the writing is big, and there could be pictures and perhaps sounds to listen to. However, the team felt that this could be too simplistic a definition. For example, what is an easy word and how big is big when it comes to letter size?

For the purposes of this audit there were certain key items that were considered to be the criteria in order that a resource could be classed as easy read. It is important to note that all the resources were not assessed on a strict quality control procedure. This preferred best practice was used as guidance in selection of resources only.

Words

- words that are used all the time with no possible ambiguity
- sentences should be short with very little punctuation
- no abbreviations or jargon should be used
- there should not be too much writing on a page

Pictures

- words should be next to the picture
- same picture should be used each time to mean the same thing

Style

- clear bold typeface is preferred
- writing should stand out against the colour of a paper or a background
- maps and charts are difficult to understand and should be discouraged
- bullets points can be useful, but not too many

Format

- Communication can be on paper
- Other formats may also be useful such as audio tape or CD or DVD or a web based multimedia format

Quality Assurance Process

- Ask the experts who will be using the resources i.e. people with learning disabilities
- Road testing resources such as a focus group allows for useful feedback and any changes

Searching for resources for the other two target groups; health professional and families/carers had less criteria attached to research. The format, style and quality assurance aspects were less of an aspect and a more open process was adopted. The question of quality is however important and the team considered that apart from good content, presentation quality including good production quality was important. Resources that originated from credible organisations were also seen as an indicator of quality and content.

3.5: Project Timetable

Each health topic was given a one-week research slot, which was felt by the team to be an adequate time frame to complete the research.

The findings of this audit should be considered a snapshot in time and the details were correct at the time of the research being carried out. However users of this report and the accompanying database should be vigilant to changes.

Detailed below is the chronological timetable of the research.

Mental Health	w/b 22 nd October 2007
Sexual Health	w/b 29 th October 2007
Women's Health	w/b 5 th November 2007
Men's Health	w/b 12 th November 2007
Nutrition	w/b 19 th November 2007
Lifestyle	w/b 26 th November 2007
Safety	w/b 10 th December 2007
Health Rights	w/b 16 th January 2008
Respiratory	w/b 23 rd January 2008
Children	w/b 6 th February 2008

3.6: Resources Format

The format of the resources includes the following data fields, all of which are searchable.

- Title: name of the resource
- Resource topic
- Resource type
 - Book
 - Booklet
 - Leaflet
 - Workbook
 - Teaching pack
 - Training pack
 - Report
 - DVD
 - CD
 - Video
 - Power point presentation
 - Online film
- Language
 - English Only
- URL
- Target Group
 - Carers and families of people with learning disabilities
 - Health professionals
 - People with learning disabilities
- Description
- Publisher
- Publication Date
- Resource Identifier (ISBN number)
- National Library for Public Health Language Control Term

All the resources are fully summarised electronically in a searchable database available on the Public Health Resource Unit website
www.phru.net/learningdisabilities

Section 4: General Audit Findings

4.1: General Findings

The general search outcome was positive across the ten health topics for each of the target groups; people with learning disabilities, health professionals and families/carers. All the health topics have some resources included.

There was some overlap in resources for each of the groups. Some of the resources selected are suitable for health professionals and also carers. In the same way some resources have been developed for carers/health professionals and people with learning disabilities.

4.2: Findings for People with Learning Disabilities

The audit process concluded with the inclusion of ninety (90) health information resources. Sexual Health, women's health and health and wellbeing had the greatest number of resources. Health rights and respiratory had the lowest number of resources.

The majority of the health information resources (64%) were sourced from organisations that have a remit for people with learning disabilities either providing a voluntary sector service (e.g. British Institute of Learning Disabilities) or a specialist academic research centre such as the Norah Fry Centre (University of Bristol). Some comments were feedback from more general organisations (subject specific) that if budgets allowed they would like to develop their stock for people with learning disabilities, but it was not a priority under their financial situations.

The majority of the resources included were either in book or booklet form (33%) and the next most popular format was CD/audiocassette/DVD at 17%.

The most immediate concern for the resources for people with learning disabilities is the lack of information or confirmation from the publishers or creators on how their resources were tested or developed. Only a few sources were able to provide information (some quite explicitly on their website or resources) on how they tested the quality of their resources. All organisations were contacted and the following could confirm (within the time of the project) that they tested or worked to produce their resources with the experts i.e. people with learning disabilities

- Mencap
- The Elfrida Society
- NHS Cancer Screening Programmes
- Scottish Nutrition and Diet Resources Initiative
- Down Syndrome Scotland
- Common Knowledge

The figure is around 20% of resources being tested on their intended target group.

4.3: Findings for Families/Carers

The audit process concluded with the inclusion of twelve (12) resources. There were very few resources found, although a number of the resources under the Health Professionals group are also aimed at Families/carers. Sexual health, mental health, children and safety are the only topics which have resources listed. There are no resources listed for the health topics Health & Wellbeing, Health rights, Men's Health, Nutrition, Respiratory or Women's Health.

The majority of the resources included were in the form of training packs, workbooks, teaching guides or packs.

4.4: Findings for Health Professionals

The audit process concluded with the inclusion of ninety (90) resources. Sexual health, mental health and women's health had the greatest number of resources. The remainder of the health topics had very few topics with the lowest being health rights and nutrition.

There were three main formats that dominated the health professionals resources. Books (21%) and reports (21%) accounted for the majority of the resources and workbooks, teaching packs and training guides accounted for 17.5% of the total resources.

Section 5: Conclusions

This audit highlights that there is still much to be done in the provision of health information resources for people with learning disabilities and for those who care and work for them. Although all the three main target groups have resources across all the health topic areas some are very poorly serviced such as health rights.

A key area that needs to be addressed is the testing and developing of appropriate resources for people with learning disabilities. There is little evidence that most organisations asking for the help or support of their client group (i.e. people with a learning disability), and this questions the usefulness or appropriateness of some resources.

Where resources have been developed by a health subject specific organisation there is very little provision for people with learning disabilities. Some very large national voluntary sector organisations do not produce any of their publications in an easy read format, and comments from their spokespeople suggest that until funding becomes better then this situation will not change.

However, this audit is a positive start as it bridges some of the gaps and shows the opportunities. By taking the audit report and the accompanying databases into the public domain it is a good starting point for some evidenced based steps forward.

The Learning Disabilities Portal is an exciting and positive step forward to meet the requirements of not just legislation, but to support the lives of people with learning disabilities and their health professionals and carers/families in the Greater Glasgow and Clyde area.

Section 6: References

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12. Van Schrojenstein Lantman-de Valk, HMJ. Health in people with intellectual disabilities: current knowledge and gaps in knowledge. *Journal of Applied Research in Intellectual Disabilities*, 18(4):325-333, 2005.
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15. The same as you. A review of services for people with learning disabilities. The Scottish Executive, December 2006.
Available URL accessed 16th March 2008
<http://www.scotland.gov.uk/Resource/Doc/159140/0043285.pdf>
16. ibid 1
17. ibid 1
18. ibid 1-15
19. ibid 15
20. Factsheet – learning disabilities. British Institute of Learning Disabilities (BILD).
21. ibid 15

Section 7: Appendices

Appendix 7.1: Health Topic Scopes

Mental Health

Anxiety
Stress
Self esteem
Dementia
Bereavement
Grieving
Depression
Manic depression and bi-polar affective disorder
Phobia
Panic attacks
Postnatal depression
Eating disorders: anorexia nervosa and bulimia nervosa
Schizophrenia
Self harm

Sexual health

Relationships
Heterosexual, gay, lesbian and bi-sexual relationships
Sexual assault/abuse
Rape
Female sexual health
Male sexual health
Masturbation
Wet dreams
Family planning
Pregnancy
Abortion
Methods of contraception
Puberty
Periods
Cervical smear screening
Sexually transmitted infections (STI)
Sexually transmitted disease (STD)
HIV and AIDS
Chlamydia
Genital warts
Genital herpes
Gonorrhoea
Vaginal discharge
Pubic lice
Syphilis
Non-specific urethritis
Hepatitis B and C

Appendix 1: Health Topic Scopes (continued)

Women's health

Reproductive health
Domestic abuse
Sexual assault and abuse
Rape
Cervical screening; pap tests
Female sexuality
Hysterectomy
Relationships (friendship and sexual)
Periods/menstruation
Premenstrual syndrome
Thrush
Cystitis
Menopause
Hormone replacement therapy
Pregnancy
Motherhood
Breastfeeding
Postnatal depression

Men's health

Men and positive mental health
Men and relationships (having friends and sexual)
Men and addictions
Men and lifestyle
Men and sex
Testicular self examination
Male sexual abuse
Male menopause

Respiratory

Aspiration
Swallowing problems
Pneumonia

Appendix 1: Health Topic Scopes (continued)

Nutrition

Healthy eating/diet
Balanced diet
Recipe and health food ideas
Diet, vitamins and minerals
Folic acid
Pregnancy and diet
Wholemeal foods
Vegetarian foods
Protein
Carbohydrates
Fruit and vegetables
High Fibre Diets
Food groups
Weight and health
Weight loss
Obesity
Overweight

Safety

Accident/injury prevention
Safety in the home
Fire safety
Road safety
Personal safety
In car safety
Accidental injury or poisoning
Fatal accidents
Contacting emergency services

Health rights

Consent

Appendix 1: Health Topic Scopes (continued)

Health & Wellbeing

Smoking

Quit/stop smoking
Health benefits of stop smoking
Withdrawal symptoms of stop smoking
Passive smoking
Secondary smoking
Young people and smoking
Women/men smoking
Pregnancy and smoking

Alcohol

Binge drinking
Sensible drinking
Units of alcohol
Alcohol and pregnancy
Being drunk
Getting help

Drugs

Drug habit/problem/addict
Prescription drugs
Over the counter drugs
Heroin
Cocaine
Amphetamine
Amyl or butyl nitrites or poppers
Ecstasy
Solvent abuse
Cannabis
Hallucinogens
Getting help

Heart/Stroke

Healthy heart
Heart disease
Heart attack
Coronary artery disease
Angina
Stroke
Cerebrovascular disease
Transient Ischemic Attacks

Physical Activity

Exercise
Sports
Games
Walking
Swimming

Appendix 1: Health Topic Scopes (continued)

Children and parenting (for parents who have learning disabilities and have children)

Parenting skills

Positive parenting

Breastfeeding

Feeding new babies

Handling babies

Taking care of your baby

Bathing your baby

Colic

Weaning

Nutrition in toddlers and young people

Cot death

Safety for baby and young children

Child development

Toilet training

Teething

Postnatal depression

Managing behaviour in children

Appendix 7.2: Sources used for Research Process

Learning Disabilities Sources

British Institute of Learning Disabilities	http://www.bild.org.uk/
Down's Syndrome Association	http://www.downs-syndrome.org.uk/
The Foundation for people with Learning Disabilities	http://www.learningdisabilities.org.uk/
The National Autistic Society	http://www.nas.org.uk/
People First (check for updates)	http://www.peoplefirstltd.com/
National Skill Bureau for Students with Disability	http://www.skill.org.uk/
Common Knowledge	http://www.cklearn.org.uk/index.html
The Royal College of Psychiatrists	http://www.rcpsych.ac.uk/
Elfrida	http://www.elfrida.com/
One for us	http://www.oneforus.com/
Acting up	http://www.acting-up.org.uk/
Media First	http://www.mediafirst.org.uk/
The Big Tree	http://www.thebigtree.org/
Change	http://www.changepeople.co.uk/
Connects	http://www.connects.org.uk/
Down's Syndrome Association	http://www.downs-syndrome.org.uk/
Pavilion Publishing	http://www.pavpub.com/
The Estia Centre	http://www.estiacentre.org/default.html
The Centre for Applied Social and Psychological Development	http://www.salomonscaspd.org.uk/index.html
NHS Scotland	http://www.healthscotland.com/index.aspx
RNIB VILD	http://www.rnib.org.uk/
FAIR (Family Advice and Resource Centre)	fair@btconnect.com
Speak Up	http://www.speakup.org.uk/default.htm
Women's Health London	http://www.womenshealthlondon.org.uk/
Life Support Productions	http://www.lifesupportproductions.co.uk/
Disabled Living Foundation	http://www.dlf.org.uk/
The Shepherd School	http://www.shepherdschool.org.uk/frames/index.htm
Down's Syndrome Scotland	http://www.dsScotland.org.uk/
Foundation for people with learning disabilities.	http://www.learningdisabilities.org.uk/
Down's Syndrome NSW	http://www.dsansw.org.au/
Ann Craft Trust	http://www.anncrafttrust.org/
Down Syndrome NSW	http://www.dsansw.org.au/
Joseph Rowntree Foundation	http://www.jrf.org.uk/
National Network for Learning Disability Nurses	http://www.nnldn.org.uk/
Learning Disabilities Network UK	http://www.learningdisabilitiesuk.org.uk/
Unit for Development for Intellectual Disabilities, University of Glamorgan	http://udid.research.glam.ac.uk/
Disability Network	http://www.disabilitynetwork.co.uk/
UK Health and Learning Disabilities Network	http://www.ldhealthnetwork.org.uk/
Norah Fry Research centre	http://www.bristol.ac.uk/norahfry/
Care and treatment of offenders with learning disabilities	http://www.ldoffenders.co.uk/
Challenging behaviour foundation	http://www.thecbf.org.uk/
Intellectual Disability Health Information	http://www.intellectualdisability.info
PWSA Prader-Willi Association UK	http://pwsa.co.uk/main.php
Scope	http://scope.org.uk
Makaton	http://www.makaton.org/about/about.htm
CRFR Centre for Research on families and relationships	http://www.crfr.ac.uk/
Scottish Consortium for Learning Disability	http://www.sclld.org.uk/
Values into Action	http://www.viauk.org/

Disabled Parents network
Disability, Pregnancy and Parenthood International
Me and Us
Quarriers
Cornerstone

<http://www.disabledparentsnetwork.org.uk/cgi-bin/s>
<http://www.dppi.org.uk/index.html>
<http://www.me-and-us.co.uk/index.html>
<http://www.quarriers.org.uk/>
<http://www.cornerstone.org.uk/site/>

Mental Health Sources

Mencap	http://www.mencap.org.uk/
MIND	http://www.mind.org.uk/index.htm
Mental Health Media	http://www.mhmedia.com/
Mental Health Foundation	http://www.mentalhealth.org.uk/
Mencap	http://www.mencap.org.uk/
Alzheimers Society	http://www.alzheimers.org.uk/index.htm
Alzheimers Scotland	http://www.alzscot.org/
British Association for Counselling and Psychotherapy	http://www.counselling.co.uk/
Depression Alliance	http://www.depressionalliance.org/index.html
Rethink	http://www.rethink.org/
Samaritans	http://www.samaritans.org/index.shtm
SAMH	http://www.samh.org.uk/frontend/index.cfm?page=1
SANE	http://www.sane.org.uk/public_html/index.shtml
The Royal College of Psychiatrists	http://www.rcpsych.ac.uk/
The Association for Post Natal Depression	http://www.apni.org/
Cruse Bereavment Care	http://www.crusebereavementcare.org.uk/
United Response	http://www.unitedresponse.org.uk/

Nutrition Sources

Blood Pressure Association	http://www.bpassoc.org.uk
Breast Feeding Network	http://www.breastfeedingnwteoek.org.uk
British Dietetic Association	http://www.nutrition.org.uk/
British Hypertension Society	http://www.bhsoc.org/
British Heart Foundation	http://www.bhf.org.uk/
British Nutrition Foundation	http://www.nutrition.org.uk//
Consensus Action on Salt and Health	http://www.actiononsalt.org.uk/
Diabetes UK	http://www.diabetes.org.uk/
Eatwell	http://www.eatwell.gov.uk/
Food standards Agency	http://www.food.gov.uk
Healthy Living	http://www.healthyliving.gov.uk/
Heart UK	http://www.heartuk.org.uk/
High Blood Pressure Foundation	http://www.hbpf.org.uk
Salt	http://www.salt.gov.uk

Sexual Health Sources

Family Planning Association
Avert
Brook
Queery
Terrance Higgins Trust
Stonewall

<http://www.fpa.org.uk/>
<http://www.avert.org/>
<http://www.brook.org.uk/content/>
<http://queery.org.uk/>
<http://www.tht.org.uk/>
<http://www.stonewall.org.uk/>

Easy Read Websites

One for Us
Ask Mencap Website
Heart and Soul
Working with words
People First
Change
ENABLE
Common Knowledge

<http://www.oneforus.com/>
<http://www.askmencap.info/>
<http://www.heartnsoul.co.uk>
<http://www.workingwithwords.org/default.htm>
<http://www.peoplefirstltd.com/>
<http://www.changepeople.co.uk/>
<http://www.enable.org.uk/easyread.php>
<http://www.ckglasgow.org.uk/>

Women's Health

Family Planning Association
National Childbirth Trust
Rape Crisis Scotland
Scottish Women's Aid
Suzy Lamplugh Trust
The Association for Post Natal Illness
Women's Aid
Women's Health
Women's Resource Centre
Zero Tolerance

<http://www.fpa.org.uk/>
<http://www.nctms.co.uk/>
<http://www.rapecrisisscotland.org.uk/>
<http://www.scottishwomenaid.co.uk/>
<http://www.suzylamplugh.org/>
<http://www.apni.org/>
<http://www.womensaid.org.uk/>
<http://www.womenshealthlondon.org.uk/>
<http://www.wrc.org.uk/>
<http://www.zerotolerance.org.uk/>

Section 8: Author Information

Joanna Ptolomey (<http://www.joannaptolomey.co.uk>) is a freelance information professional and librarian and has held positions in the NHS and private sector consultancy. Her practice portfolio covers three main areas

- Bespoke training session: accessing and using quantitative and qualitative evidenced based searching in the health and social sector
- Research services
- Consultancy: information service audits and the development of new information services policies and procedures.
- Writing for publication
- Conference work

Much of Joanna's work is in the health and social care sector and she can be contacted at info@joannaptolomey.co.uk.

Section 9: Project Team

Donna Athanasopoulos Public Education Resource Library
NHS Greater Glasgow and Clyde
Donna.athanasopolous@ggc.scot.nhs.uk

John Crawford Corporate Inequalities Team
NHS Greater Glasgow and Clyde
John.crawford@ggc.scot.nhs.uk

Nicola Robinson Primary Care Liaison Team
NHS Greater Glasgow and Clyde
Nicola.robinson@ggc.scot.nhs.uk

Joanna Ptolomey Freelance Information Specialist
info@joannaptolomey.co.uk

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John Hutchinson Web Editor PHRU
NHS Greater Glasgow and Clyde
John.hutchinson@ggc.scot.nhs.uk

Pauline Innes Knowledge Exchange PHRU
NHS Greater Glasgow and Clyde
Pauline.innes@ggc.scot.nhs.uk

Iain Stewart Information Officer, Perl
NHS Greater Glasgow and Clyde
Iain.stewart@ggc.scot.nhs.uk

Further information on the report and resources found available from:

Donna.athanasopolouos@ggc.scot.nhs.uk

Iain.stewart@ggc.scot.nhs.uk

