

## **Visual Impairment and People with Learning Disabilities**

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### **Background and Issues**

'Learning disability' as a term in the UK describes:

- A state of arrested or incomplete development of mind;
- Significant impairment of intellectual functioning
- Significant impairment of adaptive/social functioning

This means that somebody with a learning disability will have difficulties in understanding, difficulties in learning new things and generalising these to new situations. They have difficulties with social tasks (e.g. communication, self-care, awareness of and responses to danger etc.) and these difficulties will vary dependent upon the extent and nature of the disability.

### **Healthcare for People with learning disabilities**

Support for people with learning disabilities has moved away from the medical model to a social model based on inclusion and integration, which has created many challenges for healthcare support. There are a number of studies highlighting

poorer health for many people with learning disabilities arising from -

- undetected ill-health [refs 29-33]
- occurrence of other co-existing health problems [refs 1-28]
- barriers to access to healthcare services [refs 1-28]
- their need for support in seeking health care [refs 1-28]
- poor contact with primary health care services [refs 29-33]
- few healthcare professionals having specific training in caring for people with learning disabilities [refs 29-33]

Research findings indicate that training interventions can improve knowledge of and responses to people with learning disabilities and that health screening in primary care can improve the health of people with learning disabilities (see note 3 for references).

### **Visual Impairment in People with learning disabilities - the evidence**

Amongst adults, the prevalence of visual impairment increases with the severity of the learning disability and with age [34].

A literature review by the Valuing People Support Team [35] found people with learning disabilities to be between 8.5 and 200 times more likely to have a visual impairment compared to the general population.

In March 2006, the Down Syndrome Medical Interest Group reported [36] a high incidence of ocular disorder among people with Down's syndrome:

- Refractive errors and/or squint often present from an early age,
- Cataract and/or glaucoma occurring in infancy,
- Nystagmus present in at least 10% of the DS population.
- Keratoconus more common in adolescents and young adults

### **Guidelines and recommendations**

#### **The International Association for the Scientific Study of Intellectual Disability**

For adults with an intellectual disability, routine screening for age-related visual loss at 45 years and every 5 years thereafter has been recommended. If possible this should be done by an ophthalmologist. An extra vision check at age 30 years has been recommended for adults with Down syndrome. [37] IASSID also provides specific guidelines on screening for visual impairment [38] which include guidance on which children and adults should be screened for visual impairment and when; current methods for screening and a screening protocol.

## **College of Optometrists guidelines on the examination of people with learning disabilities [39]**

When examining a patient with learning disabilities, the optometrist has a duty to carry out whatever tests are necessary, using a range of tests and procedures that are appropriate to the needs of the patient and, where necessary, seeking a briefing from family members, carers and key workers.

### **Help and advice**

**Look Up** is an information service focusing on eye care and vision for people with learning disabilities - a collaboration between SeeAbility and RNIB. See Look Up website: <http://www.lookupinfo.org/index.php?id=home>

**Look Up** provide over 30 factsheets [40] for additional advice and guidance.

Of particular interest are

- **Looking for eye problems in people with learning disabilities**  
<http://www.lookupinfo.org/index.php?id=251>
- **Consent for medical treatment and operations for people with learning disabilities** <http://www.lookupinfo.org/index.php?id=402>
- **Telling the optometrist about me form**  
[http://www.lookupinfo.org/fileadmin/user\\_upload/Logos\\_PDFs/Telling the Optometrist About Me - June 2007.pdf](http://www.lookupinfo.org/fileadmin/user_upload/Logos_PDFs/Telling_the_Optometrist_About_Me_-_June_2007.pdf)
- **Feedback from the optometrist about my eye test form**  
[http://www.lookupinfo.org/fileadmin/user\\_upload/Logos\\_PDFs/Feedback from the optometrist about my eye test - June 2007.pdf](http://www.lookupinfo.org/fileadmin/user_upload/Logos_PDFs/Feedback_from_the_optometrist_about_my_eye_test_-_June_2007.pdf)

The **RNIB** offers information on visual impairment and learning disabilities services, for professionals and for service users and their families. Their National Practice and Development Team also offers training, consultancy, information and rehabilitation services:

- Visual Impairment and Learning Disabilities services  
[http://www.rnib.org.uk/xpedio/groups/public/documents/publicwebsite/public\\_scotcomplexmain.hcsp](http://www.rnib.org.uk/xpedio/groups/public/documents/publicwebsite/public_scotcomplexmain.hcsp)

## References

1. Alborz, A., McNally, R., Swallow, A., and Glendinning, C. From the cradle to the grave: a literature review of access to health care for people with learning disabilities across the lifespan: report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). 2003. Manchester, NCCSDO. 3-7-2008.  
[abstract & link to full-text: <http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=154801&tabID=289>]  
[full-text pdf: <http://www.sdo.lshtm.ac.uk/files/project/23-final-report.pdf>]
2. Barr O, Gilgunn J, Kane T *et al*. Health screening for people with learning disabilities by a community learning disability nursing service in Northern Ireland. *J Adv Nurs* 1999;**29**:1482-91.  
[PubMed abstract (PM:10354244): <http://www.ncbi.nlm.nih.gov/pubmed/10354244>]
3. Bell AJ, Bhate MS. Prevalence of overweight and obesity in Down's syndrome and other mentally handicapped adults living in the community. *J Intellect.Disabil Res* 1992;**36 ( Pt 4)**:359-64.  
[PubMed abstract (PM:1388077): <http://www.ncbi.nlm.nih.gov/pubmed/1388077>]
4. Branford D, Bhaumik S, Duncan F. Epilepsy in adults with learning disabilities. *Seizure* 1998;**7**:473-7.  
[PubMed abstract (PM:9888491): <http://www.ncbi.nlm.nih.gov/pubmed/9888491>]
5. Carter G, Jancar J. Mortality in the mentally handicapped: a 50 year survey at the Stoke Park group of hospitals (1930-1980). *J Ment.Defic Res* 1983;**27 (Pt 2)**:143-56.  
[PubMed abstract (PM:6225874): <http://www.ncbi.nlm.nih.gov/pubmed/6225874>]
6. Carvill S. Sensory impairments, intellectual disability and psychiatry. *J Intellect.Disabil Res* 2001;**45**:467-83.  
[PubMed abstract (PM:11737534): <http://www.ncbi.nlm.nih.gov/pubmed/11737534>]
7. Cassidy G, Martin DM, Martin GHB *et al*. Health checks for people with learning disabilities: community learning disability teams working with general practitioners and primary health care teams. *J Intellect Disabil*. 2002;**6**:123-36.  
[publisher abstract: <http://jid.sagepub.com/cgi/content/abstract/6/2/123>]
8. Cooke LB. Cancer and learning disability. *J Intellect Disabil Res* 1997;**41 ( Pt 4)**:312-6.  
[PubMed abstract (PM:9297608): <http://www.ncbi.nlm.nih.gov/pubmed/9297608>]
9. Cooper SA. Deficient health and social services for elderly people with learning disabilities. *J Intellect Disabil Res* 1997;**41 ( Pt 4)**:331-8.  
[PubMed abstract (PM:9297611): <http://www.ncbi.nlm.nih.gov/pubmed/9297611>]
10. Dent JA, Vergnaud S, Piachaud J. HIV infection and people with learning disabilities. *Lancet* 1994;**343**:919.  
[PubMed abstract (PM:7908380): <http://www.ncbi.nlm.nih.gov/pubmed/7908380>]
11. Emerson E. Prevalence of psychiatric disorders in children and adolescents with and without intellectual disability. *J Intellect Disabil Res* 2003;**47**:51-8.  
[PubMed abstract (PM:12558695): <http://www.ncbi.nlm.nih.gov/pubmed/12558695>]
12. Henny MJ, van Schroyen Lantman-de Valk. Health in people with intellectual disabilities: current knowledge and gaps in knowledge. *Journal of Applied Research in Intellectual Disabilities* 2005;**18**:325-33.  
[publisher abstract: <http://www3.interscience.wiley.com/journal/118711054/abstract>]
13. Holland AJ. Ageing and learning disability. *Br J Psychiatry* 2000;**176**:26-31.  
[PubMed abstract (PM:10789322): <http://www.ncbi.nlm.nih.gov/pubmed/10789322>]
14. Hollins S, Attard MT, von FN *et al*. Mortality in people with learning disability: risks, causes, and death certification findings in London. *Dev Med Child Neurol* 1998;**40**:50-6.  
[PubMed abstract (PM:9459217): <http://www.ncbi.nlm.nih.gov/pubmed/9459217>]
15. Howells G. Are the medical needs of mentally handicapped adults being met? *J R Coll Gen Pract* 1986;**36**:449-53.  
[PubMed abstract (PM:2964527): <http://www.ncbi.nlm.nih.gov/pubmed/2964527>]
16. Jansen DE, Krol B, Groothoff JW *et al*. People with intellectual disability and their health problems: a review of comparative studies. *J Intellect Disabil Res* 2004;**48**:93-102.  
[PubMed abstract (PM:14723652): <http://www.ncbi.nlm.nih.gov/pubmed/14723652>]

17. Kerr MP, Richards D, Glover G. Primary care for people with an intellectual disability: a group practice survey. *Journal of Applied Research in Intellectual Disabilities* 1996;**9**:347-52.  
[Web of Science abstract (ISI: A1996WG22700005):  
<http://apps.isiknowledge.com/InboundService.do?Func=Frame&product=WOS&action=retrieve&SrcApp=RefMan&UT=A1996WG22700005&SID=Z2l4Be1ej5oCBiOmm8l&Init=Yes&SrcAuth=ResearchSoft&mode=FullRecord&customersID=ResearchSoft&DestFai=http%3A%2F%2Fwww.isinet.com%2Fisi%2Fproducts%2Fesource%2Fservice.html>]
18. Martin DM, Roy A, Wells MB. Health gain through health checks: improving access to primary health care for people with intellectual disability. *J Intellect Disabil Res* 1997;**41 ( Pt 5)**:401-8.  
[PubMed abstract (PM:9373820): <http://www.ncbi.nlm.nih.gov/pubmed/9373820>]
19. McCulloch DL, Sludden PA, McKeown K *et al*. Vision care requirements among intellectually disabled adults: a residence-based pilot study. *J Intellect Disabil Res* 1996;**40 ( Pt 2)**:140-50.  
[PubMed abstract (PM:8731471): <http://www.ncbi.nlm.nih.gov/pubmed/8731471>]
20. Morgan CL, Ahmed Z, Kerr MP. Health care provision for people with a learning disability. Record-linkage study of epidemiology and factors contributing to hospital care uptake. *Br J Psychiatry* 2000;**176**:37-41.  
[PubMed abstract (PM:10789324): <http://www.ncbi.nlm.nih.gov/pubmed/10789324>]
21. Bond L, Kerr M, Dunstan F *et al*. Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes. *J Intellect Disabil Res* 1997;**41 ( Pt 5)**:391-400.  
[PubMed abstract (PM:9373819): <http://www.ncbi.nlm.nih.gov/pubmed/9373819>]
22. Broughton S, Thomson K. Women with learning disabilities: risk behaviours and experiences of the cervical smear test. *J Adv Nurs* 2000;**32**:905-12.  
[PubMed abstract (PM:11095229): <http://www.ncbi.nlm.nih.gov/pubmed/11095229>]
23. Howells G. Are the medical needs of mentally handicapped adults being met? *J R Coll Gen Pract* 1986;**36**:449-53.  
[PubMed abstract (PM:2964527): <http://www.ncbi.nlm.nih.gov/pubmed/2964527>]
24. Jones RG, Kerr MP. A randomized control trial of an opportunistic health screening tool in primary care for people with intellectual disability. *J Intellect Disabil Res* 1997;**41 ( Pt 5)**:409-15.  
[PubMed abstract (PM:9373821): <http://www.ncbi.nlm.nih.gov/pubmed/9373821>]
25. Pearson V, Davis C, Ruoff C *et al*. Only one quarter of women with learning disability in Exeter have cervical screening. *BMJ* 1998;**316**:1979.  
[PubMed abstract (PM:9641948): <http://www.ncbi.nlm.nih.gov/pubmed/9641948>]
26. Stein K. Caring for people with learning disability: a survey of general practitioners' attitudes in Southampton and South-west Hampshire. *British Journal of Learning Disabilities* 2008;**28**:9-15.  
[Publisher abstract: <http://www3.interscience.wiley.com/journal/120191496/abstract>]
27. Tiller S, Wilson KI, Gallagher JE. Oral health status and dental service use of adults with learning disabilities living in residential institutions and in the community. *Community Dent Health* 2001;**18**:167-71.  
[PubMed abstract (PM:11580093): <http://www.ncbi.nlm.nih.gov/pubmed/11580093>]
28. Whitfield M, Langan J, Russell O. Assessing general practitioners' care of adult patients with learning disability: case-control study. *Qual Health Care* 1996;**5**:31-5.  
[PubMed abstract (PM:10157270): <http://www.ncbi.nlm.nih.gov/pubmed/10157270>]
29. Alborz, A., McNally, R., Swallow, A., and Glendinning, C. *Op. Cit.* [abstract & link to full-text:  
<http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=154801&tabID=289>]  
[full-text pdf: <http://www.sdo.lshtm.ac.uk/files/project/23-final-report.pdf>]
30. Costello H, Bouras N, Davis H. The role of training in improving community care staff awareness of mental health problems in people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities* 2008;**20**:228-35.  
[Publisher abstract: <http://www3.interscience.wiley.com/journal/118490149/abstract>]

31. Melville CA, Finlayson J, Cooper SA *et al.* Enhancing primary health care services for adults with intellectual disabilities. *J Intellect Disabil Res* 2005;**49**:190-8.  
[PubMed abstract (PM:15713194): <http://www.ncbi.nlm.nih.gov/pubmed/15713194>]
32. Pointu A, Cole C. An education programme for social care staff: improving the health of people who have a learning disability and epilepsy. *British Journal of Learning Disabilities* 2008;**33**:39-43.  
[Publisher abstract: <http://www3.interscience.wiley.com/journal/118666784/abstract>]
33. Wilson DN, Haire A. Health care screening for people with mental handicap living in the community. *BMJ* 1990;**301**:1379-81.  
[PubMed abstract (PM:2148703): <http://www.ncbi.nlm.nih.gov/pubmed/2148703>]
34. Carvill S. *Op. Cit.* [PubMed abstract (PM:11737534):  
<http://www.ncbi.nlm.nih.gov/pubmed/11737534>]
35. Warburg M. Visual impairment in adult people with intellectual disability: literature review. *J Intellect Disabil Res* 2001;**45**:424-38.  
[PubMed abstract (PM:11679048): <http://www.ncbi.nlm.nih.gov/pubmed/11679048>]
36. Hatton, C. Key highlights of research evidence on the health of people with learning disabilities. 2008. London, Valuing People Support Team. 3-7-2008.  
Ref Type: Report  
[abstract & link to full-text:  
<http://www.library.nhs.uk/learningdisabilities/viewResource.aspx?resid=29713&code=afec67537cf19e8835b209846e9b89c4>]  
[link to full-text pdf:  
<http://valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=657>]
37. Basic medical surveillance for people with Down's Syndrome. Ophthalmic problems. 2006. Down's Syndrome Medical Interest Group. 3-7-2008.  
[abstract & link to full-text:  
<http://www.library.nhs.uk/Eyes/ViewResource.aspx?resID=30290&tabID=288>]  
[link to full-text pdf: <http://www.dsmig.org.uk/library/articles/guideline-vision-5.pdf>]
38. Health guidelines for adults with an intellectual disability. Sensory impairment. 2002. IASSID. 3-7-2008.  
[full-text pdf - scroll to section 2.2: <http://www.iassid.org/pdf/healthguidelines-2002.pdf>]
39. [IASSID guidelines on] visual impairment. 2002. IASSID.  
[full-text pdf: <http://www.iassid.org/pdf/visual-imp.PDF>]
40. Code of ethics and guidelines for professional conduct. 24. Examining the adult patient with learning disabilities. 2008. London, College of Optometrists. 3-7-2008.  
[abstract and link to full-text]  
<http://www.library.nhs.uk/Eyes/ViewResource.aspx?resID=95484&tabID=288>  
[link to full-text pdf: [http://www.college-optometrists.org/coo/download.cfm?uuid=6B61ED87-5633-B1D9-EABB112A3082F4A1&type=ethics\\_guidelines](http://www.college-optometrists.org/coo/download.cfm?uuid=6B61ED87-5633-B1D9-EABB112A3082F4A1&type=ethics_guidelines)]
41. Look Up. 2008. 3-7-2008.  
[list of factsheets & links to full-text:  
<http://www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=279261&tabID=292>]  
[organisation's homepage: <http://www.lookupinfo.org/index.php?id=home>]