SCIE RESEARCH BRIEFING

ACCESS TO PRIMARY CARE SERVICES FOR PEOPLE WITH LEARNING DISABILITIES

Definition of a briefing: A SCIE research briefing is a summary of information on a particular topic to update practice at the health and social care interface. It is a concise document summarising the knowledge base in a particular area to act as a 'launch pad' or signpost to more in-depth material. It is produced through a clear methodology involving identification of a focused question, comprehensive searching of multiple sources and filtering of materials for quality.

What is the issue?	Defining 'learning disability' is a complex and contentious issue. Recent policy defines learning disability as "*a significantly reduced ability to understand new or complex information, to learn new skills with a reduced ability to cope independently which started before adulthood, with a lasting effect on development*" ([1]). However, this may not resonate with learning disabled people's self-definition or that of their families. People with learning disabilities (PLD) experience higher rates of ill health ([2], [3], 4) and have more complex health needs ([5], [6], [7]) than the general population, including epilepsy, dental problems ([8]), mental health and behavioural disorders and nutritional disorders (9). In addition to these difficulties, PLD have problems in accessing primary health care ([10]). Access is made more difficult because of communication difficulties and barriers in encounters between health professionals and PLD and practical issues such as long waiting times (11) and lack of consultation time ([12]). This can result in a failure to access primary health services such as men's and women's health screening, cervical screening (13, [14]), genetic screening, dental checks and treatment ([15], [16]) and health promotion ([17], 18). Basic health problems may be unidentified ([5]) or regarded merely as part of the learning disability rather than a medical problem ([19]).
Why is it important?	It is vital to tackle discrimination and inequality of access for people with learning disabilities so that this population has comparable access to health initiatives and services (including GPs, dentists, opticians and chiropodists) used by non-disabled people ([1]). Experts suggest that health and social care professionals need to be aware of social inequalities, risk, potential for abuse, vulnerability and the unique challenges experienced by PLD through the course of life, and harness the expertise of carers and support networks to increase access to services ([1]). Practitioners

	should work in partnership with PLD and their carers to translate the strategic statements in the Department of Health documents "*Valuing People*" (1) and the "*NHS Plan*" (20) into reliable, predictable and practical services, support and information. PLD still living in long-term care have particular difficulties in accessing primary health services such as immunisation (9).
What are the ethical considerations?	The ability of a PLD to give informed consent to services or treatment depends on them being given full (21) and relevant (22) information. This may not be easy in some decisions, such as whether to take HRT (23), contraception (3) or have screening (24, 25) or genetic testing (26). Guidance on consent has been provided by the Department of Health at http://www.dh.gov.uk/assetRoot/04/01/90/61/04019061.pdf and by the Lord Chancellor's Department at http://www.lcd.gov.uk/family/mi/mibooklets/guide2.pdf It is important that health professionals speak directly to the PLD in language they understand rather than by default or through a carer. The use of advocates, such as specialist nurses (27) and specialist GPs may be beneficial (7, 28, 29). Communication difficulties can be alleviated by the use of training programmes for health professionals and appropriate use of communication aids (30).
What are the views of users and user groups?	A number of studies have sought the views of PLD on women's knowledge of health issues (31), accessing health services with decision-making and consent (32), how they were dealt with by the primary care team (2), health screening and the attitudes of GPs (33) and access, health needs and how these were met and quality of care (5). However, there can be ethical problems in eliciting the views of PLD particularly when communication takes place via carers (5). Carers and families present a vital link between PLD and healthcare facilities (5), give support and information (23) and have the expertise about the person concerned. However, some PLD report feeling that opportunities for independence can be limited (2). Carers may miss health problems (34) or not recognise the importance of screening (9). Common responses from PLD were that health professionals were helpful (5) and users had liked seeing them (33), but concerns were expressed about waiting times (5), anxiety whilst waiting (2, 33), the attitudes of health professionals (2, 5, 32), transport and surgery access problems (2, 5, 33), a lack of understandable information (2) and addressing carers instead of users (5, 32). Consultation with a user group in Sheffield found that users also wanted to be given more time during consultations, have the opportunity to ask questions and take information about the consultation home with them, available in different formats (written, visual, taped). Users also found the service provided by NHS Direct helpful.
What do I need to do?	Read the following Department of Health documents: • "*Once a Day: one or more people with learning disabilities are likely to be in contact with your primary healthcare team. How can you help them?*" at http://www.dh.gov.uk/assetRoot/04/04/27/79/04042779.pdf • "*The Healthy Way: How to Stay Healthy – a guide for people with learning disabilities.*" This booklet details the responses of 500 PLD on healthcare issues. Details available at: http://craw104.archive.org/ukgov/20040216083935/ http://www.doh.gov.uk/learningdisabilities/publications.htm Read:

	• "Learning Disability Today: Key issues for providers, managers, practitioners and users" (Chapter 12 – *Accessing health care: Being seen to be healthy!*). See CareData abstract at: http://195.195.162.66/dbtw-wpd/exec/dbtwpcgi.exe • Be aware of the health needs of PLD and the issues of choice and control (consent). Use this knowledge to contribute towards increasing access to healthcare and health promotion in your work. See: http://crawl04.archive.org/ukgov/20040216083935/ http://www.doh.gov.uk/learningdisabilities/hap_booklet.pdf • Be aware of Health Action Plans and the role of the health facilitator. See sections 6.12 to 6.18 of "*Valuing People*" at http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf
What are the implications?	Research in this area focuses on the involvement of specialist health care staff, particularly the community learning disability nurse (2, 9, 22, 30, 34), multidisciplinary working (11, 13, 22, 35), the need for regular screening programmes/health checks (9, 13, 29) and medication reviews (36) that are acted upon, and more support/recognition for the carers' of PLD (11, 12). There is also a need for more and better information (12, 22), better appointment systems to reduce waiting times and communication skills development (32) across all staff in primary care. Professionals, such as GPs and practice nurses need specialist skills training (particularly communication) in this field (15, 18). "*Valuing People*" (1) details specific targets and deadlines in relation to PLD to increase health care access and reduce inequalities. Further research is needed to identify the long-term clinical effectiveness of health checks for PLD (19) and the experiences of PLD themselves in accessing primary health services (37) such as walk-in centres and NHS Direct.
Who can I contact?	• Valuing People Support Team within the Department of Health at http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ LearningDisabilities/ValuingPeopleSupportTeam/fs/en • Learning Disability Task Force within the Department of Health at http://crawl04.archive.org/ukgov/20040216041858/ http://www.doh.gov.uk/learningdisabilities/taskforce.htm • National Forum for people with learning disabilities at http://www.valuingpeople.org.uk/ • The Home Farm Trust at http://www.hft.org.uk/ • The Foundation for People with Learning Disabilities at http://www.learningdisabilities.org.uk/
Where can I find examples of innovative practice?	• Strathmartine Hospital in Dundee where a team of community-based nurses covers all aspects of healthcare for PLDs. • The Wednesday Clinic in Dundee provides an access point to health services for women with learning disabilities. • In the North West, five regional networks have been established to share information and best practice, develop care pathways, solve problems and encourage the involvement of service users and carers. • St Georges' Hospital Medical School employs a number of PLD as training advisors and to teach medical students about treating PLD. See: http://www.sghms.ac.uk/depts/psychdis/advocacy/introduction.htm • Learning Disabilities Health Promotion Working Group of Glasgow held a "Healthy Day". See:

	http://www.glasgow.gov.uk/healthycities/impaired/events/ld_event_yl.htm • Learning Disabilities Health and Social Care Partnership of Devon County Council provide a website for PLD giving comprehensive details of services. See: http://www.devon.gov.uk/socserve/csd/learndis.shtml • Barnet PCT and the Institute for Applied Health and Social Policy held an event on 25th March 2003 called 'Learning from People - Getting It Right'. The day brought together people to share good practice in supporting people with learning disabilities who access and use hospital services. See: http://crawl04.archive.org/ukgov/20040216090407/ http://www.doh.gov.uk/vpst/health.htm#events • NHS Cancer Screening Programme has produced leaflets and picture books specifically for people with learning disabilities. See: http://www.cancerscreening.nhs.uk/breastscreen/news/006.html
Resource sites	• See the Valuing People Support Team website for resources linked to "Valuing People" at http://www.valuingpeople.gov.uk/papers.htm • The Learning Disabilities pages in the Department of Health website has a list of other sites of interest at http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/ LearningDisabilities/LearningDisabilityPublications/fs/ en?CONTENT_ID=4001805&chk=xpYmSv • See the Appendix to "Once a Day" for details of publications and useful names and addresses at http://www.dh.gov.uk/assetRoot/04/04/27/79/04042779.pdf • MENCAP Understanding Learning Disability at http://www.mencap.org.uk/ • See the National electronic Library for Learning Disabilities (NeLLD), part of the National electronic Library for Health, at http://www.minervation.com/ld/ • Search CareData freely available via the Electronic Library for Social Care • Connects: the Mental Health and Learning Disabilities portal at http://www.connects.org.uk/index.cfm?js=1&dom=1
Comments	Please address all comments, suggestions or ideas for improvement to the ScHARR Library at scharrlib@shef.ac.uk
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REFERENCES

(1) Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21ˢᵗ Century.* London, Department of Health. Available at: http://www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf

> Central government policy document covering England only.

(2) Martin D.M. Roy A. Wells M.B. Lewis J. (1997) Health gain through screening – users' and carers' perspectives of health care: Developing primary health care services for people with an intellectual disability. *Journal of Intellectual & Developmental Disability* **22**(4): 241-249. Abstract available from: http://195.195.162.66/dbtw-wpd/exec/dbtwpcgi.exe

> Research involved the following consultative strategies: a forum of 60 people, a questionnaire to carers which had 104 responses, service users' focus groups involving 31 PLD, interviews with 53 PLD following a health check and a carers' focus group of 7 people. The aim was to identify the experiences, expectations and opinions of PLD using primary health care services.

(3) Turner S. Moss S. (1996) The health needs of adults with learning disabilities and the Health of the Nation strategy. *Journal of Intellectual Disability Research* **40**(5): 438-450. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=8906531&dopt=Abstract

> A review of mortality and morbidity for people with learning disabilities within the context of the five *Health of the Nation* Key Areas.

(4) While A. (2001) Learning disability and equity of access. British Journal of *Community Nursing* **6**(2): 94.

> Editorial comment.

(5) Lennox T.N. Nadkarni J. Moffat P. Robertson C. (2003) Access to services and meeting the needs of people with learning disabilities [Abstract]. *Journal of Learning Disabilities* **7**(1): 34-50. Available at: http://www.ingenta.com/isis/searching/ExpandTOC/ingenta;jsessionid=413frt7r33bmu?issue=infobike://sage/jld/2003/00000007/00000001&index=4

> Research involved an interview-based survey, consisting of quantitative and qualitative questions, being administered to 49 PLD concerning service access, health needs, meeting needs and quality of care.

(6) Coyle D. Northway R. (1999) Promoting health: the challenge for the community learning disability nurse. *Mental Health Care* **2**(7): 232-235. Abstract available at: http://www.blackwell-synergy.com/links/doi/10.1046/j.1365-2702.2003.00697.x/full/

> An overview of how access to primary health care services for PLD can be improved.

(7) Curtis J. Taylor B. Bartlett E et al (1999) Pharmacist support for people with learning disabilities. *The Pharmaceutical Journal* **263**(7072): 826-831. Available at: http://www.pharmj.com/cgi-bin/htm_hl?DB=editorial&STEMMER=en&WORDS=pharmacist+support+peopl+learn+dis

abl+&COLOUR=Red&STYLE=s&URL=http://www.pharmj.com/Editorial/19991120/article
s/learningdisabilities.html

> A briefing paper to enable pharmacists to provide support to PLD, their relatives and carers.

(8) Gordon S.M. Dionne R.A. Snyder J. (1998) Dental fear and anxiety as a barrier to accessing oral health care among patients with special health care needs. *Special Care in Dentistry* **18**(2): 88-92. Abstract available at:
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9680
917&dopt=Abstract

> A questionnaire survey of people with special health care needs on dental fear and anxiety: there were 536 responses.

(9) Paxton D. Taylor S. (1998) Access to Primary Health Care for Adults with a Learning Disability. *Health Bulletin* **56**(3): 686-693.

> Research involved the completion of health assessment screening forms (by researchers) and interviews of 71 PLD to enable a system to be set up for accessing primary health services.

(10) World Health Organisation (2004). *Primary health care and community health.* Available at: http://www.euro.who.int/healthtopics#PRIMARY

> WHO definition of primary care.

(11) Large J. Jenkins L. (1999) Don't overlook a special group of patients. *Practice Nurse* **17**(3): 178-181.

> Research involved the health screening (with measurable outcomes) of 11 PLD.

(12) Hogg J. (2001) Essential healthcare for people with learning disabilities: barriers and opportunities. *Journal of the Royal Society of Medicine* **94**: 333-336. Abstract available at:
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=retrieve&db=pubmed&list_uids=11418
702&dopt=Abstract

> An overview healthcare for PLD, concentrating on the quality of primary health services, education and information.

(13) Nightingale C. (2000) Barriers to health access: a study of cervical screening for women with learning disabilities. *Clinical Psychology Forum* **137**: 26-30

> Research involved a qualitative study with staff from 62 general practices about attitudes to females with LD and cervical screening.

(14) Whitfield M. Langan J. Russell O. (1996) Assessing general practitioners' care of adult patients with learning disability: case-control study. *Quality in Health Care* **5**: 31-35. Abstract available at:
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1015
7270&dopt=Abstract

> Research involved a case-control study with 78 adult patients and 78 controls with a structured interview study of 62 general practitioners.

(15) Allison P.J. Hennequin M. Faulks D. (2000) Dental care access among individuals with Down syndrome in France. *Special Care in Dentistry* **20**(1): 28-34. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=11203873&dopt=Abstract

Research involved a cross-sectional survey of parents of individuals with Down's Syndrome (DS) and whether there were differences in treatment between the DS individuals and other siblings: 204 questionnaires were returned.

(16) Pratelli P. Gelbier S. (1998) Dental services for adults with a learning disability: care managers' experiences and opinions. *Community Dental Health* **15**(4): 281-285. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9973731&dopt=Abstract

Descriptive survey collecting qualitative and quantitative data by semi-structured interviews with 75 managers of 80 long term homes for people with learning disabilities.

(17) Sutton J.P. DeJong G. (1998) Managed Care and People With Disabilities: Framing the Issues. *Archives of Physical Medicine and Rehabilitation* **79**: 1312-1316. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9779692&dopt=Abstract

An overview of access to health care for people with disabilities in the US.

(18) Parrish A. (1998) Community care for people with a learning disability. *British Journal of Community Nursing* **3**(7): 352-355.

An overview of service access for PLD and the role of specialist nurses.

(19) Martin D.M. (1999) A Comparative Review of Primary Health Care Models for People With Learning Disabilities: Towards the Provision of Seamless Health Care. *British Journal of Learning Disabilities* **27**: 58-63. Abstract available at: http://www.bl.uk/services/information/welfare/issue6/mhsuk.html

A comparison of a number of primary care health check models for PLD.

(20) Department of Health (2000) *The NHS Plan.* London, Department of Health. Available at: http://www.dh.gov.uk/assetRoot/04/05/57/83/04055783.pdf

Central government policy document.

(21) Parrish A. Markwick A. (1998) Equity and access to health care for women with learning disabilities. *British Journal of Nursing* **7**(2): 92-96. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9510684&dopt=Abstract

An assessment of the main issues relating to health care access for women with LD.

(22) Broughton S. (2002) A review of the literature: interventions to maximise capacity to consent and reduce anxiety of women with learning disabilities preparing for a cervical smear test. *Health Services Management Research* **15**(3): 173-185. Abstract available at:

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=1218
4837&dopt=Abstract

   Literature review.

(23) McCarthy M. (2002) Responses to Women with Learning Disabilities as they go
Through the Menopause. *Tizard Learning Disability Review* **7**(1): 4-12. Abstract available
at:
http://dandini.cranfield.ac.uk/vl=7046869/cl=42/nw=1/rpsv/catchword/pavpub/13595474/v7n
1/s2/p4

   Research involved analysis of questionnaires sent to: GPs (73 returned), day and
   residential services staff (66 returned) and family carers (15 returned) and semi-structured
   interviews with 30 women with LD on experiences of the menopause amongst women
   with LD and the available support.

(24) Davies N. Duff M. (2001) Breast cancer screening for older women with intellectual
disability living in community group homes. *Journal of Intellectual Disability Research*
45(3): 253-257.

   A postal survey of women aged ≥ 50 years with intellectual disability living in
   community group homes.

(25) Wells M. Turner S. Martin D. Roy A. (1997) Health gain through screening – coronary
heart disease and stroke: developing primary care services for people with intellectual
disability. *Journal of Intellectual Disability Research*, **22**(4): 252-263.

   Report of the findings of health checks of 120 people with intellectual disability.

(26) Department of Health (2003) *Our Inheritance, our future – realising the potential of
genetics in the NHS*. London, Department of Health. Available at:
http://www.dh.gov.uk/assetRoot/04/01/92/39/04019239.pdf

   White Paper produced by the Department of Health

(27) McCray J. Carter S. (1999) Access unrestricted. *Nursing Times* **95**(23): 47-49.

   A review of how primary care staff can give PLD full access to health care services.

(28) Beange H. (1996) Caring for a vulnerable population. *Medical Journal of Australia* **164**:
159-160. Available at: http://www.mja.com.au/public/issues/feb5/beange/beange.html

   An assessment of the services available to PLD in Australia.

(29) Kenny C. (1999) The gentle touch. *Nursing Times* **95**(24): 36-37.

   Four brief case studies about the work of learning disability nurses.

(30) Dodd K. Brunker J. (1999) 'Feeling Poorly': Report of a Pilot Study Aimed to Increase
the Ability of People with Learning Disabilities to Understand and Communicate About
Physical Illness. *British Journal of Learning Disabilities* **27**: 10-15.

   Research involved a pilot study with questionnaires of 10 PLD to test the effectiveness of
   communication aids.

(31) McCrae D. (1997) Health care for women with learning disabilities. *Nursing Times* **93**(15): 58-59.

> Research involved administering a questionnaire to 24 women with LD about their knowledge and use of a number of health care services.

(32) Joseph Rowntree Foundation (1999) *Adults with learning difficulties' involvement in health care decision-making.* Findings October 1999 – Ref 029. Available at: http://www.jrf.org.uk/knowledge/findings/socialcare/029.asp

> A summary of the report *"Best practice? Health care decision-making by, with and for adults with learning disabilities"*

(33) Martin D.M. Roy A. Wells M.B. (1997) Health gain through health checks: improving access to primary health care for people with intellectual disability. *Journal of Intellectual Disability Research* **41**(5): 401-408. Abstract available from: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9373820&dopt=Abstract

> Research involved an assessment of a forum discussion involving 60 people, a questionnaire to carers (104 responses), service users' focus groups (36 people), interviews with PLD following a health check (52 people) and a questionnaire on physical activity to 110 participants and 46 people from the general population. The aim was to identify PLD in need of health care services and encourage GP's to offer comprehensive health checks.

(34) Thornton C. (1999) Effective health care for people with learning disabilities: a formal carers' perspective. *Journal of Psychiatric & Mental Health Nursing* **6**(5): 383-390.

> Research involved a qualitative approach and the use of descriptive analysis of 6 focus group and 11 one-to-one interviews of health care professionals and carers about the perceptions and experiences of accessing primary health care for PLD.

(35) Bond L. Kerr M. Dunstan F. Thapar A. (1997) Attitudes of general practitioners towards health care for people with intellectual disability and the factors underlying these attitudes. *Journal of Intellectual Disability Research* **41**(5): 391-400. Abstract available at: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=9373819&dopt=Abstract

> Research involved a questionnaire about intellectual disability attitudes being sent to GPs in two areas: there were a total of 257 responses.

(36) Chambers R. Milsom G. Evans N. Lucking A. Campbell I. (1998) The Primary Care Workload and Prescribing Costs Associated with Patients with Learning Disability Discharged from Long-stay Care to the Community. *British Journal of Learning Disabilities* **26**: 9-12.

> Study with a control group of 136 patients with a learning disability at 21 practices of workloads, health checks and medication reviews.

(37) Bollard M. (1997) Promoting the health care needs of people with learning disabilities. *British Journal of Community Health Nursing* **2**(1): 46-50.

Research involved a postal survey of GP's of healthcare issues for PLDs: 25 replies were received.