

Care of People with Learning Disabilities

One in a series of curriculum statements produced by
the Royal College of General Practitioners:

- 1 Being a General Practitioner
- 2 The General Practice Consultation
- 3 Personal and Professional Responsibilities
 - 3.1 Clinical Governance
 - 3.2 Patient Safety
 - 3.3 Clinical Ethics and Values-Based Practice
 - 3.4 Promoting Equality and Valuing Diversity
 - 3.5 Evidence-Based Practice
 - 3.6 Research and Academic Activity
 - 3.7 Teaching, Mentoring and Clinical Supervision
- 4 Management
 - 4.1 Management in Primary Care
 - 4.2 Information Management and Technology
- 5 Healthy People: promoting health and preventing disease
- 6 Genetics in Primary Care
- 7 Care of Acutely Ill People
- 8 Care of Children and Young People
- 9 Care of Older Adults
- 10 Gender-Specific Health Issues
 - 10.1 Women's Health
 - 10.2 Men's Health
- 11 Sexual Health
- 12 Care of People with Cancer & Palliative Care
- 13 Care of People with Mental Health Problems
- 14 Care of People with Learning Disabilities
- 15 Clinical Management
 - 15.1 Cardiovascular Problems
 - 15.2 Digestive Problems
 - 15.3 Drug and Alcohol Problems
 - 15.4 ENT and Facial Problems
 - 15.5 Eye Problems
 - 15.6 Metabolic Problems
 - 15.7 Neurological Problems
 - 15.8 Respiratory Problems
 - 15.9 Rheumatology and Conditions of the Musculoskeletal System (including Trauma)
 - 15.10 Skin Problems

Royal College of General Practitioners
1 Bow Churhyard | London | EC4M 9DQ
Phone: 020 3188 7400 | Fax: 020 3188 7400

CONTENTS

[Acknowledgements]	3
Key messages	3
[Introduction]	4
Rationale for this curriculum statement	4
UK health priorities	5
[Learning Outcomes]	6
Primary care management	7
Person-centred care	7
Specific problem-solving skills	7
A comprehensive approach	8
Community orientation	7
A holistic approach	8
Contextual aspects	8
Attitudinal aspects	9
Scientific aspects	9
Psychomotor skills	7
The knowledge base	8
[Teaching and Learning Resources]	9
Examples of relevant texts and resources	9
Web resources	9
[Promoting Learning about the Care of People with Learning Disabilities]	10
Work-based learning – in primary care	10
Work-based learning – in secondary care	10
Non-work-based learning	10
Learning with other healthcare professionals	10
[Appendix 1]	11
Diagnostic overshadowing	11
[Appendix 2 Meeting health needs in primary care]	15
Meeting health needs in primary care	12
[References]	13

ACKNOWLEDGEMENTS

This curriculum statement is based on the work of the Royal College of General Practitioner's Mental Health Task Group.

The Royal College of General Practitioners would like to express its thanks to the Group and to these individuals for their contributions.

Authors:	Dr Graham Martin & Dr Mike Deighan
Contributors:	Professor Andre Tylee, Dr Chris Drinkwater, Dr Chris Manning, Dr Claire Chappell, Dr Clare Gerada, Dr David Shiers, Dr David Smart, Dr Gabriel Ivbijaro, Dr Graham Archard, Dr Huw Lloyd, Dr Helen Lester, Dr Barbara Nagy, Dr Pat Wood, Dr Richard Byng, Professor Steve Field, Dr Stephen Kelly, Dr Amar Rughani, John Shaw, the RCGP Learning Disabilities Group, the RCGP Mental Health Task Group, RCGP Northern Ireland Council
Editors:	Dr Mike Deighan, Dr Amar Rughani, Professor Steve Field
Guardian:	Dr Peter Lindsay
Created:	December 2004
Date of this update:	February 2009 June 2011
Version number:	1.2
Previous versions:	1.0 issued January 2006, corrected and re-issued February 2007 1.1 issued February 2009

Key messages

In managing patients with learning (intellectual) disabilities, general practitioners should:

- Be aware of likely associated conditions and knowing where to obtain specialist help and advice
- Understand how psychiatric and physical illness may present atypically in patients with learning disabilities who have sensory, communication and cognitive difficulties
- Use additional skills of diagnosis and examination in patients unable to describe or verbalise symptoms.

INTRODUCTION

Rationale for this curriculum statement

~~Due to normalisation¹ the large mental handicap hospitals are now empty and all people with learning disabilities now have a general practitioner (GP). There are over 200,000 patients with moderate, severe or profound learning disabilities, (intellectual disabilities), living with their families, in residential care homes or in supported living.² These patients will have been identified before age 18 and will have an IQ estimated at less than 70. The condition is life long, and may be defined^{3,4} as 'significantly reduced ability to understand new and complex information, to learn new skills (impaired intelligence) with a reduced ability to cope independently (impaired social functioning), starting before adulthood with a lasting effect on development'. Often there are associated co-morbidities, in particular epilepsy, mental illness and behavioural disorders.~~

Table 1: Prevalence – a list of the commoner conditions

<i>Diagnosis</i>	<i>Possible number of patients on GP list of 2000</i>
Down's syndrome	2
Fragile X syndrome	1
Cerebral palsy	1
Autistic spectrum disorder	1
Miscellaneous conditions	3

~~These figures represent the number of patients that will have an intellectual disabilities condition in an 'average' list – however, it fails to represent the impact that this has on GP workload and social services:~~

- ~~• Patients with learning disabilities have 2.5 times as many associated medical problems as non-learning disabled control patients⁵~~
- ~~• The number of repeat prescription drugs prescribed by primary care are about three times those for non-learning disabled control patients~~
- ~~• Learning disability is a major economic burden on the NHS, the local authority social services and on the social security system⁶~~

~~—Patients with learning disabilities have an increased incidence of psychiatric illness, epilepsy and behavioural difficulties. About 30% have epilepsy, and perceptual problems are very common as over 30% have visual problems and over 30% have hearing problems.~~

~~—A large proportion of those with Down's syndrome develop dementia and some become hypothyroid. Continence and ambulation problems are extremely common. Many are unable to take responsibility for their own health or read instructions, and are dependent on a range of family and paid carers, because of their limited intellectual capacity.~~

~~—Morbidity and mortality rates are considerably increased and life expectancy significantly reduced.⁷ It is believed that these adverse findings could be significantly reduced by better training of clinicians, better communications and increased continuity of care.~~

~~—Many authorities believe that these patients with significant clinical conditions would benefit from being identified from a learning disability register so that they may be offered regular structured health reviews,⁸ with implementation of the resulting health action plan. As psychiatric illness is common and difficult to identify, the Psychiatric Assessment Schedule for Adults with Development Disability (PAS ADD) questionnaire⁹ or similar validated tool, may also be useful.~~

UK health priorities

~~Valuing People,² the first government white paper for people with learning disabilities for 30 years, sets out the government strategies including health. There are perceived health inequalities for this vulnerable group. Access to primary care is one issue highlighted by Mencap's Campaign *Treat me Right*¹⁰ and the Disability Rights Commission Formal Investigation.¹¹~~

~~The closure of the large mental handicap hospitals has led to relocation of patients, some nursing staff and consultants into the community. Primary care is now regarded as the main service provider for all patients with learning disabilities with support from the specialist community learning disabilities teams, which usually include consultant psychiatrists and nurses.~~

~~Valuing People set the following targets for patients with learning disabilities (PWLD):~~

- ~~• Health facilitators will be appointed from each local community team to support PWLD in getting the health care they need~~
- ~~• All PWLD will be registered with a GP by 2004~~
- ~~• All PWLD will have a Health Action Plan by June 2005.~~

~~The intention is that GPs can identify their PWLD to offer additional services, for example health reviews/action plans that may include medication review, flu vaccination, and checks of sight and hearing.~~

~~A comprehensive list of achievable targets for health checks for people with learning disabilities is described by Beange *et al.*;¹² minimum annual checks required to be offered to those in residential care homes consist of 'sight and hearing, review of medication and any associated condition that is not the primary underlying condition'.¹³~~

~~The Mental Capacity Bill will formalise financial and welfare arrangements for those PWLD who lack the capacity to decide for themselves. Adults are usually assumed to have capacity to decide for themselves but when this is in doubt, as with PWLD, their capacity may need to be assessed before major medical and life decisions, for example about operations or change of residence, are taken.~~

~~In October 2004 the National Institute for Health and Clinical Excellence (NICE) published guidelines for the management of epilepsy in primary and secondary care.¹⁴ Separate guidance for patients with intellectual disabilities preceded these guidelines.¹⁵~~

~~This Curriculum statement has been updated in the light of Sir Jonathan Michaels *Health for All* which obliged undergraduate and postgraduate education to include details of the care of patients with intellectual disability and the entire National Health Service to make "special allowance" for the needs of patients with intellectually disability.~~

~~Up to the mid 1980's the majority of those adults with intellectual disability resided away from main-stream medicine in long stay hospitals. The increased health needs leading Prof Mike Kerr to describe his crises of care¹:~~

~~A difference in health because of:~~

- ~~• Increased mortality~~
- ~~• Increased morbidity~~
- ~~• Increase in negative determinants of health such as poverty~~

~~A difference in health care because of:~~

- ~~• Unequal access to services~~
- ~~• Inequality of services~~

The term “learning disability” is the description currently used in UK medicine and amongst those adults in the community affected by it, whereas professionals and academics are increasingly using the descriptive term “intellectual disability”, the two terms being essentially interchangeable.

The DOH 1998 definition is:

A significantly reduced ability to understand new or complex information, to learn new skills, with reduced ability to cope independently, starting before adulthood (age 18 years) with a lasting effect on development

Those affected have

- Impaired intelligence
- Impaired social functioning
- Difficulties with communication

Government policy and the law in this area will vary across the four UK Nations and this statement needs to be read in this light.

LEARNING OUTCOMES

The following learning objectives describe the knowledge, skills and attitudes that a GP requires when managing people with learning disabilities (also called intellectual disabilities).

This curriculum statement should be read in conjunction with the other RCGP curriculum statements in the series. The full range of generic competences is described in the *core* RCGP curriculum statement 1, *Being a General Practitioner*.

Primary care management

- Demonstrate an awareness that a significant minority of any practice population will include patients who have mild learning disabilities, who may need no particular special services, but who may have reading, writing and comprehension difficulties.
- Demonstrate an awareness that there will be a few with special needs accessing services with moderate, severe and profound learning disabilities who need to be identified, monitored and reviewed appropriately.
- Demonstrate an awareness of likely associated conditions, ~~and the knowledge of where to obtain specialist help and advice~~ the high mortality, the high morbidity and the difference in morbidity compared to the rest of the population.
- Demonstrate an understanding of supporting adolescents with intellectual disability as they become adults and no longer have the multidisciplinary support of community paediatricians.
- Demonstrate an ability to create and maintain a register of adults with intellectual disability in the practice and correlate this to the shared local PCT and social services registers.
- Demonstrate an ability to understand the importance of the annual health check to an adult with intellectual disability.
- Demonstrate an ability to manage and undertake annual health checks within the primary care team and arrange the necessary referrals and follow up of conditions detected by tailoring chronic disease management to the particular needs of this group of the practice population.
- Demonstrate their understanding of the role of the GP to ensure equal access to mainstream services ensuring those services make “reasonable adjustment” to the needs of patients with intellectual disability whenever that is needed.

Person-centred care

- Demonstrate an awareness of the particular importance of a person-centred approach when consulting, often with communications involving carers.
- ~~Demonstrate respect for the patient’s autonomy, which may be limited, and an awareness of how communicating via carers may skew the doctor–patient relationship.~~
- Demonstrate respect for the patient’s rights to make decisions about some aspects of their lives in accordance with the Mental Capacity Act 2005 in England and Wales, common law in Northern Ireland and relevant legislation in Scotland.
- Demonstrate an awareness of residential situations, and attendance at day centres and an awareness of how communicating via carers may affect the doctor–patient relationship.
- Demonstrate the ability to optimise communication through the use of consulting skills and communication aids.
- Demonstrate an understanding of the importance of continuity of care in this group.
- Demonstrate an awareness of the issues of capacity and consent, and the mechanisms by which these can be determined.

Specific problem-solving skills

- Describe how psychiatric and physical illness may present atypically in patients with learning disabilities who have sensory, communication and cognitive difficulties.
- Demonstrate an understanding of the need to use additional enquiry, appropriate tests and careful examination in patients unable to describe or verbalise symptoms.
- Demonstrate an appreciation of the significance and prevalence of oropharyngeal disorders and dysphagia in patients with intellectual disability.
- Demonstrate an awareness of the concept of diagnostic overshadowing. (see Appendix 1).

A comprehensive approach

- Describe the associated medical problems in commonly encountered conditions that make up learning disabilities, including Down's and fragile X syndromes, cerebral palsy and autistic spectrum disorder.
- Demonstrate an understanding of the psychiatric disorders prevalent in the adult with intellectual disability and how their diagnosis, detection and management differs particularly with regard to:
 - emotional and behavioural disorders
 - bereavement reactions
 - anxiety and depression
 - schizophrenia
 - bipolar affective disorder
 - Alzheimer's disease
 - autistic spectrum conditions
- Demonstrate an understanding of developmental disability and the disorders related to neurologically based disorders originating before birth and affecting the patient throughout life. In particular to understand the diagnosis and management of patients with autistic spectrum conditions.
- Demonstrate an understanding of how patients with borderline intelligence have difficulty coping with complex executive mental functions and how this can affect their behaviour.
- Demonstrate an understanding of how health promotion can be overlooked in the care of PWLD and the remedial steps, such as importance of tailoring health promotion that can be taken to the needs of this special group.
- Demonstrate an understanding of how adults with intellectual disability are subject to poly-pharmacy and how this can be made safer.

Comment [k1]: Text in green has been moved from the Knowledge Base section

Community orientation

- Demonstrate an awareness that the health needs of patients with learning disabilities are met appropriately by primary care and community services.
- Describe the roles of paid carers, respite care opportunities, voluntary and statutory agencies and an ability to work in partnership with them so there is cooperation without duplication.
- Demonstrate an appreciation of the risk to adults with intellectual disability of physical, sexual and emotional abuse.

A holistic approach

- Demonstrate a holistic approach to patients with learning disabilities, considering likely bio – psycho – social and cultural factors.
- Describe the impact of learning disabilities on family dynamics and the implications for physical, psychological and social morbidity in the patient's carers.

- Demonstrate an understanding that by the time the patient with intellectual disability has reached adulthood the parents have gone through a different series of transitions to other parents and subsequently may go through a bereavement process differing from those whose child without intellectual disability dies.

Contextual aspects

- Demonstrate an awareness of the need to provide more time in the consultation in order to deal more effectively with people with learning disabilities.
- Demonstrate an understanding of the impact of the doctor's working environment on the care provided to PWLD, e.g. the measures taken to compensate for sensory impairment.

Attitudinal aspects

- Demonstrate an understanding that all citizens should have equal rights to health, and equitable access to health and health information according to their needs.
- Demonstrate an understanding that integration is not simply a matter of healthcare professionals acquiring skills but rather of healthcare professionals showing commitment. Inclusion begins with commitment to the development of fully accessible services.⁴⁶²
- Demonstrate an understanding that PWLD are more prone to the effects of prejudice and unfair discrimination, and that doctors have a duty to recognise this within themselves, other individuals and within systems, and to take remedial action.
- Appreciate and be aware of your own feelings and attitudes to difficult decisions in the care of adults with intellectual disability.
- Appreciate the emotional and sexual needs of adults with intellectual disability and how they can be expressed.

Scientific aspects

- Demonstrate an awareness of the evidence regarding the health needs of people with learning disabilities (see Appendix 2).
- Demonstrate an understanding of the evidence regarding the effectiveness of routine health interventions including annual health checks.
- Demonstrate an understanding of the importance of developing and maintaining continuing learning on physician-based issues that are barriers to health care including:
 - a lack of specialist knowledge about health issues of people with intellectual disabilities
 - a lack of awareness of appropriate specialist support services (behavioural support teams or psychiatric or neurological assessment) and their availability.
- Demonstrate the use of screening tests for adults with intellectual disability to detect neurological and psychiatric problems such as dementia and depression.

Psychomotor skills

- Demonstrate the skills to conduct a physical and mental state assessment.

The knowledge base

Symptoms:

- ~~Withdrawal, challenging behaviour, tearfulness, agitation, weight loss.~~

Common and/or important conditions:

- ~~Epilepsy – increased incidence and complexity with severity of learning disability~~
- ~~Sensory impairments – hearing and vision, earwax~~
- ~~Psychiatric problems – emotional and behavioural disorders, sexual and physical abuse, schizophrenia, bipolar affective disorder, Alzheimer’s disease in Down’s syndrome~~
- ~~Obesity – predisposes to other health problems~~
- ~~Gastrointestinal – swallowing problems, reflux oesophagitis, *Helicobacter pylori*, constipation, gastric carcinoma~~
- ~~Respiratory problems – chest infections, aspiration pneumonia~~
- ~~Cerebral palsy – especially with severe learning disability~~
- ~~Orthopaedic problems – joint contractures, osteoporosis~~
- ~~Dermatological problems.~~

Emergency care:

- ~~In urgent life-threatening cases, treatment needs to proceed without consent in the best interests of person with limited capacity.~~

Treatment:

- ~~Hurdles in the delivery of treatment due to difficulties reading instructions and treatment labels~~
- ~~The risks of ‘over the counter’ prescriptions in some patients with a degree of independence, who may not fully understand how to take treatments or what the treatment is for~~
- ~~Implementation depends on carers and the additional difficulties with drug delivery in inspected residential care homes~~
- ~~Hard to identify side effects.~~

Resources:

- ~~Specialist learning disability teams and non-medical agencies.~~

Prevention:

- ~~Health reviews proposed for people with learning disabilities.~~

[TEACHING AND LEARNING RESOURCES]

Examples of relevant texts and resources

- ~~Beange H, Lennox N, Parmenter T. Health targets for people with learning disabilities / *Intellect Dev Disability* 1999; 24(4): 283–97~~
- ~~Gates B, Barr O. (eds). *Oxford Handbook of Learning and Intellectual Disability Nursing* Oxford: 2009~~
- ~~Code of Practice – Mental Capacity Act 2005 HMSO~~
- ~~Hoghton M. and the RCGP Learning Disabilities Group *A Step by Step Guide for GP Practices : Annual Health Checks for People with a Learning Disability* London: RCGP, 2010~~
- ~~Holt G, Hardy S. State of the Union *Advances in Mental Health and Learning Disabilities* 2007, 1(1) 3-41 (details care of adults with intellectual disability in England, Northern Ireland, Scotland and Wales).~~
- ~~Lindsay P. *Care of Patients with Learning Disabilities Update Series, 2003*~~
- ~~Lindsay P. (ed) *The Care of the adult with Intellectual Disability in Primary Care* Radcliffe Press 2011 ISBN 978 184619 479 5~~
- ~~Piachaud J. Teaching learning disability to undergraduate students *Advances in Psychiatric Treatment* 2002; 8: 334–41~~
- ~~Phillips A, Morrison J, Davis RW. General practitioners' educational needs in intellectual disability health *J Intellect Disabil Res* 2002; 48: 142–9~~
- ~~van Schrojenstein Lantman De Valk HM, Metsemakers JF, Haveman MJ, Crebolder HF. Health problems in people with intellectual disability in general practice: a comparative study *Fam Pract* 2000; 17(5): 405–7~~

Web resources

Royal College of GPs website

The RCGP website has a specific learning disabilities section where material is available to download to support annual health checks

www.rcgp.org.uk/clinical_and_research/circ/innovation_evaluation/learning_disabilities_resource.aspx

e-GP

The e-GP resource provides a programme of e-learning modules covering the RCGP curriculum. It includes a number of modules on the care of people with a learning disability in the community, including annual health checks.

www.e-gp.org/

gptom.com

This site includes a toolkit to support GP staff in delivering the DES.

www.gptom.com/

Signpost Sheffield

A PCT website with downloadable GP resource pack for health checks

www.signpostsheffield.org.uk

Oxleas NHS Foundation Trust

This site offers downloadable health check information and resources for GPs
www.oxleas.nhs.uk/gps-referrers/learning-disability-services/health-check-resources/

Easyhealth

This website has downloadable easy read information leaflets and books about health issues for people with a learning disability.
www.easyhealth.org.uk

SeeAbility

This site provides information about vision and hearing, including eye and hearing checks and promotes positive lifestyles for people with LD.
www.seeability.org

Valuing People Now

A useful source of Department of Health publications and support.
www.valuingpeople.gov.uk

Mencap

Mencap works with people with learning disabilities to fight discrimination.
www.mencap.org.uk

Improving Health and Lives: Learning Disabilities Observatory

The Public Health Learning Disabilities Observatory.
www.improvinghealthandlives.org.uk

British Institute of Learning Disabilities (BILD)

www.bild.org.uk

CIPOLD

Confidential Inquiry into premature deaths of people with learning disabilities.
www.bris.ac.uk/cipold/

Understanding Intellectual Disability and Health

A web-based learning resource run by St George's, University of London
www.intellectualdisability.info

www.ncl.ac.uk/nnp/teaching/resources/learning.pdf

Newcastle University

www.intellectualdisability.info

Learning about Intellectual Disabilities and Health, a web-based learning resource

www.repsych.ac.uk/publications/booksbeyondwords.aspx

Books Beyond Words, help communication with people with LD

www.mencap.org.uk

Mencap is the UK's leading learning disability charity

www.dsmig.org.uk

Down's Syndrome Medical Interest Group

~~www.nas.org.uk/nas/jsp/polopoly.jsp?d=1422~~

~~Autistic spectrum disorder—page for GPs~~

~~www.nice.org.uk~~

~~Site for NICE Guidelines~~

~~www.doh.gov.uk~~

~~Site for Department of Health~~

~~www.fragilex.org.uk~~

~~Fragile X society~~

~~www.scope.org.uk~~

~~Cerebral palsy website~~

~~The 'contact a family' directory. Information on: conditions underlying learning disabilities; medical descriptions; and details of inheritance patterns and prenatal diagnosis. Also section on behavioural phenotypes~~

PROMOTING LEARNING ABOUT THE CARE OF PEOPLE WITH LEARNING DISABILITIES

Work-based learning – in primary care

Primary care both inside and outside the practice is the ideal environment to learn about the care of people with learning disabilities. Specialty registrars (GP) should take the opportunity to gain a better understanding of the practice's patients that are looked after in partnership with the specialist team. Attending clinic appointments with their patients will help the specialty registrar (GP) gain a better understanding of the patient's journey.

Work-based learning – in secondary care

The specialty registrar should spend time during their GP training placement with his or her local learning disability specialist and attend specialist clinics to gain a better understanding of the care of patients with learning disabilities.

Non-work-based learning

The care of people with learning disabilities is an excellent subject for discussion with the GP trainer and in groups of specialty registrars. Discussion of the issues with patients and carers will help the specialty registrar gain valuable insights into their health and social care needs. Postgraduate deans are responsible for the training of learning disability specialists as well as GPs. The local deanery will have a variety of learning opportunities that a specialty registrar could attend if he or she wants to learn more.

The Partners in Practice project provides a valuable resource for those organising GP training programmes. Partners in Practice is a three-year collaboration between the University of Bristol, the University of the West of England and the Peninsula Medical School. The project is about training healthcare workers, the majority of whom are non-disabled, to work more effectively with disabled people as patients and service users. Disabled people have directly influenced the education of future healthcare professionals by determining the curriculum's learning outcomes, setting standards, delivering the curriculum and assessing practice. Partners in Practice has created a curriculum framework that 'embeds disability equality in healthcare education, thereby enabling future generations of doctors, nurses, midwives, dentists radiographers, physiotherapists, occupational therapists and other health and social care professionals to eliminate disability discrimination from clinical practice'. This curriculum framework is called Different Differences: disability equality for healthcare education.

www.bris.ac.uk/pip/differentdifferences.html

Learning with other healthcare professionals

The care of people with learning disabilities is a multiprofessional activity that involves the patient, his or her carers and professionals from health and social care. Learning with other professionals is, therefore, very important to gain a better understanding of their roles and how best care may be delivered.

[APPENDIX 1]

Diagnostic overshadowing

Diagnostic overshadowing is when a person's presenting symptoms are put down to their learning disability, rather than the doctor seeking another, potentially treatable cause.

For example, when a person presents with a new behaviour or existing ones escalate, doctors should consider:

- *Physical problems:* pain or discomfort, e.g. from ear infection, toothache, constipation, reflux oesophagitis, deterioration in vision or hearing
- *Psychiatric causes:* depression, anxiety, psychosis, dementia
- *Social causes:* change in carers, bereavement, abuse.

Source: Newcastle University¹⁷.

[APPENDIX 2]

Meeting health needs in primary care

Studies of community based populations of people with intellectual disabilities have uncovered three main areas of deficit in care delivery.¹⁸

Untreated, yet treatable, medical conditions

- Most individuals have a range of conditions that would normally be self-presented to the GP. These include simple conditions such as impacted earwax or dermatitis, and more serious problems such as breast lumps or major cardiac arrhythmias.

Untreated specific health issues related to the individual's disability

- Known health needs are often not addressed. A common example is that people with Down's syndrome do not receive regular thyroid screening in spite of the high frequency of hypothyroidism.

A lack of uptake of generic (non-targeted) health promotion

- People with intellectual disabilities receive fewer health promotion measures than their non-disabled peers. These include relatively simple procedures such as weight and blood pressure measurement, and more complex processes such as mammography and cervical smears.

[REFERENCES]

1. Nirje B. The normalisation principle and its human management implications. In: Flynn RJ and Nitsch KE (eds). *Normalisation, Social Integration and Community Services* Baltimore: University Park Press
2. Department of Health. *Valuing People: a new strategy for learning disability for the 21st century* London: Department of Health, 2001
3. World Health Organization. *ICD10 Manual* Geneva: WHO, 1992
4. American Psychiatric Association. *DSM IV* Arlington: American Psychiatric Association, 1994
5. van Schrojenstein Lantman De Valk HM, Metsemakers JF, Haveman MJ, Crebolder HF. Health problems in people with intellectual disability in general practice: a comparative study *Fam Pract* 2000; 17(5): 405-7
6. Smith K, Shah A, Wright K, Lewis G. The prevalence and costs of psychiatric disorders and learning disabilities *Br J Psychiatry* 1995; 166(1): 9-18
7. Hollins S, Attard MT, von Fraunhofer N, McGuigan S, Sedgwick P. Mortality in people with learning disability: risks, causes and death certification findings in London *Dev Med Child Neurol* 1998; 40(1): 50-6
8. RCGP Working Party. *Primary Care for People with a Mental Handicap*. Occasional Paper 47. London: RCGP, 1990
9. Psychiatric Assessment Schedule for Adults with Developmental Disability, www.pasadd.co.uk [accessed January 2007]
10. Mencap. 'Treat Me Right.' Better healthcare for people with a learning disability London: Mencap, 2004, www.mencap.org.uk/document.asp?id=316 [accessed December 2008]
11. Disability Rights Commission. *Equal Treatment: closing the gap. A formal investigation into health inequalities experienced by people with learning disabilities or mental health problems* Stratford Upon Avon: DRC, 2005, www.equalityhumanrights.com/en/publicationsandresources/Pages/publications.aspx [accessed December 2008]
12. Beange H, Lennox N, Parmenter T. Health targets for people with an intellectual disability *J Intellect Dev Disabil* 1999; 24(4): 283-97
13. Department of Health. *Care Standards Act, Sect 23(1), (2000), National Minimum Standard 19.4 National Minimum Standards for Care Homes for Younger Adults Dec 2001* London: HMSO, 2001
14. NICE. *Clinical Guidelines 20: the epilepsies* London: NICE, p. 18
15. Working Group of IASSID. Clinical guidelines for the management of epilepsy in adults with an intellectual disability *Seizure* 2001; 10: 401-9
16. MacKean S, Heyman B, Swain J, Gillman M. *Primary Health Care for Adults with Learning Difficulties*, 1999, www.city.ac.uk/sonm/dps/research/research_reports/heyman_b/phcald.pdf [accessed January 2007]
17. Newcastle University. *The Role of Doctors in Treating People with Learning Disability*, www.ncl.ac.uk/nnp/teaching/disorders/learning/ld_role.html [accessed January 2007]
18. Kerr M. Intellectual disabilities assessment in primary care *Psychiatry* 2003; 2: 9

Formatted: Bullets and Numbering

¹ Kerr M. Intellectual disabilities assessment in primary care *Psychiatry* 2003; 2: 9

² MacKean S, Heyman B, Swain J, Gillman M. *Primary Health Care for Adults with Learning Difficulties*, 1999, www.city.ac.uk/sonm/dps/research/research_reports/heyman_b/phcald.pdf [accessed January 2007]