Royal College of General Practitioners

Royal College of General Practitioners
Curriculum Statement 14

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
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- 15.8 Respiratory Problems
- 15.9 Rheumatology and Conditions of the Musculoskeletal System (including Trauma)
- 15.10 Skin Problems

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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 normalisation,[1] 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

Diagnosis	*Possible number of patients on GP list of 2000*
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 patients[5]
- 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 system.[6]

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) questionnaire[9] 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]

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.

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 an awareness of residential situations, and attendance at day centres.
- 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 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 how health can be overlooked in PWLD and the remedial steps, such as health promotion, that can be taken.

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.

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.

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.[16]
- 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.

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.
- 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.

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 pylorii*, 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 *J Intellect Dev Disability* 1999; 24(4): 283–97
Lindsay P. *Care of Patients with Learning Disabilities* Update Series, 2003
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

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.rcpsych.ac.uk/publications/bbw	Books Beyond Words, help communication with people with LD
www.mencap.org.uk//index.asp	Mencap is the UK's leading learning disability charity
www.dsmig.org.uk	Down's Syndrome Medical Interest Group
www.nas.org.uk	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
www.cafamily.org.uk/dirworks.html	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 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 University[17]

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/treatmeright [accessed January 2007]

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.drc-gb.org/health [accessed January 2007]

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