

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
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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

This curriculum statement has been updated in the light of Sir Jonathan Michael's *Health for All*. The report 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 intellectual disability.

Up to the mid 1980s the majority of those adults with intellectual disability resided away from mainstream medicine in long-stay hospitals. The increased health needs lead Prof. Mike Kerr to describe his crises of care. There is a difference in health because of:

- Increased mortality
- Increased morbidity
- Increased negative determinants of health such as poverty.

There is 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 are 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, the high mortality, the high morbidity and the difference in morbidity compared with 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. Do this by tailoring chronic disease management to the particular needs of this group of the practice population.
- Demonstrate an 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 patients’ 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.

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 his or her 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, 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 importance of tailoring health promotion 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.

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 from other parents. They 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.¹
- 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.
- 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.

Teaching and Learning Resources

Examples of relevant texts and resources

DEPARTMENT FOR CONSTITUTIONAL AFFAIRS. *Mental Capacity Act 2005: code of practice* London: HMSO

GATES B, BARR O (eds). *Oxford Handbook of Learning and Intellectual Disability Nursing* Oxford: Oxford University Press, 2009

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 (ed). *The Care of the Adult with Intellectual Disability in Primary Care* Oxford: Radcliffe Press, 2011

Web resources

Royal College of General Practitioners

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 several 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 a 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-to-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 learning disabilities.

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

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 his or her GP training placement with the 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.

References

- 1 KERR M. Intellectual disabilities assessment in primary care *Psychiatry* 2003; **2**: 9
- 2 MACKEAN S, HEYMAN B, SWAIN J, *et al.* *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]

