3.11 THE CLINICAL EXAMPLE ON

Care of People with Intellectual Disability

This statement is part of the curriculum produced by the Royal College of General Practitioners (RCGP) which defines the learning outcomes for the discipline of general practice and describes the skills you require to practise medicine as a general practitioner in the National Health Service (NHS) of the United Kingdom. Although primarily aimed at the start of independent work as a general practitioner, it must also prepare the doctor beyond the training period and provide support for a professional life of development and change.
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KEY MESSAGES

As a general practitioner (GP) caring for adult patients with intellectual disability, you should:

• Recognise the importance of distributive justice, irrespective of the innate abilities of each patient
• Recognise that in every consultation you must make the effort to identify, monitor and review the progress of all patients who have difficulties with communication, social relationships and managing their own affairs
• Recognise that respect for diversity may involve challenging the values of the local community and society in general
• Be aware of the atypical morbidity and mortality prevalent in patients with intellectual disability and the atypical presentation of acute and chronic physical and psychiatric disorders
• Be aware of the additional skills of diagnosis and examination needed in patients unable to describe or verbalise symptoms and where to obtain specialist advice and help
• Be aware of the effects intellectual disability has on the life history of the patient and family, particularly at times of transition
• Be aware of the effects intellectual disability has on the aging process, particularly in the development and recognition of dementia
• Understand the value of conducting regular (annual) health checks
• Appreciate the role of your own patients in the evolution of services for patients with intellectual disability. All mainstream services should offer patients with intellectual disability professional resources and facilities that are appropriate and tailored to their needs.
Amy lives in a residential home with 40 other residents, supported by a staff some of whom are permanent and experienced and some of whom are employed by an agency for periods of weeks or months. She has moderate intellectual disability and attends a local training centre five days each week. Her parents live near the home and they visit her regularly – every other weekend she returns home and stays overnight.

She is 41 years old and the staff bring her to see you saying that recently her behaviour has changed. She is accompanied on this occasion by a carer who has looked after her for years and relates a detailed history, together with her concerns:

- Amy has become aggressive, especially at meal times. During a meal with the other residents she can lash out and hit a member of staff or someone sitting next to her
- Her appetite has decreased and there is concern she has lost weight
- Whereas before she used to be the first ready to go to the training centre every morning, she is now rarely ready and needs help with dressing before she goes
- She used to recount to her parents what she had made and done each day but now remains quiet when they visit

You ask about her general health:

- She frequently wets herself
- Her periods are no problem now – she has not had one for seven months
- Her sleep is disturbed and she wanders from her room at least once each night
- Her bowels open every day as before but she has become incontinent of faeces

To help you understand how the GP curriculum can be applied to this case, ask yourself the following questions:

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LEARNING OUTCOMES

The following learning outcomes or objectives relate specifically to the care of people with intellectual disability. These learning outcomes are in addition to those detailed in the core statement, Being a General Practitioner. The core statement and this statement should be used in conjunction with the other curriculum statements. In order to demonstrate the core competences in the area of intellectual disability, GPs will require knowledge, skills and attitudes in the following areas:

The RCGP areas of competence

1 Primary care management

This area of competence is about how you manage your contact with patients, dealing competently with any and all problems that are presented to you. (This area of competence is not limited to dealing with the management of the practice.)

This means that as a GP you should:

1.1 Be aware of likely associated conditions, the high mortality, the high morbidity and the difference in morbidity compared to the rest of the population
1.2 Understand the need to support adolescents with intellectual disability as they become adults and no longer have the multidisciplinary support of community paediatricians
1.3 Create and maintain a register of adults with intellectual disability in the practice and correlate this to the shared local health and social services registers
1.4 Understand the importance of the annual health check to an adult with intellectual disability
1.5 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
1.6 Understand your role in ensuring equal access to mainstream services, ensuring those services make ‘reasonable adjustment’ to the needs of patients with intellectual disability, whenever required
1.7 Provide more time in the consultation in order to deal more effectively with people with intellectual disability
2 Person-centred care

This area of competence is about understanding and relating to the context of your patients as individuals, and developing the ability to work in partnership with them.

This means that as a GP you should:

- **2.1** Show respect for the patient’s right 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, the Adults with Incapacity (Scotland) Act 2000.
- **2.2** Be aware of residential situations and attendance at day centres, daytime activities available locally to adults with intellectual disability, including those provided by the voluntary sector.
- **2.3** Be aware of how communicating via carers may affect the doctor–patient relationship.
- **2.4** Optimise communication through the use of consulting skills and communication aids.
- **2.5** Be aware of the issues of capacity and consent, and the mechanisms by which these can be determined.

3 Specific problem-solving skills

This area of competence is about the context-specific aspects of general practice, dealing with early and undifferentiated illness and the skills you need to tolerate uncertainty, and marginalise danger, without medicalising normality.

This means that as a GP you should:

- **3.1** Describe how psychiatric and physical illness may present atypically in patients with intellectual disability because of sensory, communication and cognitive difficulties.
- **3.2** Demonstrate the necessary skills to conduct a physical and mental state assessment in a patient with intellectual disability with regard to the higher prevalence of some problems, such as respiratory conditions and epilepsy.
- **3.3** Understand the need to use additional enquiry, appropriate tests and careful examination in patients unable to describe or verbalise symptoms.
- **3.4** Understand the significance and prevalence of oropharyngeal disorders and dysphagia in patients with intellectual disability and its relevance to the high prevalence of respiratory disorders in these patients.
- **3.5** Be aware of the concept of diagnostic overshadowing when a person’s presenting symptoms are put down to the disability, rather than the doctor seeking another, potentially treatable cause.
- **3.6** Understand the psychiatric disorders prevalent in the adult with intellectual disability and how their diagnosis, detection and management differ particularly with regard to:
  - **3.6.1** emotional and behavioural disorders
  - **3.6.2** bereavement reactions.
3.6.3 anxiety and depression
3.6.4 schizophrenia
3.6.5 bipolar affective disorder
3.6.6 Alzheimer’s disease
3.6.7 Autism and autistic spectrum conditions

3.7 Understand developmental disability and the neurologically based disorders that originate before birth and affect the patient throughout life. In particular, you need to understand the diagnosis and management of patients with autistic spectrum conditions.

### 4 A comprehensive approach

This area of competence is about how you as a general practitioner must be able to manage co-morbidity, co-ordinating care of acute illness, chronic illness, health promotion and disease prevention in the general practice setting.

This means that as a GP you should:

4.1 Understand how patients with borderline intelligence have difficulty coping with complex executive mental functions and how this can affect their behaviour.

4.2 Understand how health promotion can be overlooked in the care of patients with intellectual disability and the importance of tailoring health promotion to the needs of this special group, particularly with regard to the difficulties of routine screening, such as cervical cytology, mammography, abdominal aortic aneurysm and bowel cancer screening.

4.3 Understand how adults with intellectual disability are subject to poly-pharmacy and how this can be made safer.

### 5 Community orientation

This area of competence is about the physical environment of your practice population, and the need to understand the inter-relationship between health and social care, and the tensions that may exist between individual wants and needs and the needs of the wider community.

This means that as a GP you should:

5.1 Describe the roles of paid carers, respite care and voluntary and statutory agencies, and demonstrate an ability to work in partnership with these so that there is co-operation without duplication based on a free flow of communication which, when necessary and possible, maintains confidentiality.

5.2 Understand Recognise the risk to adults with intellectual disability of physical, sexual, financial, institutional, discriminatory and emotional abuse.
6 A holistic approach

This area of competence is about your ability to understand and respect the values, culture, family structure and beliefs of your patients, and understand the ways in which these will affect the experience and management of illness and health.

This means that as a GP you should:

- **6.1** Understand the impact of intellectual disability on family dynamics and the implications for physical, psychological and social morbidity in the patient’s carers
- **6.2** Understand 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 if their child dies they may go through a bereavement process that differs from those whose child without intellectual disability dies (see also 3.09 End-of-Life Care)

The essential features of you as a doctor

The three essential features (EFs) below are concerned with the features of you as a doctor which may influence your ability to apply the core competences to real life in the work setting.

**EF1 Contextual features**

This essential feature is about understanding your own context as a doctor and how it may influence the quality of your care. Important factors are the environment in which you work, including your working conditions, community, culture, financial and regulatory frameworks.

Examples of this are:

- **EF1.1** Offering consultations at times which provide optimal care of the patient by ensuring access to key workers and services
- **EF1.2** Understanding the impact of the doctor’s working environment on the care provided to patients with intellectual disability, e.g. access, atmosphere in the waiting area, the measures taken to compensate for sensory impairment
**EF2 Attitudinal features**

This essential feature is about your professional capabilities, values, feelings and ethics and the impact these may have on your patient care.

Examples of this are:

- **EF2.1** Being aware of your own feelings and attitudes to disability
- **EF2.2** Being aware of your own feelings and attitudes to difficult decisions in the care of adults with intellectual disability
- **EF2.3** Respecting the equal rights of all citizens to health care, health information and health promotion
- **EF2.4** Appreciating that inclusion begins with and depends on commitment to the development of a fully accessible service
- **EF2.5** Being aware of the sometimes negative response of the community to the presence of adults with intellectual disability, especially in the area around communal homes, including 'hate crimes'
- **EF2.6** Understanding the emotional and sexual needs of adults with intellectual disability and how they can be expressed

**EF3 Scientific features**

This essential feature is about the need to adopt a critical and evidence-based approach to your work, maintaining this through lifelong learning and a commitment to quality improvement.

Examples of this are:

- **EF3.1** Understanding the technical and ethical difficulties of designing research studies using bio-medical models
- **EF3.2** Having an awareness of the evidence regarding the health needs of people with intellectual disability
- **EF3.3** Understanding the evidence regarding the effectiveness of routine health interventions, including annual health checks
- **EF3.4** Understanding the importance of developing and maintaining continuing learning of physician-based issues that are barriers to healthcare, including:
  - **EF3.4.1** a lack of specialist knowledge about the health issues of people with intellectual disability
  - **EF3.4.2** a lack of awareness of appropriate specialist support services (behavioural support teams or psychiatric or neurological assessment) and their availability
- **EF3.5** Demonstrating the use of screening tests for adults with intellectual disability to detect neurological and psychiatric problems such as dementia and depression
LEARNING STRATEGIES

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 intellectual disability. GP specialty trainees should take the opportunity to gain a better understanding of the practice’s patients who are looked after in partnership with the specialist team and other agencies.

Work-based learning – in secondary care
As a GP trainee you should spend time during your GP training placement with your local intellectual disability specialist and attend specialist clinics to gain a better understanding of the care of patients with intellectual disability. You should also actively assist in the annual health checks.

Non-work-based learning
The care of people with intellectual disability is an excellent subject for discussion with your GP trainer and in groups with other specialty trainees. As a GP trainee, discussing issues with patients and carers will help you gain valuable insights into the health and social care needs of those with intellectual disability. Postgraduate deans are responsible for the training of intellectual disability specialists as well as GPs. The local deanery will have a variety of learning opportunities that specialty trainees can attend if they want to learn more.

Learning with other healthcare professionals
The care of people with intellectual disability is a multi-agency activity that involves the patient, his or her carers and professionals from health and social care. Your learning with other professionals is, therefore, very important to gain a better understanding of their roles and how best care may be delivered.
LEARNING RESOURCES

Examples of relevant texts and resources

- Ali A and Hassiotis A. Illness in people with intellectual disabilities is common, under-diagnosed and poorly managed British Medical Journal 2008; 336: 570–1
- Cooper S-A, Melville C, Morrison J. People with intellectual disabilities. Their health needs differ and need to be recognised and met British Medical Journal 2004; 329;: 414–15
- Danielsson S, Gillberg IC, Billstedt E, Gillberg IC. Epilepsy in young adults with autism: a prospective population-based follow-up study of 120 individuals diagnosed in childhood Epilepsia 2005; 46(6):918–23

Kerr M. Improving the general health of people with learning disabilities *Advances in Psychiatric Treatment* 2004; 10: 200–6


Lindsay P and Burgess, D. Care of patients with intellectual or learning disability: no more funding so will there be any change? *British Journal of General Practice* 2006; 56(523): 84

Martin G. Support for people with learning disabilities: the role of primary care *Primary Care and Community Psychiatry* 2005: 10(4):133–42

Martin G and Lindsay PJ. Dying and living with learning disability: will health checks improve the quality of life? *British Journal of General Practice* 2009; 59(564): 480–1


Morgan CL, Scheepers MIA, Kerr MP. Mortality in patients with intellectual disability and epilepsy *Current Opinion in Psychiatry* 2001; 14: 471-5

National Patient Safety Agency. Understanding the patient safety issues for people with learning disabilities, 2004, [www.nrls.npsa.nhs.uk/resources/?EntryId45=92328](http://www.nrls.npsa.nhs.uk/resources/?EntryId45=92328)


Sir F, Smith LK, McGrother CW. Mortality in adults with moderate to profound intellectual disability: a population-based study *Journal of Intellectual Disability Research* 2007; 51(7); 520-527

Straetmans JMJAA, van Schrojenstein Lantman-De Valk HMJ, Schellevis FG, Dinant G-J. Health problems of people with intellectual disabilities: the impact for general practice *British Journal of General Practice* 2007, 57; 64–66


van Schrojenstein Lantman-De Valk HMJ, Metsemakers JFM, Haveman MJ, Crebolder HFJM. Health problems in people with intellectual disability in general practice: a comparative study *Family Practice* 2000; 17(5); 405-7
• van Schrojenstein Lantman-De Valk HMJ. Health in people with intellectual disabilities: current knowledge and gaps in knowledge *Journal of Applied Research in Intellectual Disabilities* 2005; 18: 325–33

**Web resources**

**British Institute of Learning Disabilities (BILD)**
BILD aims to improve the lives of all people with an intellectual disability.
[www.bild.org.uk](http://www.bild.org.uk)

**Confidential Inquiry**
Confidential inquiry into premature deaths of people with learning disability.
[www.bris.ac.uk/cipold](http://www.bris.ac.uk/cipold)

**The Challenging Behaviour Foundation**
A resource on information on challenging behaviour in people with intellectual disability and resources available to support them.
[www.challengingbehaviour.org.uk/](http://www.challengingbehaviour.org.uk/)

**Down’s Syndrome Association**
A useful resource on people with Down's Syndrome and support for them and their families.

**Down Syndrome Medical Interest Group**
This site provides information for healthcare professionals on 'best practice' medical care for people with Down syndrome in the UK and Ireland.
[www.dsmig.org.uk](http://www.dsmig.org.uk)

**Easyhealth**
This website has downloadable easy-to-read information leaflets and books about health issues for people with an intellectual disability.
[www.easyhealth.org.uk](http://www.easyhealth.org.uk)
GMC Learning Disabilities website
This site aims to help doctors provide better care for people with learning disabilities by identifying the issues, highlighting patient perspectives, and showing how to put GMC guidance into practice. It includes interactive learning sessions.
www.gmc-uk.org/learningdisabilities

gptom
This site has a toolkit to support GP staff to deliver the Department of Education and Skills (DES).
www.gptom.com

Improving Health and Lives
The Public Health Learning Disabilities Observatory.
www.improvinghealthandlives.org.uk

Intellectual Disability
A useful learning resource for medical, nursing and other healthcare professionals, who are required to support equal access to their services for all disabled people.
www.intellectualdisability.info

Mencap
Mencap works with people with intellectual disability to fight discrimination.
www.mencap.org.uk

National Autistic Society
The National Autistic Society website includes information for professionals
www.autism.org.uk

Oxleas NHS Foundation Trust
Oxleas NHS Foundation Trust provides community health, mental health and intellectual disability services. See the website for downloadable health check information and resources for GPs.
www.oxleas.nhs.uk/gps-referrers/learning-disability-services

Respond
An organisation that provides counselling services to people with intellectual disability who have experienced trauma in their lives.
Royal College of General Practitioners (RCGP)

The online learning environment (OLE) has a specific section on intellectual disability where including downloadable material is available to download to support annual health checks. See Care of the Adult with Learning Disability (edited by Matt Hoghton, RCGP Special Interest Group in Intellectual Disability). This is the free learning for health portal with eight completed modules for GPs, practice nurses and other primary care staff on the care of people with a learning disability in the community, including annual health checks.

www.rcgp.org.uk

There is also an e-GP course on Intellectual Learning Disability, including sessions on demographic characteristics and hidden history, access, effective communication, working with carers, sensory issues, syndromes and pathology, epilepsy, and health checks.

www.e-gp.org

Other RCGP learning disability resources can be accessed at


Intellectual disability resources in the online learning environment (OLE) include a course on autism in general practice

http://elearning.rcgp.org.uk/

Seeability

This site provides information about vision and hearing, including eye and hearing checks, and promotes positive lifestyles for people with intellectual disability.

www.seeability.org

Signpost Sheffield

A PCT information website about the Joint Learning Disabilities Service in Sheffield, designed for service users, families, carers and staff. This website has a downloadable GP resource pack for health checks.

www.signpostsheffield.org.uk

Society for the Study of Behavioural Phenotypes

This is a useful site for the non-specialist when encountering a patient with a rare syndrome.

www.ssbp.org.uk

Valuing People

A useful source of Department of Health publications and support for people with intellectual disability.

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