The RCGP Curriculum: Clinical Modules

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> 3.11 Care of People with Intellectual Disability

Summary

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

- Recognise the importance of the principle of fairness and equality, 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.

Knowledge and skills guide

Core Competence: Fitness to practise

This concerns the development of professional values, behaviours and personal resilience and preparation for career-long development and revalidation. It includes having insight into when your own performance, conduct or health might put patients at risk, as well as taking action to protect patients.

This means that as a GP you should:

- Be aware of your own feelings and attitudes to disability
- Be aware of your own feelings and attitudes to difficult decisions in the care of adults with intellectual disability

Core Competence: Maintaining an ethical approach

This addresses the importance of practising ethically, with integrity and a respect for diversity.

This means that as a GP you should:

- Respect the equal rights of all citizens to health care, health information and health promotion
- Appreciate that inclusion begins with and depends on commitment to the development of a fully accessible service
- 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 the Adults with Incapacity (Scotland) Act 2000

Core Competence: Communication and consultation

This is about communication with patients, the use of recognised consultation techniques, establishing patient partnership, managing challenging consultations, third-party consulting and the use of interpreters.

- Be aware of residential situations and daytime activities available locally to adults with intellectual disability, including those provided by the voluntary sector
- Be aware of how communicating via carers may affect the doctor-patient relationship
- Optimise communication through the use of consulting skills and communication aids
- Be aware of the issues of capacity and consent, and the mechanisms by which these can be determined

Core Competence: Data gathering and interpretation

This is about interpreting the patient's narrative, clinical record and biographical data. It also concerns the use of investigations and examination findings, plus the adoption of a proficient approach to clinical examination and procedural skills.

This means that as a GP you should:

- Describe how psychiatric and physical illness may present atypically in patients with intellectual disability because of sensory, communication and cognitive difficulties
- 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
- Understand the need to use additional enquiry, appropriate tests and careful examination in patients unable to describe or verbalise symptoms
- Understand the significance and prevalence of oropharyngeal disorders and dysphagia in people
 with intellectual disability and its relevance to the high prevalence of respiratory disorders in
 these patients

Core Competence: Making decisions

This is about having a conscious, structured approach to decision-making; within the consultation and in wider areas of practice.

- 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
- Understand the psychiatric disorders prevalent in the adult with intellectual disability and how their diagnosis, detection and management differ particularly with regard to –
 - emotional and behavioural disorders
 - o bereavement reactions
 - o anxiety and depression
 - o schizophrenia
 - o bipolar affective disorder
 - o Alzheimer's disease
 - o Autism and autistic spectrum conditions
- 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

Core Competence: Clinical management

This concerns the recognition and management of common medical conditions encountered in generalist medical care. It includes safe prescribing and medicines management approaches.

This means that as a GP you should:

- Understand the need to support adolescents with intellectual disability as they become adults and no longer have the multidisciplinary support of community paediatricians
- 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
- Understand the importance of the annual health check to an adult with intellectual disability
- 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
- 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
- Provide more time in the consultation in order to deal more effectively with people with intellectual disability

Core Competence: Managing medical complexity

This is about aspects of care beyond managing straightforward problems. It includes multi-professional management of co-morbidity and poly-pharmacy, as well as uncertainty and risk. It also covers appropriate referral, planning and organising complex care, promoting recovery and rehabilitation.

- Be aware of likely associated conditions, the high mortality, the high morbidity and the difference in morbidity in people with intellectual disability compared to the rest of the population
- Understand how patients with borderline intelligence have difficulty coping with complex executive mental functions and how this can affect their behaviour
- 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
- Understand how adults with intellectual disability are subject to poly-pharmacy and how this can be made safer

Core Competence: Working with colleagues and in teams

This is about working effectively with other professionals to ensure good patient care. It includes sharing information with colleagues, effective service navigation, use of team skill mix, applying leadership, management and team-working skills in real-life practice, and demonstrating flexibility with regard to career development.

Core Competence: Maintaining performance, learning and teaching

This area is about maintaining performance and effective CPD for oneself and others, self-directed adult learning, leading clinical care and service development, participating in commissioning, quality improvement and research activity.

This means that as a GP you should:

- Understand the technical and ethical difficulties of designing research studies using bio-medical models
- Have an awareness of the evidence regarding the health needs of people with intellectual disability
- Understand the evidence regarding the effectiveness of routine health interventions, including annual health checks
- Understand the importance of developing and maintaining continuing learning of physicianbased issues that are barriers to healthcare, including:
 - o a lack of specialist knowledge about the health issues of people with intellectual disability
 - o a lack of awareness of appropriate specialist support services (behavioural support teams or psychiatric or neurological assessment) and their availability

Core Competence: Organisational management and leadership

This is about the understanding of organisations and systems, the appropriate use of administration systems, effective record keeping and utilisation of IT for the benefit of patient care. It also includes structured care planning, using new technologies to access and deliver care and developing relevant business and financial management skills.

This means that as a GP you should:

Understand 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

Core Competence: Practising holistically and promoting health

This is about the physical, psychological, socioeconomic and cultural dimensions of health. It includes considering feelings as well as thoughts, encouraging health improvement, preventative medicine, self-management and care planning with patients and carers.

This means that as a GP you should:

- Understand the impact of intellectual disability on family dynamics and the implications for physical, psychological and social morbidity in the patient's carers
- 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)
- Understand the emotional and sexual needs of adults with intellectual disability and how they can be expressed
- Demonstrate the use of screening tests for adults with intellectual disability to detect neurological and psychiatric problems such as dementia and depression

Core Competence: Community orientation

This is about involvement in the health of the local population. It includes understanding the need to build community engagement and resilience, family and community-based interventions, as well as the global and multi-cultural aspects of delivering evidence-based, sustainable healthcare.

- Recognise the risk to adults with intellectual disability of physical, sexual, financial, institutional, discriminatory and emotional abuse
- Be aware of the sometimes negative response of the community to the presence of adults with intellectual disability, especially in the area around communal homes, such as 'hate crimes'
- Offer consultations at times which provide optimal care of the patient by ensuring access to key workers and services
- Describe the roles of 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

Case discussion

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

Reflective questions

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

Core Competence	Reflective Questions
Fitness to practise	Do I have any preconceptions about intellectual
This concerns the development of professional values, behaviours and personal resilience and preparation for career-long development and revalidation. It includes having insight into when your own performance, conduct or health might put patients at risk, as well as taking action to protect patients.	disability?
Maintaining an ethical approach	What does patient autonomy mean for this patient?
This addresses the importance of practising ethically, with integrity and a respect for diversity.	What would be my reaction to an adult without intellectual disability who presents with the same behaviour problems?

Communication and consultation	What are the difficulties in obtaining a history of
This is about communication with patients, the use of recognised consultation techniques, establishing patient partnerships, managing challenging consultations, third-party consulting and the use of interpreters.	behaviour change in an adult with intellectual disability?
Data gathering and interpretation This is about interpreting the patient's narrative, clinical record and biographical data. It also concerns the use of investigations and examination findings, plus the adoption of a proficient approach to clinical examination and procedural skills.	Who else could I ask to provide further information?
Making decisions	What is my differential diagnosis, and how would I
This is about having a conscious, structured approach to decision-making; within the consultation and in wider areas of practice.	explore it?
Clinical management	If no social cause was present, what are the alternative
This concerns the recognition and management of common medical conditions encountered in generalist medical care. It includes safe prescribing and medicines management approaches.	causes of behaviour changes?
Managing medical complexity	What is the legal situation of an adult with intellectual
This is about aspects of care beyond managing straightforward problems. It includes multi-professional management of co-morbidity and poly-pharmacy, as well as uncertainty and risk. It also covers appropriate referral, planning and organising complex care, promoting recovery and rehabilitation.	disability residing in a supported home whose parents visit at least weekly? How does the practice co-ordinate health promotion for patients living in residential care?
Working with colleagues and in teams	Who are the other members of this patient's care team
This is about working effectively with other professionals to ensure good patient care. It includes sharing information with colleagues, effective service navigation, use of team skill mix, applying leadership, management and team-working skills in real-life practice, and demonstrating flexibility with regard to career development.	of which I am a member?
Maintaining performance, learning and	What are the difficulties of getting research evidence
teaching This is about maintaining performance and effective CPD for oneself and others. This includes self-directed adult learning, leading clinical care and service development, participating in commissioning*, quality improvement and research activity.	about the management of patients with intellectual disability?

Organisational management and leadership This is about the understanding of organisations and systems, the appropriate use of administration systems, effective record keeping and utilisation of IT for the benefit of patient care. It also includes structured care planning, using new technologies to access and deliver care and developing relevant business and financial management skills.	How can a practice prepare for acute episodes of illness in adults with intellectual disability?
Practising holistically and promoting health This is about the physical, psychological, socioeconomic and cultural dimensions of health. It includes considering feelings as well as thoughts, encouraging health improvement, preventative medicine, selfmanagement and care planning with patients and carers.	What does the bio-psycho-social model mean for patients with intellectual disability?
Community orientation This is about involvement in the health of the local population. It includes understanding the need to build community engagement and resilience, family and community-based interventions, as well as the global and multi-cultural aspects of delivering evidence-based, sustainable healthcare.	What are the community resources available to this patient in my practice area?

How to learn this area of practice

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.

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.

Self-directed 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.

Useful learning resources

Books and publications

- 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
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- Department of Health 2012 Winterbourne View Hospital DOH Review and Response www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response
- Disability Rights Commission. Equal treatment: closing the gap. A formal investigation into the physical health inequalities experienced by people with learning disabilities/mental health problems, 2006
- Gates B and Barr O (eds). Oxford Handbook of Learning and Intellectual Disability Nursing Oxford: Oxford University Press, 2009
- Heslop P, Blair P, Fleming P et al. Confidential Inquiry into premature deaths of people with learning disability (CIPOLD): Executive Summary Norah Fry Research Centre, 2013.
 www.bris.ac.uk/cipold/finalreportexecsum.pdf
- HMSO. Code of Practice Mental Capacity Act 2005 London: HMSO Publications
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- Holt G and Hardy S. (2007). State of the Union Advances in Mental Health and Learning
 Disabilities 1 (1) 3–41: this document details care of adults with intellectual disability in England,
 Northern Ireland, Scotland and Wales
- Kerr M. Improving the general health of people with learning disabilities *Advances in Psychiatric Treatment* 2004; 10: 200–6
- Lindsay P (ed). The Care of the Adult with Intellectual Disability in Primary Care Oxford: Radcliffe Press, 2011
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- 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
- Matthews T, Weston N, Baxter H, Felce D, Kerr M. A general practice-based prevalence study of epilepsy among adults with intellectual disabilities and of its association with psychiatric disorder, behaviour disturbance and carer stress *Journal of Intellectual Disability Research* 2008; 52(2): 163–73
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- Melville CA, Hamilton S, Hankey CR, Miller S, Boyle S. The prevalence and determinants of obesity in adults with intellectual disabilities *Obesity Reviews* 2007; 8: 223–30
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- Whitaker S and Read S. The prevalence of psychiatric disorders among people with intellectual disabilities: an analysis of the literature *Journal of Applied Research in Intellectual Disabilities* 2006; 19; 330–45

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

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

Down's Syndrome Association

A useful resource on people with Down's Syndrome and support for them and their families. www.downs-syndrome.org.uk

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

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

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. www.respond.org.uk/

Royal College of General Practitioners (RCGP)

The RCGP website has a specific section on intellectual disability including downloadable material to support annual health checks. www.rcgp.org.uk/clinical-and-research/clinical-resources/learning-disabilities.aspx

There is also an *e*-GP course on Intellectual 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

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. https://signpostsheffield.sheffield.gov.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