



Disability

Contents

Definition	97
Curriculum in practice	97
Rationale and general practice context	98
Training outcomes of the five domains of general practice	99
Learning objectives across the GP professional life	100
<i>Medical student</i>	100
<i>Prevocational doctor</i>	102
<i>Vocational registrar</i>	104
<i>Continuing professional development</i>	106
References	107

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Definition

Modern concepts of disability have broadened the traditional focus on individual impairment to one that recognises that the effect of impairment on an individual depends not only on the underlying condition, but also on environmental and social factors. Therefore, a person with an impairment may not necessarily be disabled or handicapped by it. Alternatively, inadequate supports in an environment may lead to an unnecessary handicap as a result of an impairment. This holistic concept of disability, which combines medical and social models, is reflected in the World Health Organization's International Classification of Functioning, Disability and Health (ICF).^{1,2} The concept of support needs – which can assist the person to overcome some of these limitations – has recently been added to the classification. There are three main types of disability.

Physical disability – disability associated with physical impairment and physical activity limitation such as when performing day-to-day activities.

Intellectual disability – the presence of significant limitations in intellectual functioning (usually defined as IQ less than 70), and in adaptive behaviour (conceptual, social and practical skills). This type of disability originates before the age of 18 years.³

Developmental disability – the presence of physical, intellectual and/or social (autism spectrum disorders) impairment with deficits in adaptive functioning, with an onset in the developmental period. Intellectual disability may be a prominent feature in people with developmental disability.

Important note: unless otherwise stated, this curriculum uses the term 'disability' to include physical, intellectual and developmental disability.

Some disabilities are often associated with comorbid conditions, for example, intellectual disability and epilepsy, cerebral palsy and vision impairment or epilepsy.⁴ These comorbidities, and their associated cognitive and communication difficulties, can present barriers to accessing healthcare. Clinicians should not let the disability distract from or overshadow these health problems, rather they should approach them as they would with a person without a disability.

Other disabilities may also be acquired in adult life including sensory, psychiatric, musculoskeletal and neurological disabilities. These can have a significant impact on the affected person's life and as such need to be addressed.

Curriculum in practice

Typical cases that illustrate how the disability curriculum applies to general practice include:

- Joni, 18 years of age, has Down syndrome. She presents with her family who are concerned she has been spending a lot of time with her new boyfriend, whom she met through her workplace. Her parents say that they think that Joni may be sexually active and that she is not capable of making any decisions for herself.
- Zack, 38 years of age, has an intellectual disability. He has recently moved to new supported accommodation in your area and arrives with a disability support worker for treatment of a laceration, which occurred while preparing dinner. Zack has minimal medical records and you are not sure of when Zack last visited a general practitioner.

Rationale and general practice context

In 2003, an estimated 3.9 million Australians had some degree of disability. Of these 1.2 million (6% of the population) had severe or profound core activity limitations. These include increases in intellectually disabling conditions, sensory or speech impairment or psychiatric disability. The reported prevalence rates of disabling conditions associated with childhood, such as attention deficit hyperactivity disorder and autism-related disorders, has substantially increased in the past decade.^{5,6}

People with disability make up a significant part of most general practice populations. These people may have multiple comorbidities and GPs have a key role in the management of these disabilities and associated health problems.^{7,8} In addition, the disability itself can be a barrier to accessing health services, and the GP will often have a role in facilitating appropriate and timely access to services, as well as providing ongoing management of health issues.

According to the Australian Institute of Health and Welfare, in 2007–2008, 46% of people aged 15–64 years with severe or profound disability reported poor or fair health, compared to 5% for those without a disability.⁵

People aged under 65 years with severe or profound disability had a higher prevalence rate of all types of selected long term health conditions than people without a disability. The prevalence of physical long term health conditions was higher for people with both mental health problems and severe or profound disability than for those with mental health problems but no disability.⁷

Australian GPs and registrars indicate that they receive inadequate training to care for people with intellectual disability and consider they need better training in the assessment of behaviour problems, mental disorders, communication, sexuality, neurological problems and an increased understanding of other common comorbidities – be they related to a syndrome or not.^{8–10} The vast majority of GPs are interested in improving their skills, knowledge and management of this patient population.¹¹

In addition to disability related conditions, people with disability will have the full range of medical conditions affecting people without disabilities and will require access to appropriate services. This includes the need for access to the full range of preventive health services such as smoking cessation, nutritional and other population based health initiatives.

People with disability come from a wide range of backgrounds. Practitioners need to recognise the special issues (including discrimination) facing people with disabilities from diverse backgrounds including issues of gender difference; ethnicity and poverty; and issues of sexuality, including sexual preference.

Training outcomes of the five domains of general practice

1. Communication skills and the patient-doctor relationship

- DIST1.1 Use communication to build the foundation of good general practice management of patients with disabilities.
- DIST1.2 Use appropriate additional communication skills and strategies when a patient with disabilities has significant communication difficulties, whether due to cognitive, social or physical impairment.
- DIST1.3 Ensure good communication between doctor and patient and, where appropriate, family and/or support workers.

2. Applied professional knowledge and skills

- DIST2.1 Understand that people with disabilities have the same medical issues as the rest of the population, although certain disabilities may be associated with an increased (or decreased) risk of particular medical conditions.
- DIST2.2 Know the cause or underlying pathology of the disability and use this to inform medical management.
- DIST2.3 Employ the same diagnostic and management strategies and standards that apply to patients without a disability when providing medical care to people with a disability, irrespective of the medical condition and underlying disability.

3. Population health and the context of general practice

- DIST3.1 Understand how people with disabilities often encounter barriers to participating in and accessing the services they choose and require.
- DIST3.2 Be aware of the social, financial and legal frameworks and services that support people with a disability and their families and carers within the community.
- DIST3.3 Know population based measures for disability prevention (eg. periconception folate supplementation).

4. Professional and ethical role

- DIST4.1 Ensure focusing the patient encounter on, and maintaining respect for, the person with the disability.
- DIST4.2 Be aware of the impact of the disability on the person's life and the need to employ the same standards of care that apply to patients without a disability.
- DIST4.3 Understand that patients and families come from diverse social and cultural backgrounds and how this may influence their attitudes and knowledge with respect to disability.

5. Organisational and legal dimensions

- DIST5.1 Understand how legislative frameworks empower individuals and protect those who are not able to advocate for themselves.
- DIST5.2 Ensure that good practice procedures, including those for regular review and follow up, underpin proactive medical management of people with a disability.
- DIST5.3 Understand that good practice procedures and systems are particularly important to the care of people including those with a disability, who find it difficult to understand and organise their medical care.

Learning objectives across the GP professional life

Medical student

1. Communication skills and the patient-doctor relationship

- DISLM1.1 Describe the centrality of effective and efficient communication in people's physical, emotional and social wellbeing across the lifespan in relation to people with a disability.
- DISLM1.2 Identify the roles and responsibilities of each person in a communication exchange when managing a person with a disability.
- DISLM1.3 Explain how different types of disability may have an impact on communication.
- DISLM1.4 Describe the range of communication techniques, including behaviours that are used by people with disabilities.
- DISLM1.5 Demonstrate skills and appropriate strategies to optimise communication with people with communication difficulties due to cognitive and/or physical impairment.

2. Applied professional knowledge and skills

- DISLM2.1 Describe the genetic basis, pathophysiology and for major disabilities outline the implications of these conditions for various organ systems including:
 - DISLM2.1.1 Down syndrome
 - DISLM2.1.2 fragile X syndrome
 - DISLM2.1.3 intellectual disability
 - DISLM2.1.4 autism spectrum disorders
 - DISLM2.1.5 cerebral palsy
 - DISLM2.1.6 developmental delay
 - DISLM2.1.7 acquired brain injury
 - DISLM2.1.8 quadriplegia and hemiplegia.
- DISLM2.2 Explain the importance of making a diagnosis of the underlying cause of a person's disability, where possible.
- DISLM2.3 Outline the likelihood of comorbidities that exist with various syndromes/aetiological diagnoses and their interactions.
- DISLM2.4 Explain the features and implications of the aetiological (eg. Down syndrome, fragile X syndrome) and functional (eg. cerebral palsy, intellectual disability, autism) diagnostic labels of developmental disability for medical care.
- DISLM2.5 Describe how medication and medical and psychiatric conditions may affect behaviour.
- DISLM2.6 Recognise common psychiatric disorders in people with intellectual disabilities that present as changed or disturbed behaviour.
- DISLM2.7 Explain the importance of proactive orderly health management and preventive health strategies for people with a disability, particularly people who have a cognitive and/or communication impairment.

3. Population health and the context of general practice

- DISLM3.1 Describe the barriers (including physical, communication, attitudinal) to medical care and community participation that may be encountered by people with disabilities.
- DISLM3.2 Describe the effect of sociocultural factors on the behaviour and lifestyle of people with disabilities.

4. Professional and ethical role

- DISLM4.1 Outline the importance of shared responsibility, teamwork and a co-ordinated and multidisciplinary approach to ensure that patients receive high quality medical care.
- DISLM4.2 Critically reflect on your own and the community's attitudes toward people with developmental and acquired disability.
- DISLM4.3 Identify the role of the health professional in providing quality healthcare to people with disabilities within a wider service system.
- DISLM4.4 Describe the fundamental ethical and legal principles underlying the provision of healthcare, particularly as they apply to people with cognitive and/or communication impairment in a clinical setting. These should include the concepts of duty of care, informed consent and information sharing issues.
- DISLM4.5 Outline the repercussions of a diagnosis of a disability in a family member on the lives of parents, siblings and the community.
- DISLM4.6 Demonstrate recognition of some of the commonly held attitudes toward sexuality and disability, and understand how they influence the individual's opportunities for full sexual and emotional development.

5. Organisational and legal dimensions

- DISLM5.1 Outline the importance of practice procedures that support the proactive provision of healthcare including procedures for annual health reviews, patient follow up and recall, and the provision of screening and preventive healthcare.
- DISLM5.2 Outline the role of guardianship and administrative boards and tribunals.
- DISLM5.3 Describe the role that social and financial services have in supporting the person with a disability to play a valued role in their community, and to have the life patterns and opportunities available to their nondisabled peers.

Learning objectives across the GP professional life

Prevocational doctor

Assumed level of knowledge – medical student

1. Communication skills and the patient-doctor relationship

- DISLP1.1 Demonstrate courteous and respectful treatment of people with disabilities.
- DISLP1.2 Work effectively with carers, support workers and advocates to optimise health outcomes for people with disabilities.
- DISLP1.3 Develop skills in obtaining recent and past medical history from carers and available patient records.

2. Applied professional knowledge and skills

- DISLP2.1 Describe the known aetiological factors in each of the major developmental disabilities and know how to approach the task of establishing an aetiological diagnosis, including how to access relevant information and resources.
- DISLP2.2 Appreciate the availability and importance of preconception review, advice and medications (eg. folate replete diet and supplementation in anticonvulsant use).
- DISLP2.3 Demonstrate awareness of the likelihood of comorbidities that exist with various syndromes/aetiological diagnoses and their interactions.
- DISLP2.4 Describe possible underlying factors in changed, or challenging behaviour, as a presentation in people with intellectual disability and acquired brain impairment.
- DISLP2.5 Demonstrate an understanding of the clinical management of the sexual health of people with disabilities and in particular, developmental disabilities.
- DISLP2.6 Outline the possible challenges of performing procedures on people with disabilities and be able to discuss ways in which these may be anticipated and managed.
- DISLP2.7 Demonstrate awareness that the indicators (especially symptoms) of serious illness may be difficult to elicit in people with cognitive impairment, and determine ways to overcome these difficulties.

3. Population health and the context of general practice

- DISLP3.1 Outline the advances in international descriptions of disability in terms of organ impairment, activity limitation and participation restriction, and their influence on medicolegal statements.
- DISLP3.2 Be aware of the research evidence related to the health status, need for screening and health needs of people with disabilities.
- DISLP3.3 Describe the range of social, financial and legal services available to support people with a disability and their families and carers, and know where to find further information about these services.

4. Professional and ethical role

- DISLP4.1 Demonstrate advocacy for providing quality healthcare to people with disabilities within the working environment.
- DISLP4.2 Comply with ethical and legal principles underlying the provision of healthcare, particularly as they apply to people with a cognitive and/or communication impairment in a clinical setting. These should include the concepts of duty of care, informed consent and information sharing issues.

5. Organisational and legal dimensions

- DISLP5.1 Identify practice procedures that support the proactive provision of healthcare including procedures for annual health reviews, patient follow up and recall, and the provision of immunisation, screening and preventive healthcare.
- DISLP5.2 Consider the appropriate clinical environment for the patient with a disability to optimise their access, ease, comfort and participation in the consultation.
- DISLP5.3 Demonstrate how to establish if a patient with a disability has the capacity to give consent and, if not, know from whom consent should be obtained.
- DISLP5.4 Demonstrate an understanding of the role of the Public Guardian and the Guardianship and Administration Act or legislative equivalent that applies to your local jurisdiction.

Learning objectives across the GP professional life

Vocational registrar

Assumed level of knowledge – prevocational doctor

1. Communication skills and the patient-doctor relationship

- DISLV1.1 Demonstrate a range of communication strategies to optimise the participation in the consultation of a patient with communication difficulty resulting from a disability.
- DISLV1.2 Demonstrate an ability to communicate effectively with carers and/or advocates who are providing support to a person with a disability, taking account of both the need to share information with those involved in the patient's care and the patient's right to confidentiality.
- DISLV1.3 Demonstrate how to provide sensitive genetic counselling and advice for patients and their families, and know where to source further genetic information and advice.

2. Applied professional knowledge and skills

- DISLV2.1 Demonstrate an understanding of the concept and importance of behavioural and physical phenotypes.
- DISLV2.2 Demonstrate an understanding of the health inequalities experienced by people with intellectual disability, the associated barriers to health equity and the role of the GP in overcoming these barriers.
- DISLV2.3 Describe the role of the main services and systems available within the community that support people with disabilities and their families.

3. Population health and the context of general practice

- DISLV3.1 Demonstrate recognition of the need for health surveillance of groups with developmental disability including mortality, morbidity and level of population screening.
- DISLV3.2 Demonstrate encouragement and facilitation of people with disabilities to participate in health promotion programs, especially good nutrition and exercise.
- DISLV3.3 Demonstrate provision of proactive care to families of a person with a developmental disability based on an understanding of family lifecycle and changing individual and family needs. This includes being sensitive to the effect on the carer's physical and mental health and identifying appropriate local supports and resources.
- DISLV3.4 Outline the public health implications of antenatal testing and folate supplementation. Also describe the impact of the underlying intent and basis of these on the individual with a developmental disability, their family and their community.
- DISLV3.5 Demonstrate awareness of the need to initiate and provide an annual health assessment for people with cognitive impairments, including examination.
- DISLV3.6 Act as an advocate for people with disabilities and their families, to enhance their access to health and community services.
- DISLV3.7 Identify the range of social, financial and legal services available to support people with disabilities and their families and carers, and know where to find further information about these services.

4. Professional and ethical role

- DISLV4.1 Demonstrate respect for the right of the individual with a disability to make life choices that may involve a risk to their health, and understanding of the need to balance this right to autonomy with duty of care.
- DISLV4.2 Describe the importance of being part of a multidisciplinary team in working with people with disabilities, appreciate the value and role of all members of a multidisciplinary healthcare team, and understand how the medical practitioner can contribute to the healthcare of people with a developmental disability through such a team.
- DISLV4.3 Outline the different cultural understandings of disability and their effect on family reactions and responses to the diagnosis of a developmental disability.

5. Organisational and legal dimensions

- DISLV5.1 Demonstrate practice procedures which support the proactive provision of healthcare, including procedures for annual health reviews; patient follow up and recall; and the provision of immunisation, screening and preventive healthcare.
- DISLV5.2 Demonstrate practice process to establish if a patient with a disability has the capacity to give consent and, if not, know from whom consent should be obtained.
- DISLV5.3 Demonstrate practice mechanisms in place to ensure compliance with the role of the Public Guardian and the Guardianship and Administration Act, or legislative equivalent that applies to your local jurisdiction.
- DISLV5.4 Outline the practice procedures, which ensure the appropriate clinical environment is in place, for patients with disabilities to optimise their access, ease, comfort and participation in the consultation.

Learning objectives across the GP professional life

Continuing professional development

Assumed level of knowledge – vocational registrar

1. Communication skills and the patient-doctor relationship

DISLC1.1 Demonstrate regular review of communication skills with people with cognitive and physical impairment as part of ongoing professional development activities.

2. Applied professional knowledge and skills

DISLC2.1 Demonstrate regular review of advances in knowledge and practice in the care of people with disabilities.

3. Population health and the context of general practice

DISLC3.1 Maintain up-to-date knowledge of the social, financial and legal services available to support people with a disability, and their families and carers, and where to find further information about such services.

DISLC3.2 Demonstrate that preventive health measures, including immunisation and population screening, are inclusive of the needs of people with disabilities.

DISLC3.3 Demonstrate ability to perform a comprehensive screening health assessment on a person with a disability, and understanding the high risk conditions associated with each particular disability.

4. Professional and ethical role

DISLC4.1 Maintain up-to-date knowledge of changes in legislative requirements for people with disabilities.

DISLC4.2 Consider further courses or specialist training in the area, as appropriate for the skill required.

5. Organisational and legal dimensions

DISLC5.1 Regularly review practice procedures that support the proactive provision of healthcare including procedures for annual health reviews; patient follow up and recall; and the provision of immunisation, screening and preventative healthcare.

DISLC5.2 Regularly review potential practice procedures to ensure access for people with disabilities.

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