

Disability

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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 the 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 new and holistic concept of disability, which combines the 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.

The main types of disability are:

- Physical disability** A disability associated with physical impairment and physical activity limitation in performing required day to day activities.
- Intellectual disability** The presence of significant limitations in intellectual functioning (usually defined as IQ less than 70), and in at least two areas of adaptive behaviour (eg. self care, communication, social skills) with an onset in the developmental period.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 (eg. intellectual disability and epilepsy, cerebral palsy and vision impairment or epilepsy). Clinicians need to be aware of the likelihood of these comorbidities, and recognise that cognitive and communication difficulties can present barriers to accessing health care. Clinicians should not let the disability distract from or overshadow these health problems, but to approach them as in any other 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 need to be addressed.

Rationale

In 1998, an estimated 16.2% of Australians reported one or more physical/diverse disabling conditions, 2.7% reported one or more intellectually disabling conditions, 7.5% reported sensory or speech impairment and 12% reported a psychiatric disability.⁴ People with disability make up a significant part of most general practice populations due to multiple comorbidities, and general practitioners have a key role in the management of these disabilities and associated health problems. In addition, the disability itself can be a barrier to accessing health services, and the general practitioner will often have a role in facilitating appropriate and timely access to services, as well as providing ongoing management of health issues.

Australian general practitioners and registrars indicate that they receive inadequate training to care for people with intellectual disability and consider that 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.⁵⁻⁷ The vast majority of general practitioners are interested in improving their skills, knowledge and management of this population.⁸

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.

The five domains of general practice – disability

Communication skills and patient-doctor relationship

Effective communication forms the foundation for good general practice management of disabilities. When a patient has significant communication difficulties, whether due to cognitive, social or physical impairment, then additional communication skills and strategies will be required of the medical practitioner to ensure good communication between doctor, patient and, where appropriate, family and/or support workers.

Applied professional knowledge and skills

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. Knowing the cause of the disability therefore informs medical management. The guiding principle when providing medical care to people with a disability, whatever the aetiology, is to employ the same diagnostic and management strategies and standards that apply to patients without a disability.

Population health and context of general practice

People with disabilities are part of, and contribute to, their communities, however, they often encounter barriers to participating in and accessing the services they choose and require. Medical practitioners must 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. General practitioners need to be aware of population based measures for disability prevention (eg. periconception folate supplementation).

Professional and ethical role

Patients and families come from diverse social and cultural backgrounds that may influence their attitudes and knowledge with respect to disability. When working with, and providing care to, people with a disability, fundamental principles that guide good practice include clearly focusing on and respecting the person with the disability, an awareness 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.

Organisational and legal dimensions

Legislative frameworks empower individuals and protect those who are not able to advocate for themselves. Good procedures, including those for regular review and follow up, underpin proactive medical management and 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

Communication skills and the patient-doctor relationship

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

Applied professional knowledge and skills

- Describe the genetic basis and pathophysiology of major disabilities, including Down syndrome, fragile X syndrome, intellectual disability, autism spectrum disorders, cerebral palsy, developmental delay, acquired brain injury, quadriplegia, hemiplegia and the implications of these conditions for various organ systems.
- Explain the importance of making a diagnosis of the underlying cause of a person's disability.
- Outline the likelihood of comorbidities that exist with various syndromes/aetiological diagnoses and their interactions.
- 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.
- Describe how medication and medical and psychiatric conditions may affect behaviour.
- Recognise common psychiatric disorders in people with intellectual disabilities that present as changed or disturbed behaviour.
- 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.

Population health and the context of general practice

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

Professional and ethical role

- Outline the importance of shared responsibility, teamwork and a coordinated and multidisciplinary approach to ensure that the patient receives high quality medical care.
- Critically reflect on your own and the community's attitudes toward people with developmental and acquired disability.
- Identify the role of the health professional in providing quality health care to people with disabilities within a wider service system.
- Describe the fundamental ethical and legal principles underlying the provision of health care, particularly as they apply to people with a cognitive and/or communication impairment in a clinical setting, including the concepts of duty of care, informed consent and information sharing issues.
- Outline the repercussions of a diagnosis of a disability in a family member on the lives of parents, siblings and the community.

- 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.
- Demonstrate respect for modesty of patient and need of patient for privacy during physical examination.

Organisational and legal dimensions

- Outline the importance of practice procedures that support the proactive provision of health care, including procedures for annual health reviews, patient follow up and recall, and the provision of screening and preventative health care.
- Outline the role of guardianship and administrative boards and tribunals.
- 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

Communication skills and the patient-doctor relationship

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

Applied professional knowledge and skills

- 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.
- Appreciate the availability of and importance of preconception review, advice and medications (eg. anticonvulsant use, folate replete diet/supplementation).
- Demonstrate awareness of the likelihood of comorbidities which exist with various syndromes/ aetiological diagnoses and their interactions.
- Describe possible underlying factors in changed or challenging behaviour as a presentation in people with intellectual disability and acquired brain impairment.
- Demonstrate an understanding of the clinical management of the sexual health of people with disabilities and in particular, developmental disabilities.
- 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.
- Demonstrate awareness that the indicators (especially symptoms) of serious illness may be difficult to elicit in people with disabilities with cognitive impairment, and determine ways to overcome these difficulties.

Population health and the context of general practice

- Outline the advances in international descriptions of disability in terms of organ impairment, activity limitation and participation restriction and their influence on medicolegal statements.
- Be aware of the research evidence related the health status, need for screening and health needs of people with various disabilities.
- 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 such services.

Professional and ethical role

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

Organisational and legal dimensions

- Identify practice procedures that support the proactive provision of health care, including procedures for annual health reviews, patient follow up and recall, and the provision of immunisation, screening and preventive health care.
- Consider the appropriate clinical environment for the patient with a disability to optimise their access, ease, comfort and participation in the consultation.

- 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.
- Demonstrate understanding of the role of the Public Guardian and the Guardianship and Administration Acts or legislative equivalent that applies to the local jurisdiction.

Learning objectives across the GP professional life

Vocational registrar

Assumed level of knowledge – prevocational doctor

Communication skills and the patient-doctor relationship

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

Applied professional knowledge and skills

- Demonstrate an understanding of the concept and importance of behavioural and physical phenotypes.
- Demonstrate 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 those barriers.
- Describe the role of the main services and systems available within the community that support people with disabilities and their families.

Population health and the context of general practice

- Demonstrate recognition of the need for health surveillance of groups with developmental disability including mortality, morbidity and level of population screening.
- Demonstrate encouragement of people with a disability to participate in health promotion programs, especially good nutrition and exercise.
- Demonstrate provision of proactive care to families who have a member 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 being able to identify appropriate local supports and resources.
- Outline the public health implications of antenatal testing and folate supplementation, and the impact of the underlying intent and basis of these on the individual with a developmental disability, their family and their community.
- Demonstrate awareness of the need to initiate and provide an annual health assessment for people with cognitive impairments, including examination.
- Act as an advocate for people with a disability and their families to enhance their access to health and community services.
- Identify 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 such services.

Professional and ethical role

- 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 the duty of care.
- 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 health care team, and understand how the medical practitioner can contribute to health care of someone with a developmental disability through such a team.
- Outline the different cultural understandings of disability and their effect on family reactions and responses to the diagnosis of developmental disability.

Organisational and legal dimensions

- Demonstrate practice procedures that support the proactive provision of health care, including procedures for annual health reviews, patient follow up and recall, and the provision of immunisation, screening and preventive health care.
- 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.
- 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 the local jurisdiction.
- Outline practice procedures in place to ensure the appropriate clinical environment is in place for the patient with a disability 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

Communication skills and the patient-doctor relationship

- Demonstrate regular review of communication skills with people with cognitive and physical impairments is part of ongoing professional development activities.

Applied professional knowledge and skills

- Demonstrate regular review of advances in knowledge and practice in the care of people with disability.

Population health and the context of general practice

- 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.
- Demonstrate that preventive health measures including immunisation and population screening are inclusive of the needs of people with disabilities.
- Demonstrate ability to perform a comprehensive screening health assessment on a person with a disability, understanding the high risk conditions associated with each particular disability.

Professional and ethical role

- Maintain up-to-date knowledge of changes in legislative requirements for people with disability.
- Consider further courses or specialist training in the area, as appropriate for the skill level required.

Organisational and legal dimensions

- Regularly review practice procedures that support the proactive provision of health care, including procedures for annual health reviews, patient follow up and recall, and the provision of immunisation, screening and preventative health care.
- Regularly review potential practice procedures to ensure access for people with disability.

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