

Health Care in People with Intellectual Disability

**Guidelines for
General Practitioners**

**Produced by
Centre for Developmental
Disability Studies**

ISBN 0-646-45673-3

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Guidelines for General Practitioners* was published by the
Centre for Developmental Disability Studies for NSW Health

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These guidelines are not a definitive statement of the correct procedures in the treatment of people with intellectual disability, but a general guide to be followed subject to medical practitioner judgement. Every care has been taken to reproduce this material as accurately as possible but the authors and publisher takes no responsibility for errors, omissions or inaccuracies contained herein, or for the consequences of any action taken by any person as a result of anything contained in the publication.

ACKNOWLEDGEMENTS

We thank A/Professor Nicholas Lennox, University of Queensland for permission to reproduce the *Syndrome Specific Checklist* (Appendix 1)

The Project Team gratefully acknowledges the assistance of the New England Division of General Practice. We would particularly like to thank Dr Cheryl McIntyre (Inverell) and Dr Mark Henschke (Armidale) from the New England Division of General Practice for permission to adapt their *Intellectual/Developmental Disabilities Health Checklist* into the *Health Assessment Tool* (Appendix 2A).

We thank the Guardianship Tribunal for permission to reproduce its information sheets on substitute medical consent requirements (Appendix 2B).

We also thank those General Practitioners and other doctors with expertise in intellectual disability, who reviewed the draft Guidelines.

These Guidelines were produced with funding from NSW Health.

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BACKGROUND

About the Guidelines

These Guidelines are designed to assist general practitioners to provide comprehensive health care to people with intellectual disability. The Guidelines are based on the best evidence available at the time of development. They provide information about commonly occurring health conditions that need to be screened for in people with intellectual disability. The Guidelines do not focus on the management of these health conditions, as the principles of management are similar to those in the general population. Where these differ, due to the different circumstances of people with intellectual disability, this is highlighted. Associated with these Guidelines is a Health Assessment Tool, a checklist to ensure that the major health issues are identified.

While the Guidelines refer to people with intellectual disability, many of the principles of diagnosis and management are equally applicable to people with other developmental disabilities, such as cerebral palsy.

Guideline development

The Centre for Developmental Disability Studies (CDDS) is an academic unit associated with the Faculty of Medicine, University of Sydney. CDDS conducts research, teaching and clinical practice in developmental disability. CDDS was contracted by the NSW Health to develop these Guidelines as part of a broader strategy to enhance the capacity of general practitioners (GPs) to effectively assess and treat people with intellectual disability. The Guidelines are based on a comprehensive review of current literature and advice from GPs and other doctors with expertise in the area of intellectual disability medicine. The Guidelines have been reviewed by an Advisory Group consisting of a consumer representative, a doctor with expertise in intellectual disability, a Clinical Nurse Consultant and representatives from the NSW Alliance of GPs, NSW Council for Intellectual Disability, NSW Department of Ageing, Disability and Home Care and NSW Health.

Using the Guidelines

The Guidelines are divided into 3 main parts.

Part 1 – Health status and practical guidelines to treating people with intellectual disability

Part 2 – Background and supporting information on intellectual disability

Part 3 – Appendices - A health assessment tool and other resources to augment diagnosis and treatment.

Part 1: Ensuring Optimal Quality Health Care

Principles to guide patient care

People with intellectual disability are entitled to the same health care that is available to others in the community. The NSW Disability Services Act (1993) outlines the fundamental principles in delivering services to people with intellectual disability in NSW. It provides the framework for health professionals, as well as other service providers for working with people with intellectual disability. Both the NSW Anti-Discrimination Act and the Federal Disability Discrimination Act state that health services cannot discriminate against people with a disability.

Health status of people with intellectual disability

Research shows that people with intellectual disability:

- Tend to have a higher level morbidity than the general population, with health problems often being multiple, chronic and complex (Beange, McElduff & Baker, 1995).
- Have a higher prevalence of certain medical conditions, as well as life style related health risks such as obesity and poor physical fitness.
- Experience greater barriers in accessing health care (Durvasula & Beange, 2001).
- Are less likely to be offered preventative health measures such as blood pressure screening, cancer screening and routine immunisations (Beange & Bauman, 1990; Kerr, Richards, & Glover, 1996; Wilson & Haire, 1990).

As a result of these factors, which are compounded by communication and cognitive difficulties, the health conditions of people with intellectual disability are more likely to be under-diagnosed and under-treated (Beange & Bauman, 1990; Lennox & Kerr, 1997; Wilson & Haire, 1990).

Factors contributing to under diagnosis / under treatment

- Cognitive and communication difficulties can make it difficult for people with intellectual disability to recognise and communicate pain, discomfort or other symptoms of ill health. As a result, reliance is often placed on family members or support workers to bring health problems to the attention of the General Practitioner, and to provide a medical history. However, these support people may also be unaware of symptoms, and with a turnover in support staff, an accurate history may be difficult to obtain.

- Physical examination may be difficult due to anxiety or challenging behaviours in the person with intellectual disability.
- The combination of difficulties with communication, accurate history taking and physical examination may mean that assessments are lengthy, and this time is not always available in a busy general practice.
- Negative attitudes and perceptions about the quality of lives of people with intellectual disability can also affect assessment and management.
- **“Diagnostic overshadowing”** – this is a phenomenon where clinicians may ascribe physical or behavioural symptoms to the intellectual disability, and not look for associated physical or mental health disorders. The disability is often seen as the illness and other general health evaluation is not conducted. This can lead to some conditions being overlooked.

Case study

Frank is a person with severe intellectual disability. He presented with serious self-injurious behaviour, hitting the side of his face. The staff member accompanying Frank did not know him well. The doctor attributed his behaviour as being typical of someone with a severe intellectual disability. Frank was later found to have a dental abscess that had previously been missed.

Frequently occurring health conditions

Prevalence studies have identified that certain medical conditions and risk factors occur more frequently in people with intellectual disability. The International Association for the Scientific Study of Intellectual Disability (IASSID) has made recommendations for the detection and management of these conditions in people with intellectual disability (see <http://www.iassid.org>).

The IASSID Health Guidelines for Adults recommend action in the following areas:

Dental health	Sensory impairments
Nutrition	Constipation
Epilepsy	Thyroid disease
Mental health	Gastro-oesophageal reflux disease and H.pylori
Osteoporosis	Medication review
Immunisation status	Physical activity and exercise
Comprehensive health assessments	Genetics
Women’s Health	

Common health problems in people with intellectual disabilities

- **Respiratory illness** - common in those with dysphagia, immobility or scoliosis. It is and is the most common cause of death in people with intellectual disability. In those with dysphagia, aspiration may cause recurrent chest infections or chronic wheezing.
- **Vision impairment** – ocular disorders are common especially in those with Down syndrome, and include refractive errors, cataracts and degenerative corneal changes.
- **Hearing impairment** – highest prevalence in people with Down syndrome, but all with intellectual disability are at increased risk. Both conductive and sensorineural loss can occur. Many cannot indicate hearing loss, so need to do routine screening.
- **Oral health problems** - Up to 7 times more common than in the general population, especially periodontal disease, dental caries and moderate to severe malocclusion.
- **Nutrition problems** – both overweight and underweight are common conditions. Those with dysphagia are especially likely to be underweight.
- **Gastro-oesophageal reflux disease and helicobacter pylori infection** – especially common in those with severe levels of intellectual disability, cerebral palsy, or if in residential care.
- **Constipation** – especially in those with dysphagia, underweight or reduced mobility.
- **Epilepsy** – prevalence ranges from 14-44% (Bowley & Kerr, 2000).
- **Mental health problems** are common. In an Australian cohort of children and young people with intellectual disability, 41% had severe emotional and behaviour disorder (Einfeld & Tonge, 1996). Depression, dementia and schizophrenia occur more commonly than in the general population.
- **Thyroid disease** – both hyperthyroidism and hypothyroidism can occur. People with Down syndrome are especially at risk of hypothyroidism.
- **Osteoporosis, osteopenia** – risk factors are hypogonadism, Down syndrome, immobility, underweight and long term anticonvulsant therapy.
- **Obesity and poor physical fitness** – these life-style related conditions are especially seen in those with mild and moderate levels of intellectual disability. These should not be considered to be inevitable in people with intellectual disability.
- **Genetic disorders** – increasingly being recognised as causes for intellectual disability. Diagnosis is important, even in adults. (See Table 1)
- **Polypharmacy** – many are on multiple medications that are not regularly reviewed, and are therefore at increased risk of side effects or drug interactions.

Table 1 summarises the current recommendations for detection and management of the common health problems seen in people with intellectual disability. These are based on a number of sources, including the *IASSID Health Guidelines*.

Table 1: Health evaluation and treatment recommendations

Oral Health	Ensure at least annual dental examinations, more frequently if oral health problems are present
Vision	Routine ophthalmological assessment every 5 years from age 45 years; an extra assessment at 30 years for people with Down syndrome. For those with existing vision / ocular problems, more frequent reviews may be necessary.
Hearing	Routine audiological assessment every 5 years from age 45 years; for people with Down syndrome, assessment every 3 years throughout life.
Nutrition risk screening	Annually or more frequently if indicated. Those identified to have underweight and or dysphagia should be referred for multidisciplinary assessment that includes evaluation by a speech pathologist and dietitian.
Constipation	Risk factors include severe intellectual disability, immobility, or dysphagia with inadequate food/fluid intake. Constipation can have serious consequences such as megacolon and perforation. Treat proactively with dietary modification and medications.
Epilepsy	Those with epilepsy should have regular assessment of - seizure frequency, anticonvulsant therapy (with serum levels as indicated), anticonvulsant side effects and injury risk. An epilepsy management plan should be in place and review by a neurologist at least on an annual basis is recommended.
Thyroid disease	Symptoms may be non-specific and insidious. Both hypothyroidism and hyperthyroidism are common. Consider thyroid disease in those with behavioural or mood changes. Annual thyroid function tests are recommended all people with Down syndrome, or those with existing thyroid disease. For all others with intellectual disability who are not symptomatic, thyroid function tests are recommended every 3-5 years.
Gastro-oesophageal reflux disease (GORD)	Often unrecognised in people with severe intellectual disability. Typical symptoms of vomiting and retrosternal pain may not be present, but may refuse to eat, have agitation and distress during or after meals, self-injurious behaviour, night time coughing, dental erosions, iron deficiency anaemia, or weight loss. For those without alarm symptoms, a therapeutic trial of a proton pump inhibitor is reasonable. If alarm symptoms are present (e.g. weight loss, haematemesis, or anaemia), endoscopy is required.

<p>Helicobacter pylori infection</p>	<p>Common, especially in those who are or have been in large residential care. Sequelae of h.pylori infection include gastritis, peptic ulcer and gastric cancer, but people with intellectual disability may not be able to complain of pain. Therefore h. pylori should be screened for in high risk individuals. Many may not be able to do the diagnostic urea breath test. An alternative is to do h.pylori serology and treat if positive. Test for eradication with faecal antigen test.</p>
<p>Osteopenia/ Osteoporosis</p>	<p>More common in people with intellectual disability. Risk factors include hypogonadism, immobility, underweight, presence of Down syndrome and vitamin D deficiency. Baseline Bone Mineral Density (BMD) should be considered in all adults with intellectual disability, especially in those with risk factors, or those with a history of minimal trauma fracture. Risk factors should be treated where possible, and appropriate therapy for osteoporosis instituted (e.g testosterone/ oestrogen replacement therapy, bisphosphonates). Give advice on falls prevention measures.</p> <p>Annual vitamin D and calcium levels are recommended in those with inadequate sun exposure, multiple anticonvulsant therapy or malabsorption. Vitamin D and calcium supplements are indicated in those with low levels.</p>
<p>Medication review</p>	<p>Polypharmacy is common in people with intellectual disability, with its attendant risks of side effects and drug interactions. Review all medications 3-6 monthly – re-assess the need for continuing the medication, re-assess the dose, side effects and compliance. Webster packs and dosette boxes help to ensure compliance and minimise the possibility of medication errors. This is particularly important where there are multiple carers or support staff.</p>
<p>Immunisations</p>	<p>NHMRC recommendations for immunisation schedules should be followed. Hepatitis A immunisation is recommended for all people with intellectual disability, and Hepatitis B immunisation is recommended for those in residential or non-residential facilities. Annual influenza and 5 yearly pneumococcal vaccines are recommended for those with chronic cardiac, renal or respiratory disease, or diabetes.</p>
<p>Physical activity</p>	<p>Many people with intellectual disability have low levels of physical activity. At least 30 minutes a day of moderate intensity physical activity is recommended on most days of the week. Group activities and incentives encourage regular participation. For those with physical disabilities, activities can be modified. An assessment by a physiotherapist or exercise physiologist may be useful.</p>
<p>Genetics</p>	<p>Genetic causes for intellectual disability are common. Even in an adult, the detection of a cause is important for prognosis and allows for proactive management of associated health problems. A diagnosis can also have an impact on the individual's family, and genetic counselling may be required. A genetic assessment should be considered in all adults without a diagnosis for their intellectual disability.</p>

<p>Women's health</p>	<p>Recommendations as for the general population. Annual breast examinations with 2 yearly mammograms for women over the age of 50 years are recommended. Pap tests should be done every 2 years between the ages of 18 and 70, if the woman has ever been sexually active. Note that women with intellectual disabilities are at increased risk of sexual assault. Where the Pap test is difficult to do and sedation may be required, the issues should be discussed with all concerned and the risks and benefits balanced. (See Guidelines for Preventative Women's Health Care for Women with Disabilities for more details – http://www.csp.nsw.gov.au or http://www.cdds.med.usyd.edu.au)</p> <p>Most women with intellectual disability can manage their own menstruation, especially with education. Menstrual disorders are managed in the same way as in other women. (See website of the Centre for Developmental Disability Health Victoria for "Menstrual management and women with an intellectual disability: a guide for GPs" – http://www.cddh.monash.org/products/index-print.html)</p>
<p>Mental health problems / difficult behaviours</p>	<p>Mental health disorders are common and may present in an atypical manner. With behavioural changes, look for underlying physical health problems (e.g. pain, discomfort, thyroid disease) or external factors (e.g. change of support staff, loss of family or friends due to death, illness or moving away). Further evaluation with behavioural assessment by a psychologist, and or referral to a psychiatrist may be required (see below for a more detailed discussion.)</p>
<p>Dementia</p>	<p>People with Down syndrome are at risk of early onset Alzheimer's disease and may present with symptoms in their 40s or earlier. The differential diagnosis includes hypothyroidism, depression and sensory impairments, all of which are more common in people with Down syndrome. Dementia assessment tools specifically designed for people with intellectual disability are available. Refer to an ACAT service, psychiatrist or adult developmental disability medical service for further evaluation.</p>

In addition, some common intellectual disability syndromes are associated with specific health problems and these should be monitored closely. These are listed in Appendix 1.

Mental Health

Challenging / Difficult behaviours

- Behaviour change is a common reason for people with intellectual disability to see a GP. Often the behaviour can be an attempt by the person to communicate discomfort or distress due to illness, pain, environmental stresses and/or psychological problems. (Davis and Mohr 2004)
- Management may require a combination of medical, psychiatric or behavioural interventions. Any existing physical and/or mental health problems need to be addressed. If these are excluded as causes for the behaviour, a psychologist can do a functional assessment to determine what may be causing the behaviour and how best to manage it. With this information, a behavioural intervention support plan can be developed for support staff, families and other carers to follow.

Dual diagnosis

- In the Disability field the term *dual diagnosis* generally refers to the person as having a diagnosis of intellectual disability coexisting with a psychiatric diagnosis.
- People with intellectual disability have a higher prevalence of psychiatric conditions such as depression, schizophrenia and anxiety disorders than others in the population.
- Due to cognitive and communication problems, people with these disorders may have an atypical presentation and diagnosis may be difficult. Assessment by a psychiatrist with experience in the area of intellectual disability is useful.
- People with intellectual disability have the same right to access mental health services offered by the NSW Government, as do other citizens.

Autistic Spectrum Disorders

- These include a wide range of conditions that include autistic disorder, Asperger's syndrome and atypical autism.
- The prevalence across the spectrum ranges from 1.0 in 1000 to 3.0 in 1000.
- These disorders typically have an onset in the first 3 years of life and are characterised by language or other communication difficulties, problems in social interactions and a restricted range of activities and interests. Diagnosis is often made in childhood.
- The majority of people with autism have an intellectual disability. (American Psychiatric Association, 1994).

- Many people with autism feel anxious in an unpredictable environment, with changes to their routine, and may also feel overwhelmed in crowded or noisy environments. They may have heightened sensitivity to particular sounds (e.g. lawn mowers) or textures.
- Behaviour difficulties may occur and are often related to anxiety resulting from an unpredictable environment, or exposure to noises or textures to which an individual is susceptible. The communication difficulty often exacerbates this anxiety.
- Management of these difficult behaviours often involves multiple strategies. These may include environmental changes to ensure quieter and more predictable surroundings, use of a timetable to ensure structure to the person's activities and referral to a speech pathologist for assessment and advice on improving the person's communication. A psychologist can do a behaviour assessment and provide advice on a behaviour intervention plan. Psychotropic agents may also be required.

Comprehensive health assessment

Due to the multiple, chronic and complex nature of health conditions in many people with intellectual disability, regular (usually annual) comprehensive health assessments are recommended. The health assessment should include:

- Review of current symptoms and health problems
- Review of behavioural / emotional status
- Medication review
- Weight and nutritional assessment
- Hearing and vision screening with referral for formal testing as appropriate
- Health maintenance
 - update immunisations according to NHMRC guidelines
 - cervical and breast screening according to national guidelines
 - review diet and physical activity and advise accordingly
 - check blood pressure
 - check for skin cancers
 - check testes
 - review history of tobacco and alcohol use and advise accordingly
- Review menstrual history / menopause symptoms
- Review family / social / residential /work situation
- Identify who is the “person responsible” to give consent for medical treatment
- Full physical examination
- Investigations / referrals as indicated

A health assessment tool that includes these items can be useful in ensuring that the major areas are covered. (see Appendix 2A for an example). Such an assessment tool can be used to identify health needs and inform the development of a GP Management Plan or Team Care Arrangement (Items 721 and 723 respectively of the Medicare Benefits Schedule for Enhanced Primary Care Chronic Disease Management items).

General Practitioner: Patient Communication

Due to the high frequency of communication difficulties in people with intellectual disability, communication may take more time and the use of non-verbal communication may be necessary. The following are useful communication strategies to use with people with cognitive and /or communication difficulties:

- Always try to speak directly with the person with a disability, rather than a family member/ carer or support worker. Find out if the person wishes the carer or support worker to stay for the consultation, and if they are happy for them to speak on their behalf.
- Be aware that while the person with a disability may have difficulty in speaking, he or she may be able to understand what is said to them.
- Find out how the person communicates, e.g. how do they indicate “yes” or “no” before asking questions.
- If a person uses a communication device, ask them to show you how to use it.
- Before you start, explain what will happen in the consultation, using brief, simple and direct sentences. Some people may be anxious, and not know what to expect or how to participate.
- Before examining the person, tell or show them what you are going to do and why you are doing it. Check they understand what you have said, and that they agree. Supplement verbal communication with pictures and gestures such as pointing to parts of the body. (Iacono & Johnson 2004)
- When giving advice or instructions, check that the person has understood by asking them to repeat what you have said in their own words. Let the person know you understand them. If you have trouble understanding, ask them to repeat. Don't pretend that you understand.
- Don't ask questions in a way that suggests an answer. Check responses to your question by asking again in a different way.
- Some people may take time to answer your questions. A good rule of thumb is to wait at least 10 seconds for a response.
- Some people may not be able to read letters, make appointments, tell the time or read instructions on medications. Family members, other carers or support workers can assist here.
- Understanding the concept of time may be difficult. Use examples from their daily routines, e.g breakfast, lunch and dinner, rather than three times a day. Try to relate questions to familiar routines or events in their life.

Personal health records

Because an intellectual disability is life long, many different health professionals may be involved with the person over time. Contributing to an individualised personal health record held by the person, family member, carer or support worker can have many benefits, such as:

- Keeping track of the medical history.
- Avoiding problems arising from lost or forgotten information about immunisations, allergies and drug reactions.
- Avoiding unintentionally using medications or treatments that have previously been tried.
- Providing a record of screening tests and other preventive health care measures, with a reminder of what still needs to occur.

Consent to medical treatment and the law

In NSW the Guardianship Act 1987 spells out who is legally able to consent to medical and dental treatment. Before medical or dental treatment is provided to a patient, the medical/dental practitioner has a professional and legal responsibility to obtain consent for the treatment.

- Consent is only valid if the patient understands and agrees to the nature of the proposed treatment and its effects. The patient has a right to refuse or to withhold consent to the proposed treatment.
- If a patient is not able to comprehend the proposed treatment options or is unable to communicate their choice, the practitioner must seek lawful substitute consent. The law spells out who can legally give substitute consent. This is usually from the “*person responsible*”.

Note: support workers or other paid carers cannot act as the “person responsible”

- Medical Treatments are categorised as “Urgent”, “Minor”, “Major” and “Special”

Table 2 summarises the main types of medical treatments and the type of consent required for each. For full details and definitions, see Appendix 2B for Guardianship Tribunal of NSW fact sheets on *Person responsible*, definitions of “*minor*”, “*major*” and “*special*” *medical treatments*.

Table 2: Types of consent required for medical treatment

Category of treatment	Consent required	Action if consent not available
<p>Urgent</p> <ul style="list-style-type: none"> - to save life - prevent serious damage to health - prevent or alleviate significant pain 	NIL	N/A
<p>Minor</p> <p>All medical or dental treatments except those listed as "Major" or "Special" e.g - most medications, sedation for minor procedures</p> <ul style="list-style-type: none"> - general anaesthetic to reduce fractures or for endoscopies 	"Person responsible"	If there is no "person responsible", or cannot be contacted, can treat if patient not objecting. Make note in patient record that he/she is not objecting and that the treatment is necessary.
<p>Major</p> <p>e.g. drugs that affect CNS, except for those listed in "Minor" or "Special"</p> <ul style="list-style-type: none"> - long acting injectable hormonal substances for contraception or hormonal regulation - testing for HIV - any treatment with substantial risk 	"Person responsible"	If there is no "person responsible", or cannot be contacted, only the Guardianship Tribunal can consent.
<p>Special</p> <p>e.g. termination of pregnancy, hysterectomy, tubal ligation or other sterilisation, use of anti-androgen therapy for behaviour control</p>	Only Guardianship Tribunal can consent	N/A

NB: If person or "person responsible" objects to non-urgent treatment, only the Guardianship Tribunal can consent

Multidisciplinary approach

- Many people with intellectual disability have multiple health and functional problems, and may therefore see numerous sub-specialists and allied health professionals. As a result, care can sometimes be fragmented. Coordination of care is therefore vital and the General Practitioner is ideally placed to do this, in conjunction with the person's case manager.
- Health professionals specialised in the specific health needs of individuals with an intellectual disability are available as a support to some mainstream health services. These professionals include speech pathologists, psychologists, physiotherapists, orthotists, occupational therapists, dietitians, audiologists, and optometrists.

They may be contacted through the regional office of Department of Ageing, Disability and Home Care (DADHC), or they may be in private practice. In some areas, medical practitioners with expertise in the field of intellectual disability medicine are able to provide assessment and /or consultation.

Practical tips for consultation

- When seeing a patient with intellectual disability for the first time, plan for a longer appointment, or several short appointments to enable a full background history to be taken and physical examination to be done.
- It may not be possible to achieve all medical goals in one or two visits. Set short, medium and long-term goals and assign an order of priority.
- Ask family members/other carers/support workers to bring any previous reports or results of assessments/tests.
- Note the contact details of the person’s guardian or “person responsible”, if there is one.
- Find out how the person communicates. If the person uses a communication device, remind family members/other carers/support workers to bring the device to each consultation
- Give written instructions for any health advice or treatment regimen, as support workers change, or the person may receive care in several settings.

Part 2: The Facts

Definitions

Intellectual disability is characterised by:

- Significant limitations in a person's intellectual functioning, usually defined as an IQ <70, and
- Deficits in at least two areas of adaptive functioning such as self care, social skills and communication, and
- An onset in the developing years, usually defined as before the age of 18.

More recently, the concept of *Support Needs* that can assist the person to overcome some of these limitations has been added to the definition.

Intellectual disability is also known by other terms, e.g *Mental Retardation* (in the USA), *Learning Disability* (in the UK) and *Intellectual Handicap*. The related term, *Developmental Disability* refers to those people who have physical and/or intellectual impairment with deficits in adaptive functioning, with an onset before the age of 18 years. Intellectual disability is a subset of developmental disability and most, but not all people with a developmental disability also have an intellectual disability.

Classification of intellectual disability

Traditionally classified by IQ levels:

Mild:	IQ 50-55 to 70
Moderate	IQ 35-40 to 50-55
Severe	IQ 20-25 to 35-40
Profound	IQ < 20-25

However, classification purely by IQ is not very useful in practical terms, as it may have little relevance to the person's ability to function in various situations. Classification by type and extent of support needs yields more information. Support needs are classified according to intensity of support required, the length of time the support is required and the situations in which it is required.

The assessment of an intellectual disability requires a cognitive assessment, as well as an evaluation of adaptive behaviour skills by a psychologist. A behavioural psychologist can also assess behavioural function.

Prevalence

People with intellectual disability comprise 1.86% of the Australian population (Wen, 1997). This equates to approximately 108,000 people across NSW.

Aetiology

Aetiology for intellectual disability can be determined in over half the people seen. A structural or other defined cause is more likely to be found in people with severe intellectual disability, whereas familial causes are more common in people with a mild intellectual disability. The aetiology may be prenatal (e.g. chromosomal and genetic disorders, congenital infections, toxins), perinatal (e.g. hypoxic-ischaemic injury, prematurity) or postnatal (meningitis, traumatic brain injury). Genetic causes are increasingly being detected.

Life expectancy

The life expectancy of people with intellectual disability varies according to the level of disability and presence of associated medical conditions. Although in recent decades life expectancy has increased, it remains reduced when compared with the rest of the population.

Western Australian research shows that median life expectancies of people with mild, moderate and severe intellectual disability are 74.0, 67.6 and 58.6 years respectively (Bittles et al, 2002). The Standardized Mortality Ratio (SMR) in a northern Sydney population of people with intellectual disability was 4.9 (Durvasula, Beange & Baker, 2002). For the same level of intellectual disability, people with Down syndrome generally have lower life expectancy than those with intellectual disability from other causes. This is due to the additional risk factors for premature death such as congenital heart disease and Alzheimer's disease.

Life circumstances of people with intellectual disability

The majority of people with intellectual disability now live in the community, either independently, with families, or in supported accommodation (Braddock et al, 2001), with only a minority in institutional care. As such, this population relies on generic health care. Many people with intellectual disability work in supported or semi-supported environments and some work in open employment. People with higher support needs may attend day programs where they learn living skills.

In NSW, the Department of Ageing, Disability and Home Care (DADHC), through its own services or through the funding of non-government agencies, provides accommodation, day programs and respite care for people with intellectual disability. The aim of these is to provide a quality of life similar to that of other members of the community. The Commonwealth Government funds employment services. In NSW people with intellectual disability who receive an accommodation service from DADHC are offered annual comprehensive health checks, using an assessment tool called CHAP (Comprehensive Health Assessment Program). As a GP you may be asked to complete a section of this.

Depending on their support needs, people with intellectual disability may have a caseworker or other support worker accompany them to the medical consultation. The role of the support worker is to assess the needs of the person with intellectual disability, to plan and coordinate services (including health care services) and provide support for independent community living.

Family members or another carer may be the “person responsible”, and may lawfully be able to give or withhold consent to treatments where the person with a disability is unable to do so. Support workers cannot act as substitute decision-makers or be the “person responsible”. They can provide information on who is the appropriate “person responsible”, or whether a guardian has been appointed with medical, dental and health care functions. (See Consent, Medical Treatment and the Law)

APPENDIX 1: SYNDROME SPECIFIC LIST FOR GENERAL PRACTITIONERS

Reproduced with permission from Nick Lennox, Associate Professor and Director Queensland Centre for Intellectual and Developmental Disability, School of Population Health, University of Queensland.

	CEREBRAL PALSY 1:500	DOWN SYNDROME 1:700	PRADER-WILLI SYNDROME 1:10 000-25 000	FRAGILE X SYNDROME 1:6000	PHENYLKETONURIA 1:10 000-1:20000
AUDIOVISUAL	Visual Impairment Hearing Impairment	Visual impairment (multifactorial), cataracts Hearing impairment (multifactorial) (Annual assessments recommended)	Strabismus Myopia	Visual Impairment (multifactorial) Hearing Impairment Recurrent ear infections	
ENDOCRINE		Hypothyroidism (Annual TFT recommended)	Type 2 diabetes Hypogonadism Delayed puberty		
PSYCHIATRIC/ PSYCHOLOGICAL	Depression Variable intellectual capacity	Depression Alzheimer's type dementia -clinical onset uncommon before 40yrs	Hyperphagia Impulse control difficulties Self-injury	Attention deficit /hyperactivity Variable intellectual capacity Disabled in social functioning	Variable intellectual capacity Phobic anxiety Disabled in social functioning
C.N.S.	Epilepsy	Epilepsy Usually clonic/tonic		Epilepsy - clonic/tonic, complex partial	Epilepsy Hyperactivity Tremor, pyramidal ,signs Extrapyramidal syndromes
CARDIOVASCULAR		Congenital Heart Defects (in 40 to 50%)		Aortic dilatation, Mitral Valve prolapse	
MUSCULAR/ SKELETAL & SKIN	Orthopaedic problems Neuromuscular problems	Atlantoaxial instability Skin disorders, alopecia, eczema	Scoliosis, Kyphosis Hypotonia Skin picking	Connective tissue dysplasia Scoliosis Congenital Hip Dislocation	
OTHER	Genito-urinary problems Incontinence Constipation Dental problems Recurrent aspiration Oesophagitis, gastroesophageal reflux +/- bleeding/anaemia Swallowing/eating difficulties	Blood dyscrasias childhood leukaemia Sleep apnoea Increased susceptibility to infections, Coeliac disease	Infantile failure to thrive, then hyperphagia and severe obesity High tolerance to pain Decreased ability to vomit Sleep apnoea Osteoporosis Undescended testes Dental Abnormalities	Herniae (CT related) Abnormalities of speech and language	Eczema
INHERITANCE		Most cases are sporadic; 4% due to translocation involving chromosome 21 or rarely parental mosaicism	Mostly sporadic; Microdeletion of 15q11 in 70% ; rest - maternal disomy	X linked	Autosomal recessive

ANGELMANN SYNDROME <1:10 000		WILLIAMS ?<1:20 000		RETT 1:14 000 FEMALES		NOONAN <1:10 000		TUBEROUS SCLEROSIS 1:6 000-17 000		NEUROFIBROMATOSIS 1:3000	
AUDIOVISUAL	Glaucoma	Hyperacusis Strabismus	Refractory errors	Strabismus, refractive errors Vision/hearing impairments	Retinal tumours Eye rhabdomyomas	Hearing impairment (Glioma affecting auditory nerve)					
ENDOCRINE						Various endocrine abnormalities					
PSYCHIATRIC/ PSYCHOLOGICAL	Easily excitable Hyperactive	Variable intellectual capacity Attention deficit problems in childhood	Severe intellectual disability	Mild intellectual disability	Variable intellectual capacity Behavioural difficulties Sleep problems	Variable intellectual capacity depending on site of the tumours Epilepsy					
C.N.S.	Severe developmental delay Epilepsy	Perceptual & motor function reduced	Epilepsy Vasomotor instability	Epilepsy	Cerebral astrocytomas Epilepsy						
CARDIOVASCULAR		Cardiac abnormalities Hypertension, CVAs Chronic hemiparesis	Prolonged QT interval	Pulmonary Valvular Stenosis ASD, VSD, PDA	Rhabdomyomas Hypertension						
MUSCULAR/ SKELETAL/SKIN	Joint contractures and scoliosis (in adults)	Joint contractures Scoliosis Hypotonia	Osteopenia Fractures Scoliosis	Scoliosis Talipes equinovarus Pectus carinatum/ excavatum	Bone Rhabdomyomata	Skeletal abnormalities esp. Kyphoscoliosis					
OTHER	Speech impairment Movement & balance disorder Characteristic EEG changes	Renal abnormalities	Hyperventilation Apnoea Reflux Feeding difficulties Growth failure	Abnormal clotting factors, platelet dysfunction Undescended testes, deficient spermatogenesis Lymphoedema Hepatosplenomegaly Cubitus valgus, hand abnormalities	Kidney & lung hamartomata Polycystic kidneys Liver Rhabdomyomata Dental abnormalities Skin lesions	Variable clinical phenomena depending on the location of the neurofibroma Tumours are susceptible to malignant change Other varieties of tumours may be associated					
INHERITANCE	Variety of genetic mechanisms on Chromosome 15	Microdeletion on long arm of chromosome 7	Mainly sporadic	Autosomal dominant; may be sporadic	Autosomal dominant	Autosomal dominant					Autosomal dominant

HEALTH ASSESSMENT TOOL

APPENDIX 2A: HEALTH ASSESSMENT TOOL FOR ADULTS WITH INTELLECTUAL DISABILITY

Adapted from the New England Division of General Practice Checklist and other sources

Date

Record number.....

Last name.....

First name.....

DOB.....

Age.....

Gender M F

Person responsible / Legally appointed Guardian (Name/relationship/contact details)

.....
.....

Primary carer..... Relationship.....

Residence:

independent / share with family group home
 hostel/boarding house institution/nursing home

Accommodation Service (if not with family).....

Hours of paid support / day.....

Respite care: Yes No Hours/month.....

Day placement: Type..... Hours/week..... None

Primary Diagnosis..... Unknown

Level of intellectual disability None Mild Moderate Severe Unknown

Mobility: walks independently walks with assistance (person / stick / frame)
 transfers uses wheelchair

Communication skills: sentences words/phrases articulation difficulties
 gestures/signing communication device

Eating: independent requires assistance fed by others tube fed

Bathing: independent requires assistance fully dependent

Dressing: independent requires assistance fully dependent

Toileting: bladder continence requires supervision/ assistance bladder incontinence
 bowel continence requires supervision/assistance bowel incontinence

Domestic skills: (e.g. cooking, cleaning) Yes No

Community living skills: (e.g. shopping, banking) Yes No

Uses public transport: independent with assistance No

Literacy skills: Yes No

Deterioration of functional abilities in last 12 months: Yes No

.....

Past History:

.....

.....

Family History:

.....

Social History:

.....

Medications: (including OTC / complementary medicines)

.....

.....

.....

Allergies:

HEALTH CONDITIONS – FINDINGS/ACTION TAKEN

Condition	Findings	Details / Actions:
Epilepsy	Date last seizure: Frequency of seizures: Type: <input type="checkbox"/> Generalised <input type="checkbox"/> Focal <input type="checkbox"/> Partial complex <input type="checkbox"/> Pseudoseizures	Epilepsy management plan: <input type="checkbox"/> Yes <input type="checkbox"/> No Date of last AED review Date of last neurology review
Gastro-Oesophageal Reflux / H.pylori	<input type="checkbox"/> Recurrent vomiting distress with meals / <input type="checkbox"/> Reluctance to eat <input type="checkbox"/> Dental erosions <input type="checkbox"/> Endoscopy Date: <input type="checkbox"/> H. Pylori test Date:	Result <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal Result <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal
Dysphagia	<input type="checkbox"/> Difficulties swallowing <input type="checkbox"/> Coughs/chokes with eating/ drinking <input type="checkbox"/> Recurrent chest infections <input type="checkbox"/> Chronic wheeze <input type="checkbox"/> underweight	<input type="checkbox"/> Nutrition/swallowing risk assessment Date: <input type="checkbox"/> Dietitian referral <input type="checkbox"/> Speech pathologist referral <input type="checkbox"/> Modified Barium Swallow Date:
Bowel	<input type="checkbox"/> Recent changes <input type="checkbox"/> Constipation <input type="checkbox"/> Diarrhoea <input type="checkbox"/> Incontinence	
Bladder	<input type="checkbox"/> Toilet timed <input type="checkbox"/> Wetting accidents <input type="checkbox"/> Nocturia <input type="checkbox"/> Incontinence	
Osteoporosis	<input type="checkbox"/> Risk factors present <input type="checkbox"/> DEXA Date:	Result <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal
Behaviour	<input type="checkbox"/> Verbal aggression <input type="checkbox"/> Physical aggression <input type="checkbox"/> Self injury <input type="checkbox"/> Non compliance <input type="checkbox"/> Other	
Mental Health	<input type="checkbox"/> Anxiety <input type="checkbox"/> Depression <input type="checkbox"/> Psychosis <input type="checkbox"/> Dementia <input type="checkbox"/> Other	

Diet	<input type="checkbox"/> Low fat <input type="checkbox"/> Diabetic <input type="checkbox"/> Exclusion e.g. wheat free, dairy free <input type="checkbox"/> Soft/puree <input type="checkbox"/> High fat / high calorie	<input type="checkbox"/> Dietary advice given <input type="checkbox"/> Dietitian referral
Physical activity	Type: Minutes per session: Times per week: Intensity:	<input type="checkbox"/> Physical activity advice given <input type="checkbox"/> Physiotherapy / Exercise physiologist referral
Sleep Pattern	<input type="checkbox"/> Frequent waking <input type="checkbox"/> Snoring <input type="checkbox"/> Apnoeic episodes <input type="checkbox"/> Daytime drowsiness <input type="checkbox"/> Other sleep difficulties	<input type="checkbox"/> Referral for sleep studies
Sexual Health	<input type="checkbox"/> Never been sexually active <input type="checkbox"/> Contraception <input type="checkbox"/> Safe sex awareness	
Medications	No. of regular medications: No. of prn medications: <input type="checkbox"/> OTC/complementary medications <input type="checkbox"/> Adverse effects <input type="checkbox"/> Webster pack / dosette box	<input type="checkbox"/> Home medicine review (Item 900)
Drug Review Cigarettes:	<input type="checkbox"/> Smoker– cigarettes/day: <input type="checkbox"/> Ex-smoker <input type="checkbox"/> Never smoked	<input type="checkbox"/> Advice given
Alcohol:	<input type="checkbox"/> Standard drinks/week: <input type="checkbox"/> Non-drinker	<input type="checkbox"/> Advice given
Illicit Drugs:	<input type="checkbox"/> Other drugs:	<input type="checkbox"/> Advice given
Oral health	Last dental assessment: <input type="checkbox"/> Dental problems	<input type="checkbox"/> Dental referral <input type="checkbox"/> Advice given about oral health
Height	_____cm	
Weight	_____kg	
BMI	_____kg/m ²	
Waist /hip ratio	_____	
Blood Pressure	_____mmHg	
Urinalysis	<input type="checkbox"/> Normal <input type="checkbox"/> Protein <input type="checkbox"/> Glucose <input type="checkbox"/> Blood	

Examination Dysmorphism CVS Respiratory GIT Musculoskeletal CNS Skin Feet	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal	Genetic referral <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Hearing	Ear canals clear <input type="checkbox"/> Yes <input type="checkbox"/> No Whispered words at 3m <input type="checkbox"/> Yes <input type="checkbox"/> No Last audiometry: <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Uses hearing aids	<input type="checkbox"/> Audiometry referral Date:
Vision	Last assessment: <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Wears glasses	<input type="checkbox"/> Ophthalmologist referral <input type="checkbox"/> Optometrist referral
Women's Health Menstruation Breast check Menopause Pap test Mammogram:	<input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A	Date: <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal Date: <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal
Men's Health Testes Prostate	<input type="checkbox"/> Normal <input type="checkbox"/> Abnormal <input type="checkbox"/> Normal <input type="checkbox"/> Abnormal	
Immunisation Hepatitis A Hepatitis B Influenza Pneumovax ADT MMR	<input type="checkbox"/> childhood schedule current <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> No	Date: Date: Date: Date: Date: Date:
Lipids/BSL Cholesterol: TGs Fasting BSL:	Date: _____ mmol/L _____ mmol/L _____ mmol/L	<input type="checkbox"/> Not applicable <input type="checkbox"/> Dietary advice <input type="checkbox"/> Statin <input type="checkbox"/> Hypoglycaemic agent
Thyroid Function	Date: TSH = _____	
Atlanto-axial Instability (Down syndrome)	UMN signs <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Cervical spine Xray Date: Instability: <input type="checkbox"/> Yes <input type="checkbox"/> No	

RESOURCES

'PERSON RESPONSIBLE'

Medical and dental practitioners have a legal and professional responsibility to get consent to treatments before treating any patient.

The patient usually gives this consent. If the patient is not capable of consenting to their own treatment, the practitioner should seek consent from the patient's 'person responsible'. This is required by the *Guardianship Act 1987*.

Who is the 'person responsible'?

A 'person responsible' is not necessarily the patient's next of kin. A 'person responsible' is either:

- a guardian (including an enduring guardian) who has the function of consenting to medical, dental and health care treatments

or, if there is no guardian:

- the most recent spouse or de facto spouse with whom the person has a close, continuing relationship. 'De facto spouse' includes same sex partners.

or, if there is no spouse or de facto spouse:

- an unpaid carer who is now providing support to the person or provided this support before the person entered residential care

or, if there is no carer:

- a relative or friend who has a close personal relationship with the person

If a person identified as being a 'person responsible' declines in writing to exercise the function of 'person responsible' or a medical practitioner or other qualified person certifies in writing that the person identified as 'person responsible' is not capable of carrying out those functions, then the person next in the hierarchy is the 'person responsible'.

If the treatment is special treatment, the practitioner must seek consent from the Guardianship Tribunal before treating the person.

If there is no 'person responsible' and the treatment is major treatment, the practitioner must seek consent from the Guardianship Tribunal before treating the person.

If the practitioner considers the treatment to be urgent and necessary, they may treat without consent.

For more information about urgent, special, major and minor treatment, see **SUMMARY GUIDE** overleaf.

Rights and responsibilities of a 'person responsible'

If you are the 'person responsible' for someone who cannot consent for themselves you have a right and a responsibility to know and understand:

- what the proposed treatment is
- what the risks and alternatives are
- that you can say "yes" or "no" to the proposed treatment
- that you can seek a second opinion

The practitioner has a responsibility to give you this information and seek your consent to the treatment before treating the person.

Is there anything a 'person responsible' cannot do?

When someone is incapable of consenting to their own treatment, a person responsible cannot:

- consent to special medical treatment, such as sterilisation operations, terminations of pregnancy and experimental treatments
- consent to a treatment if the patient objects to the treatment

Complaints

Complaints about practitioners can be referred to the Health Care Complaints Commission on (02) 9219 7444 or 008 04319 (tollfree).

Need more information?

Contact the Guardianship Tribunal on 1800 46 3928 (tollfree) or (02) 9555 8500.

Summary Guide to Medical and Dental Consent for adults 16 years and over

CATEGORY	TREATMENT	WHO CAN CONSENT?
URGENT	Urgently necessary to: <ul style="list-style-type: none"> ■ save person's life ■ prevent serious damage to health ■ prevent or alleviate significant pain or distress, except if the treatment is special medical treatment 	No consent needed
MINOR	All medical and dental treatments – except those listed in MAJOR or SPECIAL . Includes: <ul style="list-style-type: none"> ■ treatment involving general anaesthetic or other sedation <ul style="list-style-type: none"> • for management of fractured or dislocated limbs • for endoscopes inserted through an orifice, not penetrating the skin ■ medications that affect the central nervous system <ul style="list-style-type: none"> • when used for analgesic, antipyretic, antiparkinsonian, antihistaminic, antiemetic, antinauseant or anticonvulsant purposes • PRN not more than three times/month • sedation in minor procedures • when such medications are used only once 	'Person responsible' can consent. If no 'person responsible' or 'person responsible' cannot be located or cannot/will not respond and patient is not objecting, the doctor or dentist may treat without consent. They must note on patient's record that the treatment is necessary to promote the patient's health and wellbeing and that the patient is not objecting.
MAJOR	<ul style="list-style-type: none"> ■ Any medical or dental treatment involving general anaesthetic – except those listed in MINOR ■ Medications that affect the central nervous system – except those listed in SPECIAL and MINOR ■ Long-acting injectable hormonal substances for contraception or menstrual regulation ■ Any treatment for the purpose of eliminating menstruation ■ Testing for HIV ■ Any treatment involving substantial risk ■ Any dental treatment resulting in removal of all teeth or significantly impairing ability to chew food 	'Person responsible' can consent. If no 'person responsible' or 'person responsible' cannot be located or cannot/will not respond, only the Guardianship Tribunal can consent. Request and consent must be in writing or, if not practicable, later confirmed in writing.
SPECIAL	<ul style="list-style-type: none"> ■ Sterilisation ■ Termination of pregnancy ■ Drugs of addiction used for more than 10 days in 30 – except when used to treat cancer or for palliative care of terminally ill patients ■ Aversives – mechanical, chemical or physical ■ Experimental treatments <ul style="list-style-type: none"> • any new treatment that has not yet gained the support of a substantial number of doctors or dentists specialising in area • use of medication that affects the central nervous system when dosage, duration or combination is outside accepted norms • androgen-reducing medications for behavioural control 	Only the Guardianship Tribunal can consent.
OBJECTIONS TO NON-URGENT TREATMENT	If the person or the 'person responsible' indicates or has previously indicated that they do not want the treatment carried out.	Only the Guardianship Tribunal can consent.

APPENDIX 3: OTHER RESOURCES

Medical/Health Information

Centre for Developmental Disability Health Victoria

Monash University, Victoria.

Aims to enhance the skills and knowledge of GPs by providing information on line.

Guidelines on menstrual management for GPs and families are freely available on line. Fact sheets on various syndromes are also available on line.

Ph: 03-9567 1520 <http://www.cddh.med.monash.edu.au>

Centre for Developmental Disability Studies

University of Sydney, NSW

Provides information on health and other aspects of developmental disability to GPs, other health professionals, families and disability staff. In collaboration with clinical associates, provides specialist clinical services for people with developmental disabilities.

Ph: 02-8878 0500 <http://www.cdds.med.usyd.edu.au>

The Centre for Genetics Education

<http://www.genetics.com.au>

Dictionary of Developmental Disabilities Terminology

A free online resource for families GPs and service providers.

<http://www.pbrookes.com/dictionary>

ddhealthinfo

Online information for medical and other health professionals about particular disabilities and syndromes. It is also designed to support people with developmental disabilities and their families in making informed health care decisions.

<http://www.ddhealthinfo.org>

DisAbility Services Division, Department of Human Services, Victoria.

Various useful publications can be down loaded from this site.

<http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/>

Down Syndrome: Health Issues

Website with articles on health issues in people with Down syndrome, and useful links.

<http://www.ds-health.com/>

FPA Health

FPA Health (formerly Family Planning NSW) offers sexuality and relationship education services for people with intellectual disability, their parents/carers and professionals working in the disability field.

Ph: 02- 8752 4300 <http://www.fpahealth.org.au>

Health Guidelines for Adults with Intellectual Disability

Provides a list of health targets to achieve health gains for people with developmental disability, developed by international experts.

<http://www.iassid.org>

Health Insite

An Australian website that aims to improve the health of Australians, by providing easy access to quality information about health, and includes information on intellectual disability.

<http://www.healthinsite.org.au>

Learning about intellectual disabilities and health

Website aims to assist health care practitioners in the provision of quality medical care to people with Down's syndrome and their families, from diagnosis to old age.

<http://www.intellectualdisability.info>

OMIM – Online Mendelian Inheritance in man

This database is a catalogue of human genes and genetic disorders

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM>

Management Guidelines: Developmental Disabilities (Version 2)

Lennox, N. (Ed.). Therapeutic Guidelines Limited, Melbourne, 2005.

Comprehensive book on the medical care of children, adolescents and adults with developmental disabilities, written for the Australian context. Also available in the eTG series of Therapeutic Guidelines.

Ph: 1800 061 260 <http://www.tg.com.au>

Preventative Women's Health Care for Women with Disabilities: Guidelines for General Practitioners.

Available on websites of NSW Cervical Screening Program and Centre for Developmental Disability Studies.

<http://www.csp.nsw.gov.au> <http://www.cdds.med.usyd.edu.au>

For hard copies, contact NSW Cervical Screening Program:

Ph: 131 556 Email: nswcsp@wsahs.nsw.gov.au

Queensland Centre for Intellectual and Developmental Disabilities (QCIDD)

QCIDD aims to improve the health and well-being of the adults with intellectual and developmental disabilities who live in Queensland. It includes information for people with intellectual disabilities and their carers about diabetes.

Ph: 07- 3840 2412 <http://www.sph.uq.edu.au/qcidd>

University of Western Ontario, Canada Developmental Disabilities Programme

Clinical bulletins on physical and mental health issues, journal abstracts, useful links.

<http://www.psychiatry.med.uwo.ca/ddp/>

Specialist Clinics

Adult Developmental Disability Clinic, Westmead

Westmead Hospital, Hawkesbury Rd, Westmead, NSW 2145

Health clinic held on alternate Fridays in the Outpatients Department .

Clinics for teenagers and adults with a dietitian and healthy lifestyle team at the recreation team premises on alternate Thursdays.

Ph: 02-9683 2898.

Chatswood Assessment Centre

46 Hercules Street, Chatswood NSW 2067

Provides multidisciplinary diagnostic and assessment service for children with developmental disability in northern Sydney.

Ph: 02-9414 0218

Child Development Unit, Children's Hospital at Westmead

Children's Assessment Centre, Level 3 Outpatient Building,

Cnr Hawkesbury Rd and Hainsworth St, Westmead, Sydney, N.S.W.

Tertiary Service. Provides comprehensive multidisciplinary approach to children with complex developmental and behavioural problems.

Ph: 02-9845 2395

Department of Ageing Disability and Home Care, Inner West Services

Level 2, Railway Parade, Burwood NSW 2134 (PO Box 78, Burwood NSW 1805)

Provides medical and psychology assessments for children and adults in Inner West Sydney.

Ph: 02-9701 6300

Diagnostic and Assessment Services, Kogarah

Corner of Railway Parade and Belgrave Street, Kogarah.

(For people in the St George/Sutherland Council areas)

- Specialty clinics for children and adults, including neurology, psychiatry, rehabilitation, nutrition and genetics.
- General medical clinics for school age children and adults, school clinics
- Feeding Clinic for children with developmental disabilities – interdisciplinary clinic with paediatric gastroenterologist, developmental paediatrician, paediatric nutritionist, speech pathologist.
- Medical and developmental / psychometric assessments for children prior to school entry, (0-6 years of age).

Ph: 02-9587 2444

Dysphagia Nutrition Clinic - Children's Hospital at Westmead

Corner, Hawkesbury Road and Hainsworth Street, Westmead, Sydney - NSW 2145
Paediatric multidisciplinary feeding/nutrition clinic; interdisciplinary team of clinical staff from Children's Hospital Westmead and The Spastic Centre.
Contact Nurse Coordinator: Ph: 02- 9845 3971 (Wed to Fri).
Dysphagia Nutrition Clinic – Westmead Hospital
Westmead Hospital, Hawkesbury Road, Westmead, Sydney – NSW 2145
Multidisciplinary dysphagia clinic for adults
Ph: 0438 549 466

Interdisciplinary Dysphagia Clinic (IDC)

Contact IDC Clinic Co-ordinator
GP Building, The University of Newcastle, Callaghan 2308
Ph: 02-4921 7352 <http://www.newcastle.edu.au/school/lang-media/about/>

NSW Developmental Disability Health Unit, Centre for Developmental Disability Studies

Royal Rehabilitation Centre Sydney, 59 Charles Street, Ryde 2112
Twice weekly medical clinic for adolescents and adults. Staffed by 4 doctors experienced in Developmental Disability Medicine with some support from allied health staff. There are also specific clinics for people with Down syndrome, Fragile X syndrome and Cornelia de Lange syndrome, as well as a Genetics clinic.
All medical services are billed directly to Medicare. The clinic takes referrals from general practitioners.
Contact: Clinic Nurse Coordinator: 02-9808 9287 (Mon & Wed)

Prader Willi Syndrome Clinic

Royal Prince Alfred Hospital, Missenden Road, Camperdown NSW 2050
Ph: 02-9515 3830

Tumbatin Developmental Clinic

Royal South Sydney Community Health Complex,
Joynton Avenue. Zetland NSW 2017
For children in Municipalities of Waverley, Woollahra, Botany, the City of Randwick and part of the City of Sydney. Offers diagnostic and assessment service for children suspected of or having a developmental delay or disability.
Ph: 02-9382 8189 or 02-9382 8191

Dental Services

Special Needs Dentistry

45 Rowntree Street, Balmain NSW 2041

Oral health management of people with intellectual disabilities, mental illness, dementia, & medically compromised patients. Includes treatment of patients under intravenous sedation & general anaesthetic, motor function therapy & oral desensitisation.

Ph: 02-9810 5507

Westmead Dental Hospital Special Care Unit,

Westmead Hospital, Dental Clinical School, Darcy Rd, Westmead NSW 2145

Dental treatment for people with intellectual disability. Free treatment for clients with a disability & a Health Care Card or Pension Card. Waiting period for non-emergency treatment is 1-2 months. Bring your Pension Card or Health Care Card, and a letter from your doctor stating your disability, Medicare number, name, address, date of birth & telephone number.

Ph: 02-9845 6766 or 02-9845 7423 Emergency treatment – Ph: 02- 9845 7363.

Outside the Sydney Metropolitan Area

Contact your local community health centre or the regional DADHC office for contact details for a dentist.

Dysphagia Services

Dysphagia Resource Centre

Provides resources for swallowing disorders

<http://www.dysphagia.com>

GISS - Gastrostomy Information and Support Society

Contact The Spastic Centre (Health & Information Training Officer),

PO Box 184 Brookvale NSW 2100

Ph: 02-9451 9022 <http://www.giss.org>

Speech Pathology, Liverpool Hospital

Ph: 02-9828 4703

Concord Hospital

Provide consultation with Speech Pathologist in the Modified Barium Swallow and Respiratory Physician as indicated.

Contact Radiology Department for bookings Ph: 02-9767 6501

Makaton Australia

For information on Makaton (key word signing; natural sign and gesture)

<http://seds.sturt.flinders.edu.au/matthews/makaton/states/index.htm>

St George Hospital Speech Pathology

This service offers:

- Speech pathology service for adults with swallowing difficulties that includes Modified Barium Swallow as indicated Ph: 02-9350 2395.
- General Paediatric Feeding Clinic (Speech Pathology and Nutrition, Paediatrician) Contact St. George Hospital Speech Pathology on Ph: 02-9350 2395.

Medical and Allied Health Professional Organisations

Australian Association of Developmental Disability Medicine (AADDM)

National organisation of doctors with special interest in developmental disability. Includes general practitioners, neurologists, physicians, psychiatrists, rehabilitation specialists and paediatricians.

Contact: Dr Donna Henderson, Centre for Developmental Disability Health Victoria
Ph: 03- 9567 1520 donna.henderson@med.monash.edu.au

Association of Doctors in Developmental Disability (ADIDD)

NSW organisation of doctors working in developmental disability

Contact: Dr Robert Leitner

C/- PO Box 90, Kogarah NSW 1485

Ph: 02- 9587 2444 <http://www.adidd.org.au>

PANDDA

Professional association of nurses in developmental disability
02-8855 3600

PSYCHDD

Special interest group of psychologists in Developmental Disability.

Locked Bag 3002, Blacktown NSW 2148

Ph: 02-9208 4408 <http://www.psychdd.com.au>

SPOT ON DD

Professional Association of speech pathologists, physiotherapists and occupational therapists working in developmental disability

Ph: 02-9310 6300 <http://www.spotondd.org.au>

Government Departments and other Disability Related Organisations

The Department of Ageing, Disability and Home Care

NSW Department that delivers a range community support services including respite care and supported accommodation services for children and adults with intellectual disability, as well as early intervention services to infants and young children who have a developmental delay. They also assist frail aged people, younger people with a disability and their carers with housekeeping and personal care by providing general domestic assistance, non-medical personal care, live-in care, live-in emergency housekeeping, essential shopping and other home based services.

Ph: 02-8270 2000 TTY (for people who are deaf): 02-8270 2167

<http://www.dadhc.nsw.gov.au>

The Guardianship Tribunal of NSW

The Guardianship Tribunal makes decisions in relation to the appointment of guardians and financial managers, or in relation to medical and dental consent, for people with disabilities who do not have the capacity to make their own decisions. The Tribunal may make a range of other orders as well.

Ph: 02-9555 8500 <http://www.gt.nsw.gov.au>

The NSW Council for Intellectual Disability

Offers information about and referrals to services and resources. Also advocates for changes to service systems and government policies so that they better meet the needs of people with intellectual disabilities.

Ph: 02-9211 1611 or 1800 424 065 (toll free)<http://www.nswcid.org.au>

Syndrome Specific Associations

Angelman Syndrome Association Inc

PO Box 554, Sutherland NSW 2232

Ph: 02 -95205857 <http://www.angelmansyndrome.org>

Association of Genetic Support of Australasia Inc (AGASA)

66 Albion Street, Surry Hills NSW 2010

Ph: 02- 9211 1462 <http://www.agsa-geneticsupport.org.au>

Australian Tuberous Sclerosis Society Inc

34 Speers Road, North Rocks NSW 2151

Ph: 02- 9630 3147

Autism Spectrum Australia (ASPECT)

PO Box 361, Forestville NSW 2087

Ph: 02-8977 8300 <http://www.aspect.org.au>

Down Syndrome Association NSW

PO Box 2356, North Parramatta NSW 2151

Ph: 02- 9683 4333 <http://www.dsansw.org.au/>

Epilepsy Association

Suite 8, 44-46 Oxford Street, Epping NSW 2121
Ph: 02- 9856 7090 or 1300 366 162 <http://www.epilepsy.org.au>

Fragile X Syndrome of Australia

132 Cowles Road, Mosman, NSW 2088
Ph: 0409 987012 <http://www.fragilex.org.au>

Noonan Syndrome Association

Contact: Diane Petrie
Association of Genetic Support of Australasia Inc (AGASA)
66 Albion Street, Surry Hills NSW 2010
Ph: 02- 9211 1462 <http://www.agsa-geneticsupport.org.au>

Prader Willi Association of NSW

PO Box 235, (North West Arm Road), Gray's Point NSW 2232
<http://www.pws.org.au/nsw>

Rett Syndrome Association of Australia

Contact – Mr Bill Callaghan (President)
PO Box 9, Cobbity NSW 2570
Ph: 02- 9615 7077 Toll Free: 1800 177 111
<http://www.rett.nesher.com.au>

Williams Syndrome Association of Australia

Contact: Diane Petrie
Association of Genetic Support of Australasia Inc (AGASA)
66 Albion Street, Surry Hills NSW 2010
Ph: 02- 9211 1462 <http://www.agsa-geneticsupport.org.au>

Academic Research Centres and Organisations

ASSID

Australasian Association for the Study of Intellectual Disability

<http://www.assid.org.au>

Centre for Developmental Disability Health Victoria

Monash University, Victoria.

Aims to enhance the skills and knowledge of GPs by providing information on line.

Ph: 03- 95671520 <http://www.cddh.med.monash.edu.au>

Centre for Developmental Disability Studies

Creates and disseminates knowledge that can improve the lives of people with developmental disabilities. Conducts research and education, and provides clinical services.

Ph: 02-8878 0500 <http://www.cdds.med.usyd.edu.au>

The International Association for the Scientific Study of Intellectual Disabilities (IASSID)

IASSID is an international and interdisciplinary scientific organisation that promotes worldwide research and exchange of information on intellectual disabilities.

<http://www.iassid.org/>

Queensland Centre for Intellectual and Developmental Disabilities (QCIDD)

QCIDD aims to improve the health and well-being of the adults with intellectual and developmental disabilities who live in Queensland. Its web site includes information for people with intellectual disabilities and their carers about diabetes.

Ph: 07- 3840 2412 <http://www.sph.uq.edu.au/qcidd/>

APPENDIX 4: REFERENCES

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