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Person-Centred Health Care Assessments and the Development of Health Care Plans Practice Package

Summary: This package has been developed in recognition of the increasing complexity of practice in this area, to build knowledge and skills that enhance effective support for people with disability, and to build capacity within the nursing profession.

Document approval

Person-Centred Health Care Assessments and the Development of Health Care Plans has been endorsed and approved by:

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Executive Director

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1. INTRODUCTION

1.1 Introduction and purpose

Welcome to the Person Centred Health Care Assessment and the Development of Health Care Plans practice package which has been developed for Nurses who provide person centred health support for people with disability. This package was developed by the Practice Leader, Nursing and Health Care, in consultation with Nurses working with people with disability across a range of practice contexts. It has been developed in recognition of the increasing complexity of practice in this area, to build knowledge and skills that enhance effective support for people with disability, and to build capacity within the nursing profession. The Practice Package is available to all Nurses supporting people with a disability and working in Family and Community Services, Ageing, Disability and Home Care (FACS, ADHC), non-government agencies (NGO), NSW Health and in private practice. This package will be available on the FACS intranet (internal access) and internet (external access).

This practice package has been developed to support nurses who are working with people and their families who support people with a disability. It has been designed to provide an overview of health conditions experienced by people with disability. The package firstly highlights the particular problems associated with developmental and intellectual disability (sometimes referred to in this section collectively as 'intellectual disability') so that a Person Centred Health Care Assessment and the Development of Health Care Plans can be completed by the nurse in order to promote consistent and efficient best practice. It also outlines current principles around best practices throught the document. This practice package is designed to complement organisation's policies and procedures, rather than replace them.

The *Practice Package* is one of a number of packages developed for professional groups working with people with disability (Dietitians, Occupational Therapists, Physiotherapists, Psychologists, and Speech Pathologists).

This practice package can be used in a number of different ways:

- As a basis for self directed learning

- As part of core standards learning

- For reference and clarification

- For part of the induction of new staff

- In conjunction with professional supervision

- With student nurses in placements

- With other professions and disciplines

This practice package forms part of the supporting resource material for the core standards program developed by Clinical Innovation and Governance. Please note that the information contained in this package is specific to all nurses working with people with a disability in New South Wales, Australia.

1.2 Common core standards

FACS has developed four practice packages that support the common core standards for practitoners who provide support to people with a disability. These are located on the FACS/ADHC website.

The common core standards cover the following areas for nurses who support people with a disability:
- Professional Supervision
- The Working Alliance
- Intellectual Disability: Philosophy, Values and Beliefs
- Service Delivery Approaches.

1.2.1 Nursing and Health Care Practice Packages

The following Nursing and Health Care practice packages have been organised according to the order they should be read. The information is further organised according to domains of practice within those standards as follows:

- **Person-Centred Health Care Assessments and the Development of Health Care Plans Practice Package**
  - Health Assessment
  - Health Planning
- **Communication and Behaviour Support Practice Package**
  - Communication
  - Behaviour Support
- **Working with People with Chronic and Complex Health Care Needs Practice Package**
  - Health Care and Support
  - Teaching and Coaching
  - Advocacy and Co-ordination
  - Education, Research and Evaluation
- **Mealtime Management Practice Package for Nurses**
  - Nutrition for Health and Wellbeing
  - Managing Dysphagia
  - Enteral Nutrition

These core standards represent fundamental areas of knowledge, skills and attitudes required by Registered and Enrolled Nurses when working with people with disability, their families and carers. The standards are not intended to restrict practice nor imply boundaries. Rather, they are intended to enhance core skills that underpin practice. Information presented in this practice package provides access to key information and resources thus contributing to FACS's knowledge translation program.

The Nursing and Health Care Core Standards are intended to provide information that is particularly useful to Registered and Enrolled Nurses new to the area of practice in disability. These may include:
- FACS staff
- NSW Health staff

- non-government agency staff (NGO)
- practice nurses working with GPs
- nurses working in specialist clinics
- private agency staff
- nursing students.

Practice contexts include:
- family homes
- general practitioner surgeries (GPs)
- residential/accommodation services
- community health services
- specialist teams
- hospitals
- nursing homes.

1.3 Copyright

The content of this package has been developed by drawing from a range of resources and people. The developers of this package have endeavoured to acknowledge the source of the information provided in this package. The package also has a number of hyperlinks to documents and internet sites. Please be mindful of copyright laws when accessing and utilising the information through hyperlinks. Some content on external websites is provided for your information only, and may not be reproduced without the author's written consent.

1.4 Disclaimer:

This resource was developed by the Clinical Innovation and Governance Directorate of Ageing, Disability and Home Care in the Department of Family and Community Services, New South Wales, Australia (FACS).

This practice package has been developed to support nurses who are working with people with a disability. It has been designed to promote consistent and efficient best practice. It forms part of the supporting resource material for the Core Standards Program developed by FACS.

This resource has references to departmental guidelines, procedures and links, which may not be appropriate for nurses working in other settings. Nurses in other workplaces should be guided by the terms and conditions of their employment and current workplace.

Access to this document to nurses working outside of FACS has been provided in the interests of sharing resources. Reproduction of this document is subject to copyright and permission. Please refer to the website disclaimer for more details.

The package is not considered to be the sole source of information on this topic and as such nurses should read this document as one of many possible resources to assist them in their work.

Whilst the information contained in this practice package has been compiled and presented with all due care, FACS gives no assurance or warranty nor makes any representation as to the accuracy or completeness or legitimacy of its content. FACS does not accept any liability to any person for the information (or the use of such information) which is provided in this practice package or incorporated into it by reference.

3. The Definition of Disability

In order to understand how the conceptualisation of disability has changed, it is first important to define what disability is.

The Disability Discrimination Act 1992 (Australasian Legal Information Institute, 2010) defines disability as:

- total or partial loss of the person's bodily or mental functions
- total or partial loss of a part of the body
- the presence in the body of organisms causing disease or illness
- the malfunction, malformation or disfigurement of a part of the person's body
- a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction
- a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment, or that results in disturbed behaviour and includes a disability that:

  - presently exists
  - previously existed but no longer exists
  - may exist in the future
  - is imputed to a person (meaning it is thought or implied that the person has disability but does not).

(AustLII, 2010)

Please note that the target group of people with disability is under review in the Disability Inclusion Bill (2014).

There are many different causes of disability for example accidents, illness or genetic disorders. A disability may affect a person's movement, their ability to learn, or their ability to communicate. Some people have more than one disability.   Although some people are born with disability, many people acquire a disability. Not all disabilities are permanent and conditions which cause disability increase with age (Australian Network on Disability, 2013).

3.1 The definition of intellectual disability

A person has an intellectual disability if they have the following:

1. An IQ that is 2 standard deviations (SD) below the mean (approx. 70, as average IQ is 100 and the SD is 15) and:
2. A significant deficit in at least one area of the following domains of adaptive functioning:
   - conceptual domain- reading writing, reasoning and knowledge
   - social domain – empathy, social judgement and making friendships
   - practical domain – personal care, daily living skills.
3. These problems must be manifest in the developmental period.

(American Psychiatric Association, 2013)

Based on the functional deficits, intellectual disability can be mild, moderate or severe and factors such as personality, coping strategies and the presence of other disabilities (motor, social or sensory) will influence a person's requirement for support with daily living.

(Centre for Developmental Disability Health, 2013)

4. Disability and Health

This section sets the scene for nursing and health care practice addressed within the Nursing and Health Care Core Standards. It provides background information about the health of people with disability and their families organised under the following headings:

- Background
- Medical Diagnoses Commonly Associated with Developmental and Intellectual Disability
- Threats to Health for People with Intellectual Disability
- Disability and Health: Lifespan Considerations
- Disability and Causes of Death
- People with Disability, their Families and Carers

The overview of health conditions experienced by people with disability highlights the particular problems associated with developmental and intellectual disability (sometimes referred to in this section collectively as 'intellectual disability'). Understanding of aetiologies and diagnoses associated with an intellectual disability, along with the family impact of disability, provide essential awareness of health risks, along with cues for assessment and monitoring. Such understanding promotes proactive, as well as responsive, health care and management which are addressed in the Nursing and Health Care Core Standards.

4.1 Background

There has been a dramatic increase in the life expectancy of people with an intellectual disability in recent years. However, a growing body of evidence demonstrates that many health problems are still not identified and that people with an intellectual disability experience significant health inequalities. There is also growing evidence that the health of caregiving family members is adversely affected.

People with disability experience the same health problems as others in the general community. With increasing life spans, disease patterns and risk factors are also increasing in line with the general population. These include rates of cancer, diabetes, arthritis, cardiovascular disease, falls, and dementia. The risks for these conditions in people with disability increase due to barriers to health care. People with an intellectual disability are less likely to be involved in preventative health care and thus are at further risk for 'lifestyle' diseases such as diabetes, cardiovascular disease, smoking-related respiratory disease, and some cancers(Dossetor, 2013; Goddard et al, 2008; Marsh & Drummond, 2008; Mott, Chau& Chan, 2007; NSW Ombudsman, 2013).

People whose main disabling condition is intellectual disability require assistance with daily living activities. They experience limitations in communication, mobility and

self-care and need lifelong support and assistance which ranges through intermittent, limited, high and pervasive. Many of these people have complex health needs.

Barriers to health care for people with intellectual disability include:
- communication difficulties that impede communication of health care needs
- poor identification and understanding of health needs (regular and special)
- fear of negative attitudes amongst health care providers
- failure of carers to recognise gradual health deterioration in people with an intellectual disability
- poor procedures for the delivery of health services including: physical inaccessibility; communication problems; time constraints; lack of knowledge; unhelpful attitudes

These factors contribute to significantly poorer health status when compared with the mainstream population (Atherton, 2006; Dossetor, 2013; NSW Health, 2012).

People with intellectual disability experience greater prevalence than their peers of numerous health conditions, many of which are preventable. Examples of these include: poor dental health; skin breakdown; osteoporosis; overweight and obesity; sensory impairments; mental ill health; effects of polypharmacy.The health of families is often negatively affected by caregiving responsibilities contributing further to poor health outcomes. Conditions that lead to intellectual disability frequently lead to health problems that are multiple and complex (NSW Health, 2012).

4.2 Medical Diagnose Commonly Associated with Developmental and Intellectual Disability

There are many causes of intellectual disability. A specific cause can be identified in many cases (~66%), but sometimes the cause is unknown. A defined cause is more likely to be identified in people with severe intellectual disability, whereas multifactorial and environmental causes are more likely in those with mild intellectual disability, cerebral palsy and autism. By its nature, intellectual disability is associated with neurological impairments for which genetic influences are being increasingly identified.

Knowledge of causes is useful for prognosis, as well as health assessment, planning and monitoring, e.g., a diagnosis of Down syndrome alerts us to increased risks for sensory impairments, heart disease, hypothyroidism, and early dementia (amongst others). Anticipating known health problems associated with specific diagnoses allows for proactive management.
(Carnaby, 2009; CDDS, 2006)

Following are outlines of medical diagnoses commonly associated with developmental and intellectual disability, along with health problems associated with these diagnoses. These outlines are designed as alerts to potential health issues and as cues to assessment and monitoring. Resources are included to enable exploration of more detailed information.

4.2.1 Autism Spectrum Disorders

The autism spectrum disorders (ASD) are a group of developmental conditions characterised by:

- problems with communication – comprehension is limited and literal; expressive language is repetitive, echolalic and stereotyped, with lack of reciprocal conversation (chat)
- problems with social development and interaction – reciprocal relationships and empathy are impaired
- restricted and repetitive interests and behaviour – routines are important and there is resistance to change
- anxiety and compulsions.

Under the DSM-5 criteria, individuals with ASD must show symptoms from early childhood, even if those symptoms are not recognized until later.

In addition, people with ASD may be overly dependent on routines, highly sensitive to changes in their environment, or intensely focused on inappropriate items. Again, the symptoms of people with ASD will fall on a continuum, with some individuals showing mild symptoms and others having much more severe symptoms.

4.2.1.2 Health issues associated with autism include:

- anxiety
- chronic gastrointestinal problems – constipation, bloating, abdominal pain, nausea, diarrhoea
- atypical sensory responses – heightened responses to light, sound, textures, taste, smell
- seizures

(Centre for Genetics Education, 2013; Howlin, 2002)

For further information see:

Autism
[http://www.intellectualdisability.info/diagnosis/autism]
Austism Spectrum Disorder –DSM 5
Autism Spectrum Disorders Fact Sheet 43
[http://www.genetics.edu.au/Information/Genetics-Fact-Sheets/FS43KBS.pdf]
Autismhelp
[http://www.autismhelp.info/default.aspx]
Health Issues Specific to Autism
http://www.autismhelp.info/health/health-issues-specific-to-autism/categories,id,466,1-1.aspx
Australian Advisory Board on Autism Spectrum Disorders
[http://www.autismadvisoryboard.org.au/]

4.2.2 Cerebral Palsy

Cerebral palsy is a non-progressive disorder of posture and movement caused by insult to the developing brain during prenatal, perinatal or postnatal life.It is a developmental disorder that may or may not be accompanied by intellectual disability.

Cerebral palsy is classified according to:

- **type** of motor disorder (the way the body is affected) – hypertonic (spastic), hypotonic, athetoid, dyskinetic, ataxic, mixed

- **distribution** of motor disorder (where the body is affected) – quadriplegic, diplegic, hemiplegic
- **severity** of motor disorder – categorised on a scale of GMFCS I-V by using the Gross Motor Function Classification System (GMFCS).

4.2.2.1 Health issues associated with cerebral palsy include:

- sensory impairments (visual, hearing, touch)
- epilepsy
- neuromuscular problems
- skeletal deformities
- osteoporosis
- incontinence
- voiding dysfunction
- constipation
- skin breakdown
- pain
- depression
- dysphagia
- eating and drinking difficulties
- malnutrition
- recurrent aspiration
- gastro-oesophageal reflux disease (GORD)
- Barrett's oesophagus
- gastric bleeding/anaemia
- poor peripheral circulation
- recurrent chest infections
- chronic lung disease
- dental problems

(CDDH, 2013; CDDS, 2006, Cerebral Palsy Alliance, 2013)

For further information see:
Cerebral Palsy Alliance
[https://www.cerebralpalsy.org.au/[
Cerebral Palsy Fact Sheet CDDH
[http://www.cddh.monash.org/assets/fs-cerebralp.pdf[
Gross Motor Function Classification System (GMFCS)
[https://www.cerebralpalsy.org.au/what-is-cerebral-palsy/types-of-cerebral-palsy/gross-motor-function-classification-system/]

4.2.3 Genetic Disorders

Many disorders associated with intellectual disability have a known genetic origin. Some are caused by chromosomal changes, e.g., trisomy 13 (Patau syndrome), 18 (Edwards syndrome), 21 (Down syndrome), XXY (Klinefelter syndrome), XO (Turner syndrome). Others are caused by changes in single or multiple genes, e.g., ASD, tuberous sclerosis, fragile X syndrome. Some genetic disorders can be controlled by environmental factors, e.g., neural tube defects may be prevented by adequate folic acid intake prior to and during pregnancy. With advances in genetic research, the identification of genetic causes is expected to expand.

Following are outlines of the more common genetic disorders and their health implications. For information about many more conditions see NSW Health, Centre for Genetics Education at http://www.genetics.edu.au/

4.2.3.1 Down Syndrome

Down syndrome is the most common chromosomal disorder affecting newborn babies. It is caused by:

- an extra chromosome 21 – trisomy 21 – in all cells of the body (~95% of all cases)
- an extra copy of chromosome 21 in some cells of the body – mosaic trisomy 21 (~1% of all cases)
- a chromosomal translocation involving chromosome 21 (~4% of all cases)

The incidence of Down syndrome increases with maternal age, but can occur at any age. In terms of genetic counselling, it is important to know that the translocation type of Down syndrome can run in families.

Down syndrome is characterised by low muscle tone, distinct facial features, general developmental delay, intellectual disability, and a variety of health problems. The expression of Down syndrome is variable with some people being severely affected and others having milder characteristics.

4.2.3.1.1 Health issues associated with Down syndrome include:
- visual impairments (including cataracts)
- hearing impairments
- hypothyroidism
- epilepsy
- congenital heart defects
- hypotonia
- cervical spine problems (atlanto-axial instability)
- sleep apnoea
- respiratory infections
- dental/oral problems
- skin disorders – eczema, alopecia
- blood dyscrasias
- leukaemia
- immune system problems – increased infections, diabetes, coeliac disease
- GORD
- constipation
- fitness and weight problems
- anxiety and depression
- early onset dementia (Alzheimer's)

(CDDS, 2006; Centre for Genetics Education, 2013; Tracy, 2011)

For further information see:
Down Syndrome Australia
[http://www.downsyndrome.org.au/]
Down Syndrome Association NSW
http://www.downsyndromensw.org.au/

4.2.3.2 Fragile X Syndrome
Fragile X syndrome is the second most common genetic cause of intellectual disability after Down syndrome. It is caused by a narrowing at the end of the X chromosome called a fragile site.The incidence of Fragile X is higher in females, but males are usually more severely affected because they do not have the protection of a second X chromosome that may be normal in females.

Fragile X syndrome is characterised by particular physical characteristics, general developmental delay, intellectual disability (100% in males), and behavioural and emotional problems.

4.2.3.2.2 Health issues associated with Fragile X syndrome include:
- visual impairments
- hearing impairment
- recurrent ear infections
- epilepsy
- cardiac defects
- scoliosis
- congenital hip dislocation
- hypotonia
- connective tissue dysplasia (loose joints)
- attention deficit/hyperactivity (ADHD)

(CDDS, 2006; Centre for Genetics Education, 2013)

4.2.3.3 Prader-Willi Syndrome

Prader-Willi syndrome is caused by gene problems on chromosome 15. It is characterised by hypotonia, and feeding problems and failure to thrive as a baby. At 2-3 years of age an insatiable appetite develops accompanied by large weight gains. Cognitive impairment ranges from mild to borderline-normal intellectual disability. Behavioural problems include temper tantrums, obsessive-compulsive behaviours, and skin picking.

4.2.3.3.1 Health issues associated with Prader-Willi syndrome include:

- strabismus
- myopia
- type 2 diabetes
- hypogonadism, undescended testes
- delayed puberty
- scoliosis, kyphosis
- hypotonia
- dental abnormalities
- sleep apnoea
- infantile failure to thrive, then
- hyperphagia
- severe obesity
- lack of gag reflex (decreased ability to vomit)
- osteoporosis
- impulse control problems
- skin picking
- self-injury

(CDDH, 2005; Centre for Genetics Education, 2013)

4.2.3.4 Tuberous Sclerosis Complex

Tuberous sclerosis (also known as epiloia) is a multisystem genetic condition that varies widely in severity. It is characterised by benign growths (tumours or lesions) in various parts of the body. Skin, brain, eyes, heart, kidneys and lungs are most commonly affected, though tumours may be found in other organs. ~50% of people with tuberous sclerosis have normal intelligence, while others will have developmental delay and some have severe intellectual disability. It is strongly associated with epilepsy and autism.

4.2.3.4.1 Health issues associated with tuberous sclerosis include:

Health problems are related to where tumours are located in the body.

- retinal tumours
- rhabdomyomata –eye, bone, heart, lung, liver
- hypertension
- cerebral astrocytoma
- epilepsy
- sleep problems
- hamartomata – kidney, lung
- polycystic kidneys
- dental abnormalities
- skin lesions – may be disfiguring and interfere with function
- behavioural difficulties

(CDDS, 2006; Centre for Genetics Education, 2013; Leung & Robson, 2007; Therapeutic Guidelines, 2012)

4.2.3.5 Inborn Errors of Metabolism

Inborn errors of metabolism refers to a group of genetic disorders causing defects in proteins (enzymes) that prevents the body from metabolising specific foods into energy. Food products that are not broken down then build up in the body and cause a wide array of symptoms. A number of these metabolic errors, if not controlled, are associated with developmental delay and intellectual disability which is variable in severity.

Inborn errors of metabolism include mucopolysaccharide (MPS) disorders such as Hurler, Hunter and Sanfilippo syndromes. These are progressive and cause damage to organs, including the brain. Children with MPS have shortened life spans.

Phenylketonuria (PKU), although rare, is probably the best known of these disorders. People with PKU are unable to break down the amino acid, phenylalanine. Newborn screening for PKU identifies those with the disorder that can then be controlled by strict adherence to a phenylalanine-free diet. If treatment is delayed or not adhered to, brain damage results.

4.2.3.5.1 Health issues associated with inborn errors of metabolism include:

Health problems are related to and vary according to the nature of the metabolic error. The range includes:

- epilepsy
- CNS symptoms – pyramidal and extrapyramidal syndromes
- cardiac problems
- connective tissues problems
- skin problems, including eczema
- respiratory problems
- nutritional problems
- visual problems – damage to cornea
- CNS problems
- hyperactivity
- phobic anxiety

(CDDS, 2006; Centre for Genetics Education, 2013)

4.2.4 Adverse Environmental Influences

Numerous factors have an influence on the development of the foetus and infant. Many environmental factors have an adverse impact on foetal and infant development, but particularly the developing brain which is highly susceptible to insult. Such factors may result in childhood developmental delay and intellectual

disability in adulthood. These adverse environmental influences will generally result in cerebral palsy (neurological damage due to an insult to the developing brain).

Following is an identification of adverse environmental developmental influences grouped as prenatal, perinatal and post-natal.

4.2.4.1 Prenatal
Factors during intrauterine life that may have an adverse effect on foetal development and result in developmental disability include:
- maternal substance abuse – alcohol (foetal alcohol syndrome), nicotineand other drugs
- harmful chemicals – pollutants, heavy metals, phenytoin
- severe maternal malnutrition
- deficiencies – iodine, folic acid
- maternal infections – rubella, cytomegalovirus, toxoplasmosis, HIV
- intrauterine cerebral infarction
- Rh incompatibility
- hyperbilirubinaemia
- complications of pregnancy – placental dysfunction, maternal disease (diabetes, heart and kidney disease).

4.2.4.2 Perinatal
Factors occurring during labour, delivery, and immediate post-delivery that may have an adverse effect on infant development and result in developmental disability include:
- severe prematurity
- very low birth weight (VLBW)
- prolonged birth hypoxia
- cerebral haemorrhage or infarct
- cerebral oedema
- birth injury
- infant jaundice (hyperbilirubinaemia causing kernicterus), septicaemia, hypoglycaemia, hyperglycaemia

It is important to note that birth hypoxia as indicated in a low Apgar score, is rarely the primary cause of neurological damage. It is more often a manifestation of a brain already vulnerable due to a pre-existing abnormality (Therapeutic Guidelines, 2012).

4.2.4.3 Postnatal – Infancy and Childhood
Factors occurring in infancy and early childhood that may have an adverse effect on development and result in developmental disability include:
- CNS infections – meningitis, encephalitis
- head injury – shaken baby syndrome, traumatic brain injury
- chronic lead exposure
- severe, prolonged malnutrition
- severe, prolonged understimulation.

4.2.4.4 Health issues associated with disability caused by adverse environmental influences include:
- failure to thrive
- sensory impairments (visual, hearing, touch)
- epilepsy
- dysphagia
- eating and drinking difficulties
- recurrent aspiration
- gastro-oesophageal reflux disease

- neuromuscular problems
- skeletal deformities
- osteoporosis
- incontinence
- constipation
- pain
- depression

- (GORD)
- gastric bleeding/anaemia
- recurrent chest infections
- chronic lung disease
- dental problems

(CDDH, 2013; CDDS, 2006, Cerebral Palsy Alliance, 2013)

4.2.5 Epilepsy

Epilepsy is an umbrella term for a set of chronic neurological disorders characterised by abnormal, episodic electrical activity in the brain that manifests as seizures. Most people with epilepsy do not have intellectual disability. However, a substantial number of people with intellectual disability have epilepsy. Although not usually the primary cause of intellectual disability, it is strongly associated, with estimates varying between 25-44% of people with intellectual disability having epilepsy (compared with ~3% of the general population) (Prasher& Kerr, 2008). Some severe epilepsy syndromes, such as West's and Lennox-Gastaut, are the primary cause of intellectual disability.

Classification of seizures and terminology change over time as knowledge increases. The following classification includes current terminology with previous terms bracketed in italics because these are still commonly used. Seizures are classified into groups and subtypes as follows.

1. Focal (partial) seizures
Seizure activity starts in one area of the brain and may spread to other areas. These seizures may be subtle or unusual, and may be mistaken for something else, e.g. daydreaming. Types of focal (partial) seizures are:
- focal seizure – awareness is retained (simple partial seizures)
- focal dyscognitive seizure – awareness altered (complex partial seizure)
- focal seizure evolving to a bilateral convulsive seizure (secondarily generalised tonic-clonic seizure).

2. Generalised seizures
Seizures arise in both hemispheres of the brain at the same time. Consciousness is lost from the outset of the seizure. Types of generalised seizures are:
- absence (petit mal):
  - typical
  - atypical
  - absence with special features
    - myoclonic absence
    - eyelid myoclonia
- tonic-clonic
- tonic
- clonic
- atonic
- myoclonic
  - myoclonic
  - myoclonic atonic
  - myoclonic tonic

3. Unknown seizures
Seizures cannot be classified as either focal or generalised. Types are:
- epileptic spasms
- other.

Status epilepticus is an acute epileptic crisis involving prolonged seizures with loss of consciousness. Definitions vary but there is some agreement on status referring to a single, unremitting seizure of five minutes duration, and recurrent seizures without regaining consciousness of greater than five minutes. The condition is a life-threatening medical emergency and treatment is usually initiated by five minutes because of neuronal risk. It may also contribute to further brain damage and disability because of oxygen deprivation.

> **SUDEP** is sudden unexpected death in someone with epilepsy, who was otherwise well, and in whom no other cause for death can be found, despite thorough post mortem examination and blood tests. The definition excludes people dying in status epilepticus and those who drown. (Chapman, Moss, Pinelli & Pollard, 2005, p.2).

Causes of SUDEP remain elusive, but suggested risk factors include:
- young adulthood
- convulsive attacks
- poor seizure control, and
- poor medication compliance (anti-epileptic drugs –AEDs)

4.2.5.1 Health issues associated with epilepsy
- status epilepticus
- risk of SUDEP
- further cognitive decline
- risk of injury during seizure
- risk of choking during seizure
- risk of drowning during seizure
- social difficulties
- sleep disturbances
- adverse effects of AEDs – neurological, GI, haematological, vertigo, sedation, drowsiness, mood, periodontal disease, skin rashes
- irritability, confusion, depression, anxiety

(Bernal, 2003; Chapman et al., 2005; Epilepsy Action Australia, 2013; Prasher& Kerr, 2008; Therapeutic Guidelines, 2012)

For further information see:
Epilepsy Action Australia
http://www.epilepsy.org.au/about-us
Epilepsy Australia.
http://www.epilepsyaustralia.net/
Epilepsy.com
http://www.epilepsy.com/epilepsy/main_epilepsy
Glossary of Terms
http://www.epilepsy.org.au/about-epilepsy/glossary#s
Seizure Types and Classification
http://www.epilepsy.org.au/about-epilepsy/understanding-epilepsy/seizure-types-classification
Sudden Unexpected Death in Epilepsy, 2005 and 2011
http://www.sudepglobalconversation.com/

4.3 Threats to Health for People with Intellectual Disability

People with intellectual disability experience the same health problems as the general population. However, because of cognitive and communication problems, their risk of developing the usual conditions such as diabetes, cardiovascular disease, cancer, etc. is increased. Added to these health problems are threats to health that are especially prevalent in people with an intellectual disability. These are outlined below.

It is necessary to have an understanding of these additional threats to health so as to be vigilant in assessing and monitoring people's health. Such understanding provides cues that support proactive health management. For example, when nurses know the risk factors for osteoporosis and are alert to who may be at risk, strategies can be implemented to prevent it or reduce its severity.

This section provides background information that underpins nursing and health practice. Management of these threats to health will be presented in the sections that address the Nursing and Health Care Core Standards.

4.3.1 Dysphagia

Dysphagia (difficulty with swallowing) occurs in the general population and may be caused by many conditions, including stroke, brain injury, Parkinson's disease, trauma, tumours, dementia and medications. Prevalence estimates for people with intellectual disability vary from 36%-73%, with dysphagia particularly prevalent in people with severe intellectual and multiple disabilities, especially those who are immobile (92.5%). The main causes in this group include cerebral palsy, Rett syndrome and the effects of medication. People with dysphagia are at very high risk of aspiration of food, fluids and saliva into the lungs

4.3.1.1.Threats to health from dysphagia include:

- aspiration
- chest infections
- chronic lung disease
- malnutrition

- obstructive sleep apnoea
- hypoxaemia during oral feeding
- asphyxia
- death

(Crawford, 2009)

4.3.2 Gastrointestinal Problems

Gastro-oesophageal reflux disease (GORD) is a chronic condition that occurs when the lower oesophageal sphincter persistently does not close properly allowing stomach contents to leak back, or reflux, into the oesophagus. It is caused by a weak sphincter; hiatus hernia, alcohol use, smoking, pregnancy, and overweight. It is especially common in people with cerebral palsy who often have a hiatus hernia, and in people with intellectual disability for whom it is a major cause of suffering and morbidity. GORD causes mucosal damage and oesophageal erosion. This may lead to **Barrett's oesophagus**, a premalignant condition associated with adenocarcinoma.

Helicobacter pylori Infection is strongly associated with peptic ulcers, chronic gastritis, and stomach cancer. It is common in people with intellectual disability, especially if living in residential care.

4.3.2.1 Threats to health from gastrointestinal problems include:

- pain
- narrowing of the oesophagus
- dysphagia
- aspiration
- loss of appetite
- dental erosion
- sleep disorders
- undernutrition and weight loss
- haematemesis(vomiting of blood)
- anaemia
- infection (including gastroenteritis)
- cancer
- behavioural problems
- death

(Beangeet al, 1999; CDDS, 2006; Somerville et al, 2008)

Note: Further gastrointestinal problems and threats are outlined in Section 2.3.7., 'Bowel Problems'.

4.3.3 Respiratory Illness

Respiratory illness is the most common cause of death in people with intellectual disability. Recurrent chest infections and pneumonia are common in people with:

- dysphagia
- aspiration
- neuromuscular weakness
- cerebral palsy
- poor cough reflex
- lung disease of prematurity
- hypotonia (decreased lung expansion)
- decreased physical activity and immobility
- skeletal deformity (scoliosis, kyphosis)
- poor dental hygiene
- smoking
- asthma
- impaired immunity

Chronic lung disease is a common outcome of pulmonary limitations and recurrent infections.

4.3.3.1 Threats to health from respiratory illness include:

- excess mucous production
- infection
- narrowed airways
- shortness of breath (dyspnoea)
- wheezing
- impaired activity tolerance
- hypoxaemia – poor tissue perfusion
- chronic lung disease – suppurative, emphysema, atelectasis
- lung cancer
- sleep disturbance
- pain
- death

(Beangeet al, 1999; CDDS, 2006; Somerville et al, 2008; Wallis, 2009)

4.3.4 Oral Health Problems

Problems with oral health are up to seven times more common than in the general population. These include dental anomalies (severe malocclusion, poor oral development), dental caries, and periodontal disease. Problems are related to conditions such as cerebral palsy, Down syndrome, and the effects of medication. However, many problems for people with disability stem from having the poorest standard of oral hygiene in the community.

4.3.4.1 Threats to health from oral problems include:

- excessive salivation (dribbling or drooling)
- rashes around face
- mouth ulcers
- tooth erosion
- dental caries
- periodontal disease
- tooth grinding (bruxism)
- localised infection, e.g., abscess
- septicaemia
- endocarditis
- pain
- loss of appetite
- malnutrition
- self-injurious behaviour

(CDDS, 2006; Watt-Smith, 2009)

4.3.5 Problems with Nutrition and Hydration

Malnutrition is common in people with intellectual disability. Underweight is associated with dysphagia and has a higher prevalence in people with cerebral palsy. People who are overweight and obese are likely to be malnourished due to poor nutritional intake and dietary imbalance which are common in people with intellectual disability.

Adequate **hydration** is problematic in the presence of dysphagia, as well as for others with intellectual disability who are not provided with adequate fluids or who forget to drink.

4.3.5.1 Threats to health from problems with nutrition and hydration include:

- malnutrition resulting in nutritional deficiencies
- underweight
- overweight and obesity
- gastric reflux
- vomiting
- type 2 diabetes
- poor energy levels
- fatigue
- impaired cognition
- constipation
- urinary tract infections
- increased seizures
- hypercholesterolaemia
- atherosclerosis
- hypertension
- cardiovascular disease
- gall bladder disease
- GI cancers
- challenging behaviour
- death
- diarrhoea

(Burton, Cox &Sandham, 2009; CDDS, 2006)

4.3.6 Type 2 Diabetes

Diabetes is a chronic condition that affects glucose metabolism. **Type 1 diabetes** is an autoimmune disease where the pancreas ceases to produce insulin necessary for glucose metabolism. The causes remain unknown but it tends to run in families. The prevalence of type 1 diabetes is not higher in people with an intellectual disability.

In **type 2 diabetes**, the pancreas either does not make enough insulin, or the body's cells become resistant to insulin, thus impairing glucose metabolism. Although there is a familial tendency for type 2 diabetes, it is strongly associated with lifestyle factors such as:

- high blood pressure
- poor diet
- overweight and obesity
- lack of exercise, and
- an 'apple' shaped body where excess weight is carried around the middle.

Other risk factors include: older age; Aboriginal or Torres Strait Islander ethnicity; Pacific Island, Indian subcontinent, or Chinese ethnicity; history of gestational diabetes; polycystic ovary syndrome.

Prevalence of type 2 diabetes is increasing in the general population, as well as in people with an intellectual disability. People with an intellectual disability are at increased risk because of lifestyle factors identified above.

4.3.6.1 Threats to health from type 2 diabetes include:

- visual problems – retinopathy, glaucoma, cataracts, blindness
- cardiovascular problems – stroke, heart attack
- peripheral vascular disease – ulcers, gangrene, amputation
- poor wound healing
- nerve damage including peripheral and autonomic neuropathies
- kidney disease
- infections–candida
- impotence
- pregnancy complications
- death

(Diabetes Australia, 2013; Therapeutic Guidelines, 2009 & 2012)

4.3.7 Bowel Problems

Incontinence of faeces is common in people with an intellectual disability. This may be caused by neurological conditions, by a lack of developmental maturation, or lack of effective training and support.

Constipationis common in people with an intellectual disability, but particularly in those with dysphagia, underweight, reduced mobility and poor diet. Constipation may be caused or exacerbated by particular medications, including anti-epileptic drugs, benzodiazepines, H2 receptor antagonists and proton pump inhibitors.

Death may result from complications of constipation because the symptoms are not always recognised.

4.3.7.1 Threats to health from bowel problems include:

- overflow diarrhoea
- faecal impaction
- bowel blockage, including volvulus
- megacolon
- haemorrhoids
- skin excoriation and breakdown
- pain
- behavioural changes
- social isolation
- death

(CDDS, 2006; Lennox &Eastgate, 2004; Pawlyn& Budd, 2009; Therapeutic Guidelines, 2012)

4.3.8 Bladder Problems

Urinary incontinence is common in people with neurological problems and developmental and intellectual disabilities. If continence has never been achieved, this is known as primary incontinence. Sometimes, incontinence develops secondary to another problem such as infection, dementia, or the effects of medication, e.g., diuretics, sedatives, antidepressants.

Urinary tract infections may be more frequent due to incomplete bladder emptying, incontinence, and poor hygiene, particularly in females.

4.3.8.1 Threats to health from bladder problems include:

- infection
- pain
- confusion
- loss of appetite
- skin excoriation and breakdown
- behavioural changes
- social isolation

(Pawlyn& Budd, 2009; Therapeutic Guidelines, 2012)

4.3.9 Vision Impairment and Eye Problems

Significant impairment of sight occurs in ~30% of people with an intellectual disability which they do not communicate to others. There is a high rate of underdetection of problems, most of which are repairable. Eye disorders are common and include strabismus, cataracts, refractive errors, and degenerative changes to the cornea. These disorders are especially common in people with Down syndrome.

People with developmental neurological conditions such as cerebral palsy may have **cortical blindness** which results from damage to the visual systems in the brain.

Eye infections are not uncommon, particularly in people who poke their eyes with their fingers. Inflammation may result from conditions such as conjunctivitis, blepharitis and styes.

4.3.9.1 Threats to health from vision impairment and eye problems include:
- developmental delay
- reduced function
- potential for accidents
- social isolation
- impaired communication
- poor coordination and balance
- inflammation, infections
- discomfort and pain
- anxiety and depression
- challenging behaviour
- blindness
- sleep disturbance (circadian rhythm disturbance associated with blindness

(CDDS, 2006; Levy, 2009)

For further information see:
Sight Problems in People with Intellectual Disabilities
http://www.intellectualdisability.info/physical-health/sight-problems-and-people-with-intellectual-disabilities
Visual Impairment: Its Effect on Cognitive Development and Behaviour
http://www.intellectualdisability.info/physical-health/visual-impairment-its-effect-on-cognitive-development-and-behaviour

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4.3.10 Hearing Impairment and Ear Problems

People with intellectual disability are at increased risk of hearing impairment with the highest prevalence occurring in people with Down syndrome, cerebral palsy, foetal rubella syndrome, congenital cytomegalovirus, kernicterus (bilirubin encephalopathy), fragile X syndrome,CHARGE syndrome, meningitis damage, older age.

Hearing impairment is classified as:
- **conductive** – sound is unable to pass freely through the outer or middle ear
- **sensorineural** – caused by damage to the cochlea in the inner ear or to the auditory nerve
- **mixed** – conductive and sensorineural loss
- **auditory processing disorder** – caused by damage to the area of brain responsible for processing auditory information (common in cerebral palsy).

Hearing impairments are unlikely to be communicated to others and diagnostic overshadowing is common because symptoms are likely to be ascribed to intellectual disability.

Ear infections such as otitis media and 'glue' ear are common. Ear drums may perforate due to infection or objects poked into the ear. These cause temporary hearing loss and may result in permanent loss.

Poor hygiene may result in wax build-up in the ear canal and reduce hearing

4.3.10.1 Threats to health from hearing impairment and ear problems include:

- developmental delay
- language impairment
- dizziness, poor coordination and balance
- social isolation
- reduced function
- potential for accidents

- infection
- discomfort and pain
- anxiety and depression
- challenging behaviour
- blindness

(CDDS, 2006; Waite, 2009)

For further information see:
Hearing Impairment and Down Syndrome.
[http://www.intellectualdisability.info/physical-health/hearing-impairment-downs-syndrome]

4.3.11 Seizures

See Section 2.2.5 'Epilepsy' for information about seizures. Seizures are repeated in this section because, apart from being a medical diagnosis, they represent a major threat to health for people with an intellectual disability. Below are repeated the threats to health.

4.3.11.1 Threats to health from seizures include:

- status epilepticus
- risk of SUDEP
- further cognitive decline
- risk of injury during seizure
- risk of choking during seizure
- risk of drowning during seizure
- social difficulties

- adverse effects of AEDs – neurological, GI, haematological, vertigo, sedation, drowsiness, mood, periodontal disease, skin rashes
- sleep disturbance
- irritability, confusion, depression, anxiety

(Bernal, 2003; Chapman et al., 2005; Epilepsy Action Australia, 2013; Prasher& Kerr, 2008; Therapeutic Guidelines, 2012)

4.3.12 Thyroid Disease

Hyperthyroidism and hypothyroidism both occur. **Hypothyroidism**is both a cause and a complication of intellectual disability. It is prevalent in people with Down syndrome (~15%) and there is increased prevalence in others with intellectual disability, particularly as they age. Some medications, such as lithium, can result in hypothyroidism. Symptoms may be insidious and non-specific so routine screening is advised. Thyroid disease should be considered with behavioural or mood changes.

4.3.12.1 Threats to health from thyroid disease include:

Hypothyroidism:
- weight gain
- hypoactivity, lethargy
- hair loss
- skin problems

Hyperthyroidism:
- weight loss
- hyperactivity
- low cholesterol
- neck discomfort

- high cholesterol
- muscle and joint pain
- constipation
- menstrual problems
- anxiety and depression

- diarrhoea, irritable bowel
- osteoporosis
- anxiety

(Beangeet al, 1999; CDDS, 2006; Therapeutic Guidelines, 2004)

4.3.13 Musculoskeletal Problems

Many people with intellectual and multiple disabilities have neuromuscular impairments that affect muscle tone, coordination, movement, and mobility. In turn, these impairments cause significant body shape distortions due to joint contractures and skeletal deformities such as scoliosis, kyphosis, sublaxed and dislocated shouldersand hips, hand and foot deformities. Body distortion may compress vital organs such as lungs, and will be accompanied by significant pain. Symptoms worsen with ageing.

4.3.13.1 Threats to health from musculoskeletal problems include:

- impaired movement and mobility
- spasm
- tight tendons
- fatigue
- acute and chronic pain
- osteopaenia and osteoporosis
- arthritis
- sleeping difficulties

- compression and distortion of organs, especially lungs
- respiratory problems
- poor saliva control
- eating and drinking problems
- elimination problems
- pressure areas

(Hill & Goldsmith, 2009; Therapeutic Guidelines, 2012; Turk, 2009)

4.3.14 Osteopaenia and Osteoporosis

Osteopaenia and **osteoporosis** both refer to bone density that is lower than normal due to calcium loss. They refer to a weakening of previously constructed bone. Osteopaenia is the milder form and may progress to osteoporosis. Both are prevalentin people with intellectual disability and risk factors include hypogonadism, amenorrhoea, immobility, inactivity, poor diet, malabsorption, underweight, Down syndrome, vitamin D deficiency, corticosteroid medication, anti-epileptic drugs.

Osteomalacia is a problem with bone development usually caused by vitamin D and concurrent calcium deficiency. It causes bone softening and results in bone pain and muscle weakness. In children it is known as **rickets**.

4.3.14.1 Threats to health from osteopaenia and osteoporosis include:

- fractures
- bone and muscle pain
- muscle weakness
- skeletal deformity

- decreasing mobility
- decreasing activity
- increased falls risk

(CDDS, 2009; Therapeutic Guidelines, 2004 & 2012)

4.3.15 Cardiovascular Disease

With the increase in life expectancy of people with an intellectual disability, the prevalence of cardiovascular disease is increasing along with the general population. People with Down syndrome have a higher risk of cardiac problems while others experience similar risk factors to the general community, e.g., hypertension, diabetes, overweight (especially abdominal), and hypercholesterolemia. However,

people with an intellectual disability are often at higher risk due to congenital defects along with barriers related to their disability, e.g., impaired understanding and communication, poor access to preventative health care.

4.3.15.1 Threats to health from cardiovascular disease include:

- cardiomyopathy
- pulmonary hypertension
- oedema
- poor peripheral circulation
- breathlessness
- fatigue
- reduced exercise tolerance
- chest pain
- heart attack
- stroke
- death

(deWinter et al, 2009; NSW Ombudsman, 2013))

4.3.16 Pain

People with an intellectual disability are at high risk of experiencing pain and for having more frequent and severe pain related to conditions identified in this section. Pain may be acute or chronic, but identification and assessment are complex due to impaired capacity to self-report. Undertreatment and lack of treatment of pain in people with an intellectual disability is common. Pain should always be considered whenever there is a change in behaviour or any self-injurious behaviour.

4.3.16.1 Threats to health from pain include:

- pain is not recognised by others
- pain is undertreated
- pain is not treated
- unnecessary suffering
- loss of appetite
- tactile defensiveness
- sleep disturbance
- reduced activity and mobility
- challenging behaviour
- self-injurious behaviour
- withdrawal
- fear and anxiety
- depression

(Baldridge&Andrasik, 2010; McKenzie, 2013; Vogtle, 2009)

4.3.17 Problems Related to Hygiene

People with an intellectual disability are often more prone to infections than the general population. Common infections include: infection of eyes and eyelids; infection of ears; infections of the scalp; infections of mouth; skin infections; food-borne infections; gastrointestinal infections; infections of hands, feet and nails; infections of the genitalia. Many of these infections are related to poor hygiene. Poor hygiene may be a problem with people who are relatively self-caring but who lack adequate training and support, and also with people who are dependent on others because of poor staff practices. The area is complex because of ethical and privacy issues related to hygiene support and the intimate care of other people.

Poor food preparation practices, along with poor toilet and hand hygiene are also responsible for infection.

Sometimes the cause of hygiene-related conditions is overlooked because of diagnostic overshadowing. There is a tendency for support staff to attribute conditions such as rashes in skin folds and foul feet to 'disability' rather than poor hygiene.

4.3.17.1 Threats to health from poor hygiene include:

- infections – eyes, ears, respiratory system, mouth, skin, GI system, urinary system, nails, feet, genitalia
- skin rashes
- accumulation of sweat, debris, etc. in skin folds, contracted joints, armpits, feet
- bad odours
- periodontal disease
- nausea
- diarrhoea
- vomiting
- itching
- pain
- social isolation

(Carnaby& Cambridge, 2006; Wilson et al., 2009)

4.3.18 Poor Physical Fitness

Many people with intellectual disability have low levels of physical activity. This may be related to physical impairments affecting mobility, or environmental and lifestyle factors. Obesity is up to three times higher than the level in the general population. Life expectancy is related to activity in those with severe intellectual disability, and immobility is a predictor for mortality.

4.3.18.1 Threats to health from poor physical fitness include:

- overweight and obesity
- poor circulation
- hypothermia
- diabetes
- cardiovascular disease
- poor musculoskeletal development
- tight tendons, contractures
- osteoporosis
- reduced function
- lethargy and fatigue
- depression
- death

(Beangeet al, 1999; Lennox, et al, 2002; Stewart, et al, 1994)

4.3.19 Women's Health Problems

Approaches to women's health are the same as for the general population; however, an awareness of complex issues related to sexual and reproductive health of women with cognitive impairments is vital. Support resources are essential for education, counselling and health management.

Onset of puberty and menarche are not usually delayed in women with intellectual disability unless low body weight and poor nutrition are factors. The incidence of menstrual disorders is difficult to assess but clinical experience suggests that problems are much the same as in the general population. The main problems for women with intellectual disability relate to menstrual managementand control, with pain and hygiene the main concerns. Menstrual suppression is sometimes practised (reference to guardianship authorities may be required).

Sexual activity is related to severity of disability, and women with mild levels of intellectual disability are likely to be sexually active. Sexual abuse is common and women with mild and severe intellectual disability are at great risk. Regular PAP tests are indicated with a history of sexual activity.

Cancer risks are similar to the rest of the population. However, early symptoms are likely to go undetected because women with an intellectual disability require support for preventative screening such as breast checks and mammography.

4.3.19.1 Threats to health from problems with women's health include:

- menstrual management
- menstrual control
- infections – candida, cystitis, UTIs
- sexually transmitted infections
- contraception
- exploitation and abuse

- premenstrual syndrome (PMS)
- dysmenorrhoea(painful period)
- menorrhagia (heavy period)
- amenorrhoea (no period)
- catamenial epilepsy (increased seizures before or during period)

(Noonan & Heller, 2002; Therapeutic Guidelines, 2004 & 2012)

4.3.20 Men's Health Problems

Approaches to men's health are the same as for the general community, viz., an awareness of and need for screening for testicular, prostate and breast cancers. However, some boys have hormone deficiencies that delay or prevent puberty. This is usually treatable. Testicular problems are more prevalent than in the general population and sometimes testicles fail to descend which increases the risk of testicular cancer tenfold. These problems are associated with low androgens (testosterone) which carry further health risks. Undescended testicles require regular monitoring.

Infections of the genitalia are common and may be associated with sexual activity and/or poor hygiene.

4.3.20.1 Threats to health from problems with men's health include:
- testosterone deficiency
- infertility
- lack of secondary sexual characteristics
- erectile dysfunction
- poor self-image
- increased fat mass
- inguinal hernia

- poor muscle development
- low energy
- mood swings, irritability
- osteoporosis
- infections – STIs, bacterial, fungal
- testicular cancer
- breast cancer
- prostate cancer

(CDDS, 2006; NSW CID, 2013; Therapeutic Guidelines, 2012; Wilson et al., 2009)

4.3.21 Mental Health Problems

People with an intellectual disability experience the same types of mental health problems as those without disability. Mental health is conceptualised along a continuum that ranges from good mental health, i.e., good emotional, cognitive and social control and interaction, to mental illness that adversely affects thinking, emotions, behaviour, and capacity to function and interact.

Prevalence rates of mental health problems are higher for people with an intellectual disability (estimates vary, but thought to be three-five times higher), and there is increasing recognition of the vulnerability of this population especially those with profound disability. However, problems with mental health often go undetected and untreated because of diagnostic overshadowing. Identification, assessment and diagnosis of problems pose many difficulties including:
- a person with intellectual disability may not be able to describe symptoms or feelings
- behaviour may be attributed to intellectual disability (diagnostic overshadowing)
- signs and symptoms may be unusual

- medications for the management of physical or behavioural problems may mask mental health problems
- inconsistent or missing historical information makes it difficult to establish patterns of illness.

The high prevalence of mental illness in people with intellectual disability may be attributed to a complex interplay of biopsychosocial stressors, including:
- fewer friendships and support networks
- increased experiences of loss, rejection, isolation and segregation
- increased likelihood of social disruptions
- low self-esteem, poor image and self-esteem
- lack of control over life and dependence on others
- poorer coping skills and abilities to manage stress
- poorer problem-solving and conflict resolution skills
- biological vulnerabilities including sensory impairments
- inappropriate living environments
- exposure to abuse, exploitation, bullying and trauma

People with autism are at higher risk of mental illness. Dementia is strongly associated with Down syndrome and is also increasing in the population of people with intellectual disability due to increasing life spans.

4.3.21.1 Threats to health from mental health problems include:

- depression
- anxiety
- psychosis
- substance misuse
- weight loss, weight gain
- fatigue, low energy
- increased energy, overactivity
- disinhibition
- sleeping problems
- memory problems
- distress
- withdrawal, social isolation
- delusions, hallucinations
- reduced function
- irritability, mood changes
- challenging behaviour
- pica
- self-harm
- panic attacks
- injury
- changed sensory perceptions
- physical problems, e.g., tachycardia, hyperventilation, headaches, pain
- death

(Cooper et al, 2007; Disability Information Service, 2012; Kitchener, et al, 2010; Therapeutic Guidelines, 2012)

4.3.22 Polypharmacy

People with an intellectual disability frequently take numerous daily medications because of the high prevalence of epilepsy, mental illness and serious disease. However, polypharmacy and inadequate medication review are acknowledged problems. People with an intellectual disability have limited or no capacity to consent or to monitor symptom efficacy and side effects of medication. This may result in ineffective medications, too many medications, unnecessarily high doses of medication, or persisting with older medications when newer ones might be more effective. The use of antipsychotics and AEDs is particularly risky in terms of inappropriate prescription, dosage, and review.

Polypharmacy leads to:
- increased drug interactions
- decreased medication compliance
- increased adverse outcomes for users.

Multiple medications are often necessary. However, regular monitoring and review are essential. It is important to include and consider both prescribed and over-the-counter (OTC) medications when monitoring and reviewing.

4.3.22.1 Threats to health from polypharmacy include:
- drug interactions
- overdose
- ineffective dose
- poor compliance
- adverse reactions
- medication administration errors
- difficulties in identifying medication-related problems (what drug caused what?)

(Beange, Lennox &Parmenter, 1999;CDDS, 2006.)

The preceding overview of health problems and threats to health highlights the complexity of health issues in people with an intellectual disability. Familiarity with these threats to health serves as cues to enable targeted comprehensive health assessment and monitoring. Proactive health management and practice are thus enhanced.

The section leads logically to nursing and health care management and the threats to health are in line with the CHAP assessment tool and the GP Health Check (Medicare Item 718 or 719). Assessment and management will be addressed in future sections of this Practice Package.

4.4 Disability and Health: Lifespan Considerations

The preceding information about health conditions and threats to health apply to people with disability across the lifespan. This section briefly highlights (and repeats) considerations specific to different lifespan phases.

When providing health care for people with an intellectual disability, it is important to adopt a lifespan approach that recognises the progression or consequences of specific health problems and therapeutic interventions. The following practice examples illustrate this concept:
- In the general population gastro-oesophageal reflux disease (GORD) does not usually manifest until adulthood. However, there is a high incidence childhood onset GORD in children with cerebral palsy. If this is not identified and treated, it can lead to oesophageal stricture or cancer in adulthood.
- The long term use of some anticonvulsants may lead to loss of bone density and result in osteoporosis.

It is therefore apparent that healthy adulthood and ageing for persons with intellectual disability requires a proactive, lifespan health care approach (Evenhuiset al, 2000).

The following sections outline some specific age-related health conditions and risk factors for people with an intellectual disability. Knowledge of these factors enables

prevention or early diagnosis of further potential impairments thus possibly increasing life expectancy.

Principles underlying health care for children, adolescents, adults, and older people with disability are the same. All have a right to access effective health care of the same standard as people without disabilities. Person-centred and family-centred approaches are expected. The bases of good health care for all are:

- health professionals must be aware of health concerns (actual and potential) for people with disability across the lifespan
- regular health reviews
- strong collaborative relationships with persons with disability, their families and carers
- access to multidisciplinary health care teams.

Attention to these issues enables identification and management of health problems that arise throughout the lives of people with disability (Therapeutic Guidelines, 2012).

4.4.1 Children with Disability – Health Considerations

Health care for children with intellectual/developmental disabilities is associated with:

- assessment of developmental status and its implications
- identification of impairments
- diagnosis of health conditions
- minimising the impact of the above problems.

It is essential to work with therapists, GPs, paediatricians, paediatric specialists, psychologists, teachers, families and carers to **minimise developmental problems**. Interventions related to minimising the effects of mobility, cognitive, and communication impairments are essential. <u>For example</u>: continence training will prevent subsequent health problems such as skin breakdown; positioning equipment will prevent increased musculoskeletal deformity; communication training will enable person to communicate pain, etc. It is important to use a strengths based approach to maximise competence in all areas.

Children with disability require the same primary health care as all children, e.g., exercise, healthy nutrition, immunisation, screening, etc. However, they are at increased risk of specific health conditions.

4.4.1.2 Specific health conditions and risks of children with disability include:

- hearing impairments(sensorineural or middle ear)
- vision impairments (cortical, cataracts, refractory and acuity defects)
- epilepsy
- musculoskeletal problems
- poor oral health
- endocrine disorders (hypothyroidism, etc.)
- behaviour disturbances (may indicate underlying health problem)

- congenital heart disease
- recurrent chest infections
- oropharyngeal dysfunction(dysphagia, etc.)
- gastro oesophageal dysfunction
- malnutrition (undernutrition and obesity)
- incontinence
- constipation
- polypharmacy

These health conditions require specialised formal assessment.
(Therapeutic Guidelines, 2012)

4.4.2 Adolescents with Disability – Health Considerations

Adolescence is a time of significant physical and psychological change. Concerns for adolescents with an intellectual disability are the same as for those without disabilities. However, additional concerns may relate to:

- anger or sadness about barriers encountered when compared to non-disabled siblings and peers
- awareness of differences
- frustration related to difficulties with independence
- frustration associated with communication limitations
- self-consciousness about the body, especially in the presence of physical difference
- fears about sexuality and relationships
- limited opportunities for private time for exploration
- uncertainty about the future – living, work arrangements, etc.

Adolescents with disability require access to the same health promotion and disease prevention education and strategies as others, e.g., healthy diet, exercise and weight management; smoking, alcohol and drug use; sexual activity, safe sex and contraception; immunisation.
<u>Note</u>: Information needs to be provided in formats that can be understood.

4.4.2.1 Specific health conditions and risks of adolescents with disability include:

- mental ill health (depression, anxiety, psychosis, etc.)
- precocious puberty (tuberous sclerosis, post-infection syndromes, TBA, hydrocephalus)
- absent or delayed puberty (Prader-Willi, Klinefelter, Turner, Noonan syndromes)
- small or ambiguous genitalia (Prader-Willi, Klinefelter, Down syndromes)
- problems associated with impaired mobility (osteoporosis, spasticity, pain, deformity, dislocations, foot problems)

- malnutrition (undernutrition, obesity)
- poor strength and fitness
- problems associated with poor personal hygiene(incontinence, menstrual management, skin care)
- vision and hearing impairments
- epilepsy (seizure patterns may change during adolescence)
- substance misuse
- abuse

Adolescence is a time to build resilience by encouraging to:
- develop trusting relationships
- focus on strengths and abilities and develop further
- explore ways to experience independence and success.
(Therapeutic Guidelines, 2012)

The transition from paediatric to adult health services occurs during adolescence and can be associated with difficulties. Planning for his transition is addressed in Section 3.2.5.

4.4.3 Adults with Disability – Health Considerations

Adults with an intellectual disability experience the same range of health problems as the general community. The major differences relate to problems being more prevalent and often unrecognised or poorly managed. There may be also be additional health problems related to the cause of a person's disability. **It is important to understand that the burden of illness is greater in people who cannot effectively express symptoms such as pain.** Pain and infection are often not recognised and may only be expressed by a change in behaviour.

Certain conditions are more common in persons with intellectual disability, and some are more likely to be missed.

4.4.3.1 Specific health conditions and risks of adults with disability include:

- vision and hearing impairments
- dental disease
- dysphagia
- GORD
- Helicobacter pylori infection
- constipation
- bowel obstruction
- incontinence
- respiratory conditions (infections, especially related to aspiration; foreign bodies in lungs)
- musculoskeletal and joint problems (unrecognised fractures, sublaxed hips, chronic pain)
- women's and men's health issues
- cryptorchidism
- inguinal hernia
- osteoporosis
- epilepsy
- skin disease
- endocrine disorders
- type 2 diabetes
- mental ill health (anxiety, depression, psychoses)
- challenging behaviour
- adverse drug effects
- substance misuse
- malnutrition
- polypharmacy

(Therapeutic Guidelines, 2012)

4.4.4 Older Adults with Disability – Health Considerations

Increasing numbers of people with intellectual disability are living into old age. However, this population consists mainly of women with mild intellectual disability, fewer comorbid conditions and higher functional skills. Although absolute numbers remain small, industrialised countries such as Australia are witnessing an overall increase in the longevity of all persons with intellectual disability which is expected to double by 2030. Because this longevity is a relatively new phenomenon, it is difficult to make generalisations regarding healthy ageing for the population (Evenhuiset al, 2000; NSW Health, 2012; Therapeutic Guidelines, 2012).

It is important to recognise that older people with disabilities carry the dual health burdens of lifelong health problems associated with their disabling impairments, as well as health conditions associated with normal ageing and lifestyle factors. These include: musculoskeletal disorders, cardiovascular disease, cancers, endocrine disorders, cognitive decline and mental health problems. Age-related health conditions sometimes occur earlier than expected in people with disability and are sometimes associated with specific diagnoses or syndromes, e.g., early dementia is associated with Down syndrome. Age-related disability exacerbates the underlying problems of people with an intellectual disability from health, functional and social perspectives.

Frailty results when people are subjected to a number of physiological problems because reserve capacities diminish. The concept applies to people with disability in whom frailty increases with age. Common medical problems may have a bigger impact on health and function that in others and there is an increased risk of further disability and death from relatively minor stressors.

Because of communication difficulties, medical and mental health problems may not present in the usual manner. Functional decline in older adults with disability must be carefully evaluated and not automatically attributed to behavioural problems or dementia. Comprehensive assessment may identify treatable conditions such as declining vision or hearing, undiagnosed medical conditions(e.g., chronic constipation, infections, UTI), affective disorders, delirium (common during hospitalisation).**Regular assessment of the older adult is essential**.

Older people with disability and complex health needs may be referred by the GP to a geriatrician or a specialised service for people with an intellectual disability which have specialist ageing clinics. Programs such as the Chronic Disease Management Program (prioritises diabetes, congestive heart failure, coronary artery disease, chronic obstructive disease, hypertension), and Community Packages (CommPacks) may be useful. These are underutilised by people with an intellectual disability.

Certain conditions are more common in older adults with intellectual disability, and many are more likely to be missed.

4.4.4.1 Specific health conditions and risks of older adults with disability include:

- sensory decline (vision and hearing deteriorate, cataracts, glaucoma)
- neurological decline and disorders (balance, co-ordination, gait, dexterity, effects of long-term medications, Parkinson's disease)
- dementia(depression and seizures sometimes seen as a lead up)
- cognitive decline
- mental health problems (depression, anxiety, delirium, psychosis)
- bereavement and grief (losses more common with ageing – often overlooked)
- cardiovascular problems (hypertension, dyslipidaemia, cerebrovascular disorders)
- respiratory deterioration(decreased pulmonary function, infections)
- gastrointestinal problems (GORD, dysphagia, chronic constipation)
- dental problems (gingivitis, unrecognised pathology)
- pain (often goes unrecognised)

- musculoskeletal problems (arthritis, contractures, impaired mobility, falls and fractures, osteoporosis)
- falls
- endocrine disorders(thyroid, diabetes, impact of oestrogen and testosterone reduction)
- malnutrition (undernutrition, high incidence of obesity, nutrient deficiencies, e.g., calcium)
- genitourinary problems (urinary incontinence, increase in UTIs)
- skin deterioration (skin thins and becomes paler, increased sunburn risk, wound healing slows, pressure area risk increases)
- thermoregulation deterioration (thinning skin, reduced sweat glands, usually more susceptible to cold)
- polypharmacy (long term medication use, unnecessary medications, medication reactions different in elderly people)

(Evenhuiset al, 2000; Therapeutic Guidelines, 2012).

In summary, a lifespan approach to health care for people with disability enables a proactive approach to the prevention, diagnosis and management of conditions that may exacerbate disability and ill health. Such an approach promotes longevity and enhances healthy living and ageing.

For further information see:
NSW CID. Adults – Signs of Illness
[http://www.nswcid.org.au/health/se-health-pages/adults---signs-of-illness.html]
NSW CID. Ageing and Health
[http://www.nswcid.org.au/health/se-health-pages/ageing-and-health-issues.html]
NSW Chronic Disease Management Program (Connecting Care in the Community)
[http://www0.health.nsw.gov.au/cdm/severe_chronic_disease_management_program.asp]
Community Packages (CommPacks)
[http://www.health.nsw.gov.au/Performance/Pages/compacks.aspx]
Rehabilitation Research and Training Center on Ageing with Developmental Disabilities – Lifespan Health and Function
[http://www.rrtcadd.org/]
IASSID. Ageing and Intellectual Disabilities – Fact Sheet.
[http://iassid.org/pdf/aging-factsheet.pdf]
Therapeutic Guidelines (2012)

4.5 Disability and Causes of Death

The poor health of people with intellectual disability is in direct relationship with life expectancy which is significantly lower than the general population; it is ~20 years lower for people with severe disabilities (Bittleset al, 2002). Studies indicate that the highest rates of death occur at the youngest and oldest ages of the population, with respiratory illness, cancer and external causes (e.g., choking) responsible for the highest number of deaths (Durvasulaet al, 2002).

Most information about the causes of death of people with an intellectual disability in NSW is derived from the Ombudsman's reports of reviewable deaths. The deaths of people who are 'in care' (disability accommodation services and licensed boarding houses) when they die are reviewable and thus data are available for analysis. The most recent report (NSW Ombudsman, 2013) provides important information for health care. Following are highlights about the **age at death of people in care** in 2010 and 2011:

- the average age of people who died in 'disability services' (FACS or NGO accommodation) was 52 years. This is ~30 years younger than in the general population.
- the average age of people who died in licensed boarding houses was 66 years
- on average, people in care died between 15 and 25 years younger than the general population.

The main causes of death include:

- respiratory diseases – mainly aspiration pneumonia and chronic lower respiratory diseases such as chronic lung disease
- heart diseases – mainly ischaemic heart disease
- cancers – mainly lung and bowel cancer
- digestive system diseases – includes volvulus, megacolon, and acute vascular intestinal disorders

- choking on food.

These causes of death are a consequence of multiple risk factors. **The most significant risks relate to:**
- problems with swallowing and eating
- lifestyle factors – smoking, obesity, poor diet, insufficient physical activity
- recurrent respiratory infections and chronic lung disease
- chronic health problems – GORD, constipation, diabetes, hypertension
- conditions such as cerebral palsy, epilepsy, Down syndrome
- multiple medications, including psychotropic medications.

(NSW Ombudsman, 2013).

These data reflect the health problems and risks to health for people with intellectual disability presented in this section, 'Disability and Health'. It is obvious that many of these deaths are preventable with the implementation of effective health care and management.

4.6 People with Disability, their Families and Carers

Despite the many positive impacts and joys derived from caring for a family member with a disability, adverse outcomes for the health and wellbeing of carers are prevalent. Many of these outcomes are related to the burden of care imposed by lack of practical supports and assistance, rather than to the individual with a disability (Kearney & Griffin, 2001; Tadema&Vsalkamp, 2010)

Caring for a family member with a disability is linked with an increase in physical and mental health problems. Australian research revealed the following:
- family carers have significantly worse mental health and wellbeing, and higher rates of depression than the general population
- more than a third of carers experience severe or extreme depression and/or stress
- twice as many carers are in poor physical health than the general population
- carers were twice as likely as non-carers to experience chronic pain
- carers are highly likely to be carrying an injury
- higher rates of poor physical health are associated with caring for a person with high support needs or more than one person with a disability. (Cummins et al, 2007; Edwards et al, 2008)

People with disability frequently have long-term chronic health conditions that require ongoing daily management, time and resources. Families experience social and financial hardship with the primary caregiver usually unable to be employed outside the home. It is important to recognise that such caregiving is not necessarily perceived as burdensome per se, and often provides fulfilment. However, it differs from paid employment as a caregiver in that it continues for long periods of time without a break. Crises are difficult to predict and the impact on family relationships is significant (Goddard, Davidson, Daly & Mackey, 2008). These factors contribute to health problems experienced by carers who find it difficult to access sufficient health care for themselves.

4.6.1 Lifelong Impact of Disability on Families

Sometimes a child's disabling condition is apparent at birth, but often identification and diagnosis are not made for months or years. Lifelong health monitoring becomes essential to assess changes in functioning and secondary health problems and this serves as a constant reminder for families. The initial impact of diagnosis and its implications are emotionally overwhelming. Associated grief may be prolonged and usually recurs throughout the life of the person with a disability. The concept of 'chronic sorrow' as a living loss is useful because it normalises such grief as a natural, understandable and non-pathological response (Kearney & Griffin, 2001; Roos, 2002)

Recurrences of grief may occur when:
- developmental milestones are not reached
- another child is born
- barriers are encountered when accessing systems such as kindergarten, primary school, high school
- the person is ill
- family stressors arise
- the child reaches puberty
- life transitions occur, e.g., leaving school
- out-of-home accommodation is sought
- person is living in supported accommodation (Therapeutic Guidelines, 2012)

It is important to understand that even when a family member with a disability lives away from the family home, in most circumstances lifelong responsibility by the family continues, and the lifelong emotional impact never ceases. Likewise, it is often assumed that the death of a person with a disability brings relief for the family. However, research indicates that anguish and heartache endure as a socially imposed 'silenced grief' (Todd, 2007)

4.7 What does this mean for your nursing practice?

Practice Points:
DISABILITY and HEALTH

- It is important to have background knowledge related to disability and health in order to provide effective and proactive health care.
- People with disability experience the same health problems as the general population, along with specific problems and risks associated with their impairments.
- People with disability experience greater barriers to health care than others.
- Same rights to health care.
- Knowledge of specific diagnoses and aetiologies of developmental and intellectual disability creates awareness of associated health conditions.
- Knowledge of additional threats to health for people with disability enables vigilance in assessing and monitoring health.
- Anticipating known health problems associated with specific diagnoses underpins proactive health management.
- If we don't have knowledge of health conditions and threats to health, we don't know what to look for (assessment).
- A lifespan approach to the health care of people with disability recognises the progression or consequences of specific health problems and therapeutic interventions.
- Healthy adulthood and ageing for people with intellectual disability require a proactive, lifespan health care approach.
- Childhood is the time to minimise developmental problems.
- Adolescence is the time to build resilience.
- The burden of illness is greater for people with disability who cannot effectively express symptoms such as pain.
- Although increasing, life expectancy for people with disability is significantly lower than the general population.
- Causes of death for people with disability are a consequence of multiple risk factors (threats to health).
- Many deaths of people with disability are preventable with the implementation of effective health care and management.
- The burden of caring for a family member with a disability is primarily related to lack of practical supports and assistance.
- Caring for a family member with a disability is linked with a significant increase in physical and mental health problems.
- The emotional impact of disability on a family is lifelong.

5. Person Centred Health Care Assessments and the Development of Health Care Plans

FACS (2012) defines person-centred approaches as follows:

> A person centred system places the person with disability at the centre of decision making when it comes to the supports and services they use.In a person centred system, the rights of people with disability, and their families and carers to make choices about their own lives are respected. A person with disability, their families and carers are heard and supported to exercise choice and to direct supports and service arrangements.

Definitions of 'person-centred' health care are numerous, but the following summary is useful and captures FACS's values:

> **Person-centred health care** places people at the centre of their own care and considers the needs of families and carers. Person-centred health care is about collaborative and respectful partnerships between service providers and users. The service provider respects the contribution service users and their families make about health in terms of values, goals, past experience and knowledge of health. The service user respects the contribution of the service provider including professional expertise and knowledge, information about options available, their values and experience.
> (Adapted from National Ageing Research institute, 2006).

Person-centred and family-centred practice involves people with a disability and their families (when appropriate) being actively involved in negotiating goals and generating and implementing relevant interventions. Person-centred health assessment is essential to the development of health care plans that incorporate person and family goals and provide maps for health care and management.

5.1 Health Assessment

Health assessment is the **systematic** approach to gathering health-related data. Assessment is used for:

- screening and diagnosis
- the documentation of baseline data
- the rationale for therapeutic interventions
- the foundation for health care planning
- the evaluation of therapeutic interventions.

Assessment is considered the most important part of health care planning and delivery. If not undertaken comprehensively and thoroughly, or if the information is inaccurate, the health of people with an intellectual disability will be further compromised.

Regular health assessments (sometimes called 'health checks') have been identified as the most effective way of achieving positive health gains. They are the key to the early detection and treatment of a wide range of actual health problems and threats to health. Research evidence supports annual health checks for people with an intellectual disability for the following reasons:

- primary care services tend to be reactive and respond to actual health problems (rather than preventing them), e.g., respond to bowel blockage rather than monitor for and prevent constipation
- people with an intellectual disability are often unaware of the implications of symptoms they experience, have difficulty communicating their symptoms, and are less likely to report symptoms
- carers may not always attribute manifestations of clinical symptoms, e.g., behaviour, to illness (symptoms often attributed to 'disability', i.e., diagnostic overshadowing)
- regular health checks provide a way to detect, treat and prevent new health problems in people with an intellectual disability
- regular health checks provide baseline information against which changes in health status can be monitored. This is particularly important in accommodation services where staff turnover is high.

The assessment of people with an intellectual disability presents many difficulties and is especially daunting when people have chronic and complex health problems. Effective health support requires careful and rigorous assessment procedures and documentation.

The establishment and maintenance of good relationships with the person to be assessed, their families and carers promotes effective assessment. Trusting relationships enable detailed information about past and present health needs.

5.1.1 Assessment Data

Health data may be broadly classified according to their source.

Primary data are obtained directly, including:
- direct assessment, observationof signs, and examination of the person
- reports of symptoms and health status from the person
- tests related to physiological functioning, e.g., blood tests, urine tests, pulmonary function tests, etc.
- imaging, e.g., x-rays, CT scan, MRIs, etc.
- standardised screens, tests and measures – physical and psychological

Secondary data are obtained indirectly from others, including:
- family, carers, support staff
- previous health records
- other health professionals
- research, knowledge, experience about specific conditions from other sources such as journals, colleagues, etc.

5.1.2 Types of Health Assessment

Comprehensive health assessment assessesthe overall health status of a person in order to plan care in partnership with the person (and significant others when appropriate).

A comprehensive health assessment gathers information related to:
- physical status – a systems approach is often used
- developmental status
- psychological and emotional status
- functional capacities and limitations
- activities of daily living (ADLs)
- risks and threats to health and wellbeing, including lifestyle risks
- cultural and spiritual beliefs
- social history
- support systems

Comprehensive health checksusually refer to regular medical assessment by a person's General Practitioner (GP). They focus primarily on medical issues, but usually consider psychosocial factors and support systems that have an impact on an individual's health.

Screening assessments are used to detect possible problems before symptoms become obvious. They may identify areas of risk for further, more detailed assessment, e.g., observation of developmental milestones.

Targeted assessments or **problem-oriented assessments**are used for specific problems and purposes, e.g. pain, body systems (respiratory, cardiac, etc.), falls risk, skin integrity, etc. These enable thorough assessment of specific health issues identified by signs and symptoms, screening, comprehensive assessment or known risk areas.

Note that health checks, screening, and targeted or problem-oriented assessments may be components of a comprehensive health assessment.

Initial health assessments are done on first contact with a service or health nurses. However, it is essential to remember that **nursing assessment is an ongoing complex process**that draws upon your skills of:
- ongoing informal clinical observations
- discussion with person with disability, family, carers, support staff
- discussion with professional colleagues
- using relevant assessment tools across environments.

Ongoing assessment is a core component of the roles of Registered and Enrolled Nurses. Whenever you have contact with a person with a disability for whom you have responsibility and/or carers, you are gathering information that must be interpreted, documented and acted upon in a timely manner when necessary.

5.1.3 Health Care Assessment Tools

Numerous **assessment tools** are available to enable the systematic gathering and documentation of data for comprehensive or targeted assessment.

Some tools are **standardised** so that comparisons can be made between an individual and the population, e.g., developmental and cognitive assessment tools such as the Bayley Scales of Infant Development, the Griffiths Mental Developmental Scales, Wechsler Intelligence Scales, Stanford Binet Intelligence Scales which can be accessed online.

Some tools are **validated** which means they have been demonstrated to do the job they are supposed to do, e.g., CHAP, The 'OK' Health Check (Matthews, 2003)

The following **Tables 1 and 2** summarise information about health assessment tools. They include comprehensive assessment tools recommended by FACS or required by Medicare, along with a number of tools useful for targeted or problem-oriented nursing assessment. Many of these tools have not been developed specifically for people with an intellectual disability. However, they may be useful due to their development for people with cognitive impairments such as dementia. The list is not exhaustive.

Some accommodation and community services may have different health care planning processes or use different comprehensive health assessment tools. However, it is important that all processes and tools used address the areas of health concern set out in the CHAP and MBS tools. These areas of health concern are presented in the preceding Section 2 'Disability and Health'. You need good working familiarity with the health problems and threats in order to use an assessment tool effectively.

Table 1.   Comprehensive Health Assessment Tools (Endorsed by NSW Government)

Name	Description	Additional Information
Medicare Benefits Schedule (MBS): Health Assessment for People with an Intellectual Disability	Time based (Items 701, 703, 705, 707)MBS assessments may be used with a person with intellectual disability. However, it is recommended that a long (705) or prolonged assessment (707) is used due to difficulties with recognising and reporting symptoms. The MBS assessment tool was designed for use with people with intellectual disability who require assistance with daily living activities. This tool allows GPs and Practice Nurses to comprehensively assess the physical, psychological and social functions of patients with intellectual disability and identify any medical intervention and preventive health care required.	MBS Health Assessment. DoHA Fact Sheet MBS Q&A Annual Health Assessment NSW Council for Intellectual Disability Fact Sheet
The Comprehensive Health Assessment Program (CHAP)	CHAP was developed by the University of Queensland's Centre for Intellectual and Developmental Disability. The assessment tool was designed to allow for improved identification and documentation of health status and needs of adults with an intellectual disability. CHAP is a two part assessment. The first section creates a comprehensive health history and is completed by the person and/or support people. The second part is completed by a health professional, i.e., the person's GP or a Registered Nurse. FACS has purchased the right under a licensing agreement to implement the CHAP in NGO and FACS operated services. The CHAP is endorsed by FACS as it was developed, tested and demonstrated to improve healthcare delivery to people with a disability in Australia. It has been validated in Australian studies. Use of CHAP is limited to services who pay for the licence. Research with GPs indicates that CHAP enhances diagnosis and communication. However, structural barriers related to: time, lack of support worker skills and lack of organisational comprehensive assessment and follow-up create problems (Lennox et al, 2013)	The Comprehensive Health Assessment Program. CHAP Brochure The Comprehensive Health Assessment Program-Version 11(FACS intranet) New Medicare items to help you to provide health assessment for people with intellectual disability(FACS intranet) NSW Council for Intellectual Disability Fact Sheet CHAP Report

Table 2. Targeted (Problem-Oriented) Health Assessment Tools

Target or Problem Area	Assessment Tool	Description	References and Additional Information
PAIN	**Pain Assessment Nursing Tool (PANT)**	This tool was developed by disability nurses working at Hunter Residences (Stockton) and is designed to assist nurses in the identification, intervention and monitoring of pain experiences for people with intellectual disability who are not adequately served by existing pain assessment systems. The package consists of three sections: 1. Clinical Indicators of Pain Checklist 2. Nursing Physical Assessment 3. Behaviour Monitoring/Intervention Tool	This tool will be reviewed by the Practice Reference Group Nursing and Health Care and will be forwarded to Clinical Innovation and Governance for endorsement and uploading to the FACS intranet. If this tool is currently not available in your region, contact the Practice Leader Nursing and Health Care.
	Abbey Pain Scale	The Abbey Pain Scale was developed to allow for the measurement of pain in people with dementia who cannot verbalise. It is an assessment tool employed as part of an overall pain management plan. It is used to assess pain in people who have with severe cognitive impairment and difficulties communicating. It can be used by people with no nursing training.	Abbey Pain Scale Tool Pain in Residential Aged Care Facilities – Includes assessment information for people with cognitive impairments.
	PAINAD	The Pain Assessment in Advanced Dementia (PAINAD) was developed to assess pain in people who are cognitively impaired, non-communicative, or suffering from dementia and unable to use self report methods to describe pain. Variables recorded include: breathing, vocalisation, facial expression and body language.	Pain Assessment in Advanced Dementia (PAINAD) Scale Pain Assessment Tool Guidelines for use: PAINAD PAINAD Instructions
	Summary of Tools	Overview of pain assessment tools. American Pain Society.	American Pain Society –

Target or Problem Area	Assessment Tool	Description	References and Additional Information
			Assessment of Pain
DISTRESS	DisDAT	Disability distress assessment tool. Identifies distress cues in people with severe communication impairments. Website includes background information, instructions and tool.	DisDAT
NEUROLOGICAL	Glasgow Coma Scale (GCS)	Tool to assess and quantify the level of consciousness of a person. Three types of responses are assessed and recorded to achieve a maximum GCS score of 15 1. Eye opening response 2. Verbal response 3. Motor response The Paediatric Glasgow Coma Scale is a modified version that may be useful for people with an intellectual disability.	Glasgow Coma Scale Rainbow Rehabilitation Center- Glasgow Coma Scales (Adult & Paediatric) Modified Glasgow Coma Scale for Infants and Children RPA ICU GCS Procedure
RESPIRATORY	Various Respiratory Assessment Guides	Respiratory assessment addressesrespiratory status and also provides information related to other systems, e.g., cardiovascular, neurological systems. Alteration in breathing is often the first vital sign observed when a person's health is deteriorating.	Quick Respiratory Assessment & Documentation Guide Respiratory Status & Perfusion Assessment Respiratory Systems Case Study Nursing Times Respiratory Assessment
	Asthma Score	The Asthma Score is a simple five step questionnaire which rates the control of asthma out of a score of 25.	About Asthma Score
NUTRITION and SWALLOWING	Nutrition and Swallowing Risk	The Nutrition and Swallowing Risk Checklist screens people for difficulties related to nutrition and swallowing. It was	Nutrition & Swallowing Checklist(FACS intranet)

Target or Problem Area	Assessment Tool	Description	References and Additional Information
	Checklist – FACS	developed to be used by people who support people with a disability.	Nutrition in Practice Manual-Checklist included in this manual Nutrition and Swallowing Policy & Procedures
BOWELS			
	Bristol Stool Chart	The Bristol Stool Chart classifiesstool form into seven categories to indicate a range from constipation to diarrhoea. Stool type is affected by bowel transit time, so the classification can be an indicator of digestive health.	ADHC Bowel Chart(FACS intranet) Bristol Stool Chart
	Various – Bowel Screening, Assessment & Management	Documents identifying and evaluating many useful bowel screening and assessment tools.	Bowel Screening, Assessment & Management Refining Continence Measurement Tools
	Community Nursing Bowel Assessment	Enable NSW bowel assessment tool.	Community Nursing Bowel Assessment. Enable NSW
WEIGHT			
	Weight Chart	FACS ADHC weight chart is designed to keep an ongoing record of a person's weight. Weight fluctuations are noted on the chart and the reasons for weight changes are assessed.	ADHC Weight Chart Included in ADHC Health Care: Policy & Procedures
	BMI Calculator	Body Mass Index (BMI) provides an estimate of total body fat.	BMI Calculator BMI Calculator. NSW Health
SLEEP	**BEARS Sleep Screening Tool**	The BEARS assessment tool assesses children from 2 to 18 years old for major sleep disorders. The assessment focuses	The Bears Sleep Screening Tool

Target or Problem Area	Assessment Tool	Description	References and Additional Information
		on: B = bedtime problems E = excessive daytime sleepiness A = awakenings during the night R = regularity and duration of sleep S = snoring	
	Sleep Basics Information	Presentation highlighting sleep hygiene and assessment.	Sleep Basics for Health Promotion
	Sleep Assessment Resources	Website that links to various sleep assessment information and tools.	Sleep Assessment & Management
	The Epworth Sleepiness Scale (ESS)	The Epworth Sleepiness Scale is an assessment used to determine a person's level of daytime sleepiness.	The Epworth Sleepiness Scale ESS
	Sleep Apnoea Screening Tool	Uses ESS to screen for obstructive sleep apnoea.	Sleep Apnoea Screening Tool
SUPPORT NEEDS	**Service Need Assessment Profile (SNAP)**	SNAP was designed in Australia to measure the support needs of a person with a disability. The output of this assessment is an individual support plan which outlines the level of support the person will need e.g. in home support services or overnight care.	Productivity Commission, Disability Care and Support, Appendix B SNAP tool information
	I-CAN	I-CAN is an Australian system for identifying and classifying a person's support needs based on the ICF framework.	Productivity Commission, Disability Care and Support, Appendix B I-CAN tool information
	Productivity Commission	Excellent summaries and descriptionsof numerous assessments for support in Appendix B. Includes FIM, D-	Productivity Commission, Disability Care and Support, Appendix B

Target or Problem Area	Assessment Tool	Description	References and Additional Information
	Report No. 54	START, I-CAN, SIS, ICAP, SNAP, as well as sample forms.	
FAMILIES	CPCHILD©	Caregiver Priorities &Child Health Index of Life with Disabilities Questionnaire, CPCHILD is a reliable and valid measure of caregivers' perspectives on the health status, comfort, wellbeing, and ease of caregiving of children with severe developmental disabilities. It is also a useful proxy measure of the health related quality of life of these children	CPCHILD© Questionnaire
URINARY INCONTINENCE	Revised Urinary Incontinence Scale (RUIS)	The RUIS is a reliable five step assessment scale used to measure urinary incontinence in a person and monitor outcomes following treatment. Its use for people with intellectual disability is limited.	Tools for Assessing and Monitoring Urinary Incontinence: The Revised Urinary Incontinence Scale (RUIS) Revised Urinary Incontinence Scale (RUIS) Refining Continence Measurement Tools
EPILEPSY	Epilepsy Management Plan	The purpose of this document is to minimise risk to the person and to plan a response to a critical event e.g. a prolonged seizure. Includes assessment processes.	Epilepsy Management Plan Epilepsy Policy and Procedures
	Epilepsy Self-Assessment Tool for Service Providers	Brief assessment that addresses epilepsy management is services.	Epilepsy Self-Assessment Tool for Service Providers
	Nursing Management of Seizures	Guidelines that include nursing assessment.	Nursing Management of Seizures

Target or Problem Area	Assessment Tool	Description	References and Additional Information
	Epilepsy Risk Assessments	Risk assessment tools for people with epilepsy: • Individual • Safety at home • Safety outside home	Three Epilepsy Risk Assessment Tools
FUNCTION	**Mobility & Functional Assessment Tools**	Summaries of various tools to assess mobility and function	Functional & Mobility Tools Overview
PRESSURE AREA RISK	**The Waterlow Scale**	The Waterlow Scale estimates the risk of pressure sore development.	Waterlow Pressure Sore Prevention/Treatment Policy The Waterlow Scale Information and Tools
	The Braden Scale	The Braden Scaleassesses the risk of pressure sore development.	Braden Scale for Predicting Pressure Sore Risk
DEVELOPMENT	**Developmental Milestones**	Developmental Milestones and the Early years Learning Framework is a useful source of information regarding expected development from birth – 5 years	Developmental Milestones
	Developmental Checklist	Developmental Checklist. Birth – 13+ years Note: Knowledge of developmental milestones allows a quick developmental screen.	Developmental Checklist
	Developmental Screening and	Document that provides detailed information about the range	Developmental Screening and

Target or Problem Area	Assessment Tool	Description	References and Additional Information
	Assessment Instruments	of screening and assessment instruments available.	Assessment Instruments
MENTAL HEALTH	Anxiety and Depression Checklist (K10)	beyondblue Depression and Anxiety Checklist is a quick and simple screening tool. It has limited application with people with an intellectual disability but its use can be facilitated for people with milder levels of ID.	Anxiety and Depression Checklist (K10). beyondblue
	Mental Health Nursing of Adults with Learning Disability	RCN (UK) Guidance document that has information regarding mental health and intellectual disability, including extensive information about assessment and suitable tools.	Mental Health Assessment Information
	Mental State Examination (MSE)	A MSE is a systematic appraisal of appearance, behaviour, mental functioning, and overall appearance of a person. It provides a 'snapshot' of a person's psychological functioning.	Mental State Examination (MSE) Also included in RCN document; Mental Health Assessment Information

5.1.4 Doing Health Assessments

Using health assessment tools involvesmany **techniques** for gathering information:

- interview, observation, examination, tests, research
- and with **input** from many sources:
- individuals, families, carers, support staff, teachers, health professionals

The tools act as a guide for systematic assessment and become a documented record.

People with an intellectual disability have cognitive impairments and many have communication problems. Therefore, it is imperative that a support person – family, carer, support worker – who knows the person well, is present during health assessment.

Prior to and during an assessment, the following considerations are necessary.

- Gain consent from person with disability and/or family or carer ('person responsible'). Document consent on record
- Organise time, place and any equipment that may be required
- Gather all relevant information, e.g., previous assessments, records, reports, etc.
- Engage with person being assessed and support person. Spend a little time establishing rapport prior to more formal assessment processes.
- Collaborate with other professionals if necessary.
- Document health assessment and all information gathered.
- If accompanying person with a disability to another health assessment, e.g., GP, specialist, ensure all documentation is current and relevant. This forms part of a person's ongoing health care assessment record.
- Report verbally and prepare written report including findings, recommendations, referrals and appointments for person being assessed and/or family or carer.
- Develop a health care plan based on the assessment and recommendations.

Important Message

Although health assessment is frequently an organised, focussed and formal process, it does not end there. Health assessment is also ongoing, dynamic and informal. Assessment is a core component of nursing practice and you are involved in assessment at all times. Every encounter and interaction with the people for whom you provide care is an **'assessment moment'**. Such moments are opportunities for observation, interpretation and problem-solving. Always record changes and act on them in a timely manner when indicated ensuring that relevant manager and carers are advised.

It is also important to work collaboratively with support staff who are your eyes and ears because they work closely with people with an intellectual disability and often know them well. Encourage support staff to **observe** carefully and to document and report all changes in the people for whom you are responsible. Although, as a Registered Nurse, you will **interpret** the observations of support staff, such observations are essential for effective health care.
(Sources used for Sections 3.1 – 3.1.4:Carnaby, 2009; Marsh & Drummond, 2008; Gates, 2006; Lennox et al, 2010;Matthews, 2003; Matousova-Done & Gates, 2006; Robertson, Roberts & Emerson, 2010; Therapeutic Guidelines, 2012)

5.2 Health Planning

Health planning is concerned with improving health. It is a dynamic and ongoing process that includes:

- assessment – data gathering and analysis
- the determination of goals
- recommendations and interventions
- implementation strategies – who will do what and when?
- evaluation of interventions and strategies against goals
- ongoing assessment – to monitor and review all processes, actions and outcomes.

In nursing, such health planning is summarised as a process of:

- assessment
- diagnosis
- planning
- implementing
- evaluating

Health planning may involve many people who will all have a different area of focus and emphasis. For example a Psychologist will focus on behaviour, a Speech Pathologist will focus on communication and the mechanics of eating and drinking, a Physiotherapist will focus on positioning and mobility, a Dietitian will focus on nutrition, an Occupational Therapist will focus on function and activity, a GP will focus on medical issues. **Registered Nurses consider the overall and bring all health assessment and planning together in the development of coordinated, comprehensive health care plans.**

Health care planning focuses on physical, psychological, emotional, environmental and social factors and goals. Such care planning is:

- systematic
- dynamic and cyclical
- interpersonal and collaborative
- person-centred
- goal-directed

Health care planning must be **documented**. This is the only way that recommendations and interventions can be consistently implemented, and the evaluation of therapeutic interventions and goals monitored. This is especially important when people with an intellectual disability live in accommodation services and are involved with multiple staff.

5.2.1 Health Care Plans and Nurses

> Wherever people with an intellectual disability live, if they are in receipt of nursing care, whether this comprises short intensive nursing interventions or long periods of care and support, then this care should be guided by a care plan…based on systematic nursing assessment. (Gates, 2006, p.vi).

Traditionally, nurses working in direct care with people with intellectual disability have been responsible for care plans that consider whole of life and all daily living

issues. However, with changing philosophies and models of service that emphasise social models of disability and person-centred approaches, nurses now focus on health issues.

Nurses work in partnerships with people with disability, families, support staff, staff from schools and day programs, medical and allied health colleagues to develop health plans that acknowledge the centrality of people with disability, their families and carers.

Registered Nurses play a central role in the development of comprehensive health care plans. To achieve effective health care planning that reflects problems identified by assessment, goals to be achieved, therapeutic interventions, and ongoing evaluation and assessment, there has to be someone to co-ordinate all parties and components, and to develop the actual plan. Registered Nurses, by virtue of their education, along with their focus on the promotion of health and wellbeing, are the **experts** in the development of health care plans.

It is important that the health care plan considers and reflects multiple specialised assessments, the person's life, and living and activity contexts. The health care plan must be flexible enough for people with disability to participate in and 'live life', rather than focusing only on health problems and should be presented in a way the person can understand where possible. **The health care plan should enhance living and wellbeing.**

5.2.2 Comprehensive Health Care Plans: Development, Review and Evaluation

Health care plans support and guide health management and practice in order to maintain and promote good health in people with an intellectual disability. Good health enables people to participate in life. Health care plans all look different and vary according to an individual's degree of complexity in terms of health and need for support. They are also shaped by various contexts, e.g., where a person lives, the purpose of the plan, organisational and service practices and requirements. For example, health care plans for a child living at home with family, a healthy person in a boarding house with lifestyle risks, and a person with high support needs and chronic and complex health problems living in a community home, will all look very different.

Health care plans also go by different names, e.g., comprehensive health care plan, health care plan, health plan, health support plan, health action plan, annual support plan. It doesn't matter what they are called, who they are for, or where they are developed – general principles apply no matter what they are called.

Comprehensive health care plans are developed to reflect information gathered by comprehensive health assessment in the categories presented in Section 3.1.2.

A comprehensive health care plan includes the following components:

COMPONENTS of a COMPREHENSIVE CARE HEALTH PLAN	
Component	**Comments and Examples**
INFORMATION about the PERSON	Name, date of birth, address, religion, ethnicity, significant others, person responsible and contact details (when relevant), Medicare number, health care card number, pension number (when relevant), GP details
MEDICAL DIAGNOSES	Examples: Intellectual disability. Cerebral palsy (GMFCS level 5). Epilepsy. Dysphagia. GORD. Recurrent chest infections. Orthopaedic deformities. Scoliosis. Osteoporosis.
ALLERGIES	Examples: Chlorhexidine – severe contact dermatitis.
RISKS and ALERTS	Examples: Seizures – never to be alone near water. Pressure – prone to pressure sores on feet. Protect feet, limit pressure (use blanket cradle). Include any potential for injury to self or others.
IMMUNISATION STATUS	Include all vaccination history, and recent and current vaccinations. Examples: Pneumovax 4/3/12. Fluvax 4/4/12; 8/4/13
PEOPLE INVOLVED	Might include health professionals, key worker, service manager, school, teachers, lifestyle educators
MEDICATIONS	Dose. Intended action. Common adverse effects.
HEALTH ISSUES	Actual and potential (health problems and threats to health). Examples: 1. **All** physical and psychological problems, e.g., pain; anxiety 2. Functional problems, e.g., immobility 3. Growth & development, e.g., underweight (156cm X 44kg = BMI 18) 4. Social and lifestyle problems and threats, e.g., becomes anxious in new situations
GOALS	For **each** health issue. Examples: 1. Pain will be controlled. Anxiety will be decreased. 2. Contractures will be prevented 3. Goal weight of 46kg will be achieved (by 'date') 4. Anxiety in new situations will be reduced
ACTIONS or INTERVENTIONS	For **each** health issue. Examples: 1. Administer regular paracetamol as prescribed. Promote comfort using Positioning Plan 2. Follow Exercise Plan. Move gently. Swimming. Remedial massage. 3. Follow Nutrition Plan. Include supplements. 4. Prepare for new social situations gently. Introduce people one at a time. Keep noise levels down.
RESPONSIBILITY	Who is responsible for actions
EVALUATION	Specify when (date) and who is responsible for evaluation
COMMENTS	Provides area for extra instructions, updating, reviews for specific health problems, etc.
APPOINTMENTS, TESTS, etc.	Include: Identify when regular appointments with GP, specialists, etc. are due. Dates of regular blood tests, e.g., AED levels, etc. Minimise radiation and venipuncture.

ATTACHMENTS	Attach all relevant assessments, plans and protocols.
	Might include: assessments by Psychologist, Physiotherapist, Speech Pathologist, Dietitian, OT
	Might include:Plans/protocols related to epilepsy, diabetes, communication, positive behaviour support, foot care, eating and drinking, nutrition, positioning, exercise, risks (and many more).

You will know what a comprehensive health care plan looks like but, as a reminder, here is a summary example of how 'health issues' and 'actions', etc. might look.

Example:EXTRACT from a SAMPLE COMPREHENSIVE HEALTH CARE PLAN for Person in Supported Accommodation					
HEALTH ISSUE	GOAL	ACTION	RESPONSIBILITY	EVALUATION	COMMENTS
PAIN	Pain will be controlled	Administer regular paracetamol as prescribed. Promote comfort using Positioning Plan.	Support staff. House manager. Registered Nurse	Registered Nurse – ongoing & review 3 months (date) General Nurses – PRN & regular 3 months (date)	Pain indicators: crying, biting finger. Report to RN if pain behaviour is present.
IMMOBILITY	Contractures will be prevented	Follow Exercise Plan. Move gently. Swimming. Remedial massage.	Support staff. House manager. Massage therapist. Physiotherapist	Physiotherapist – review 12 months (date)	Report to RN if pain behaviour is present.
WEIGHT	Goal weight 46kg will be achieved	Follow Nutrition Plan. Include supplements.	Support staff. House manager	Dietitian – review 6 months (date)	Monitor with fortnightly weighs. Report any weight loss to RN.
ANXIETY	Anxiety in new situations will be reduced	Prepare for new social situations gently. Introduce people one at a time. Keep noise levels down.	Support staff. House manager	Psychologist – review 12 months (date)	Report increased anxiety to RN.

Review and Evaluation
Good practice dictates that health care plans are subject to ongoing informal review. Any change in a person's health warrants a review of the plan where changes in interventions may be required.

Formal review and evaluation should occur at regular intervals, at least annually, unless warranted more frequently. It is a good idea to link this review with the annual GP assessment and person-centred planning processes.

Health problems must be evaluated against person's health goals. If goals are not met, then interventions must be reviewed.

For example: if hypertension is an identified health problem, and the goal of BP being maintained below 130/85 is not being met, then interventions must be reviewed. This might include an appointment with GP to review medication, a review of weight goals and management, and a review of exercise goals and activity.

Health care plans, and any accompanying processes and procedures, will vary between services and contexts. Staff in FACS services are expected to be familiar and comply with Health Care: Policy and Procedures (FACS, 2012)
[Available:
http://www.adhc.nsw.gov.au/__data/assets/file/0007/228094/Health_Care_Policy_and_Procedures_April_2012.pdf]
This document may be useful for staff in other services and is openly available.

For further information (samples of nursing care plans) see:
Nursing Care Plans: RN Central
[http://www.rncentral.com/nursing-library/careplans]
Nursing Care Plan Examples
[http://www.pterrywave.com/nursing/care%20plans/nursing%20care%20plans%20toc.aspx]

5.2.3 Planning for Consultations with GPs and Specialists

Whenever a Registered Nurse has responsibility for the health care of a person with intellectual disability, it is important accompany the person for GP and Specialist appointments whenever possible. When family or carers are able to attend, it is still useful for the Registered Nurse to attend the appointment for purposes of interpretation of information and for raising health issues.

Registered Nurses play a vital role in planning for appointments with GPs and Specialists. The following considerations are essential:

- **Frequency of appointments**:
  - **GP** – annual for GP Health Check. Every three months for people on medications. More frequently if indicated.
  - **Specialist** – usually an annual review, unless otherwise indicated.

- **Information** requested by GP or Specialist must be prepared and provided.

- Always check **access** issues, e.g., physical access (including lifting and examination aids), communication, impact of behaviour.

- The Registered Nurse should **follow-up** on any previous tests and Specialist appointments since last visit.

- It is important for the Registered Nurse to do an **audit** of records and health status since the last visit to GP or Specialist. If not done formally by the service, then the Registered Nurse needs to do informally. It is pointless getting to the appointment and not being able to give an overview of the person's health status and any problems arising. This audit should be documented in the person's file in readiness.

- **Documentation** – ensure records are up to date and any relevant test results, etc. are included in file.

- Prepare record of all **current health problems** of person with a disability.

- Ensure all information is in person's file. **Take file to appointment**.

- **Anticipate** need for any checks, referrals, tests, x-rays, etc. Remember that GPs and Specialists probably don't know the person as well as you, and nor might they be as familiar with health threats for people with an intellectual disability as you are. Examples of such anticipation might include reminding to:
  - check vitamin D levels
  - request medications that can be administered via gastrostomy
  - request a referral for an annual review by a Specialist.

- Unless person has an e-health record, you might need to **exchange** reports, test results, etc., with GP or Specialist.

- It is a good idea to ask doctor to **request** any test results be sent to person with a disability – then they will be on person's file. Ask Specialist to send a copy of report to patient (as well as GP).

- It is important for **GP to manage all prescriptions**, including Specialist recommendations for medications. In this way an overall medication record is maintained.

- **Remember:** nothing can be done without **consent** from person with intellectual disability or substitute consent from 'person responsible'. (See: FACS Decision Making and Consent Policy and Procedures)

Planning for these appointments can be complicated and should not be underestimated. Following is an example things to be considered when preparing for a visit to a Neurologist with a person with intellectual disability and epilepsy.

Example: PLANNING FOR AN APPOINTMENT WITH A NEUROLOGIST	
Neurologist will want:	**Person with disability** may need (will depend on level of support required)
- Referral - Payment (unless bulk billed) - Cards – Medicare, Pension or Health Care Card - My Health Record (red book) if available - Current medications, and history of all previous AEDs (anti-epileptic drugs) - Previous Neurologist's reports (if not regular Neurologist) - EEG reports - Epilepsy management plan - Seizure record	- Transport - Money – parking, drinks, etc. - Food, drinks, eating and drinking requirements (supplements, thickener, utensils, etc.) - Change of clothing - Incontinence issues - Midazolam - Fatigue

▪ Because of the interplay of epilepsy with female hormones, osteoporosis (2^0 to AEDs), liver function (2^0 to AEDs) and electrolytes (2^0 to AEDs), the following will also be required:
 	
   ● gynaecologist reports (&/or menstruation charts)
   ● endocrinologist reports
   ● recent DEXA (performed every two years)
   ● recent pathology results(vitamin D, LFTs, electrolytes)
   ● AED results (sometimes)
 	
▪ Reason for current visit.
	▪ Behaviour
	▪ Anything else needed by individual

For further information see:

The following resources are useful for information about GP appointments and specialist services for people with an intellectual disability.

Better Start for Children with Disability

[http://www.health.gov.au/internet/main/publishing.nsf/Content/children_disability]

CDDS (2006). Health care in people with intellectual disabilities: guidelines for general nursess.

[Available at: http://www.cds.med.usyd.edu.au/publications-home/cat_view/50-health-publications].

The Appendix includes a list of specialist clinics and services.

Centre for Disability Studies – Clinical Services.

[http://www.cds.med.usyd.edu.au/clinical-services]

NSW Council for Intellectual Disability – Fact Sheets

Including:

Personal Health Records

[Available: http://www.nswcid.org.au/health/se-health-pages/personal-health-records.html]

Going to the Doctor

[Available: http://www.nswcid.org.au/health/se-health-pages/going-to-the-doctor---tips--tricks.html]

Finding the Right Doctor

[Available: http://www.nswcid.org.au/health/se-health-pages/finding-the-right-doctor.html]

Annual Health Assessments

[Available: http://www.nswcid.org.au/health/se-health-pages/annual-health-assessments.html]

Specialised Intellectual Disability Health Services

[Available: http://www.nswcid.org.au/health/se-health-pages/specialised-intellectual-disability-health-services.html]

5.2.4 Planning for Hospitalisation

NSW Health and FACS have endorsed the following joint guideline:
NSW Health and Ageing Disability and Home Care Joint Guideline: supporting residents of ADHC operated and funded accommodation supported services who present to a NSW Public Hospital
[Available: http://www0.health.nsw.gov.au/policies/gl/2013/pdf/GL2013_001.pdf]

The Joint Guideline incorporates the NSW Health policy:
- Disability – People with a disability: responding to their needs during hospitalisation, [Available:
  http://www0.health.nsw.gov.au/policies/pd/2008/PD2008_010.html]

and FACS's:
- Health Care Policy and Procedures[Available;
  http://www.adhc.nsw.gov.au/__data/assets/file/0007/228094/Health_Care_Policy_and_Procedures_April_2012.pdf]

The Joint Guideline aims to ensure that all staff working in NSW hospitals and disability support accommodation services are aware of respective roles before, during, and after transfer of care of people with disability. It includes information related to planned and emergency hospital admissions.

Practice will vary according to service requirements and practice contexts. However, the Joint Guideline provides a framework and important information for all. It is underpinned by the following principles:
- person centred approach
- patient centred care
- communication
- sharing information
- sharing expertise
- capacity to consent.

Useful comprehensive **Hospital Support Plans** are included in the Appendix of the Joint Guideline.

Following is an example that highlights issuesNurses need to consider when planning for hospital admission of a person with intellectual disability.

Example: PLANNING for HOSPITAL ADMISSION
▪ **Talk with hospital staff** (try to include family member) BEFORE the admission – preferably NUM of intended ward (this can change!). **Discuss**:
● health plans – including any palliative or future care plans, communication plans, hospital support plan, etc.
● equipment requirements – manual handling, electric bed, bed cradle, air mattress, hoist and sling, etc.
● management – pressure, feeding regimes, eating and drinking, etc.
● responsibilities – personal care, medications, etc.
● any risks and safety issues.
▪ Leave copies of all **plans**. Also take another set at admission.
▪ Attend **Pre-Admission Clinic** (preferably with person responsible). All of the above might be addressed at this time. Discuss issues related to induction of anaesthesia, recovery ward, risks, signing of consents. Clarify fasting requirements, cessation of any

> meds prior (e.g., blood thinners), what meds to take, etc.
>
> - Prepare all necessary **personal items** and clothing needed in hospital. <u>Examples</u>: medications, communication aids, continence aids, AFOs, sleep inserts, hearing aids, glasses, formula, thickener, specialised utensils, significant possessions (for security and distraction).
> - **Escort** person with disability to hospital (or meet there).
> - **Take relevant files, Medicare and Health Care cards**, **My Health Record** (when available)
> - Go to **ward** with person with disability. Try to see the Nurse Manager (often NUM). You may have to go through all this again!
> - Identify **unique managementstrategies** that can be implemented by hospital staff to work effectively with person with disability. <u>Examples</u>:Joe needs the framed photo of his mother with him to settle. Always introduce yourself and smile before saying anything to Susan.
> - Negotiate **support** for person during hospital stay.
> - Ascertain how often you need to **visit.**
> - Assess need for a **case conference** prior to discharge. Arrange to take place a couple days before discharge with all key people. Ensure person with a disability is at centre of decision-making.
> - Ensure person with a disability **NEVER leaves without a completed discharge summary**.
> - **Follow up** discharge summary and any changes to medications and health care plans. Ensure recommendations and changes are documented.
>
> **Note:**
> For an **emergency hospital admission**, services generally have relevant hospital transfer documentation. If the person is to stay in the hospital, then the above points apply (with the exception of the pre-admission clinic).
>
> See the [Joint Guideline](#) for detail.

It is essential to remember that hospitalisation is likely to be confusing and scary for people with an intellectual disability. Disorientation, confusion, and fear are likely which may be expressed as agitation and possibly, aggression. A person's functional skills are often further impaired while in hospital and routine skills may be forgotten (e.g., toileting, brushing teeth, etc.)

It is also a demanding time for families and carers.Numerous factors contribute to difficulties with hospitalisation in this very vulnerable population. These include:

- communication impairments
- impaired reasoning
- fear and confusion may be expressed as challenging behaviour
- fears of family members
- poor understanding of issues related to intellectual disability on the part of hospital staff
- inadequate preparation of staff
- inadequate hospital systems
- need for many people with an intellectual disability to have support person with them during hospitalisation.

Whenever possible, careful **preparation** that includes family members and carers, is vital. Nurses are in a position to **educate** hospital staff and every opportunity must be used.

Many services have developed strategies and protocols to make the hospital experience less stressful for people with an intellectual disability and staff who work with them. For example: Northern Sydney Central Coast Health has developed the **'Top 5' protocol**[http://www.nscchealth.nsw.gov.au/carersupport/cc/Top5.shtml]to support residents of Central Coast group homes. The protocol identifies five strategies that willhelp settle, calm, and care for a person with cognitive impairment. These are recorded on form and included in hospital documentation. See website for resources. Identify any strategies or protocols used in your work environment.

For further information see:
Good to Great eLearning Program ELMO. Hospitalisation Guideline Module
[www.elearn.com.au/adhc/goodtogreat]
Login details:
Username: adhc
Password: goodtogreat
The Hospital Communication Book
[http://www.surreyhealthaction.org/assets/files/Hospital%20Communication%20Book%20-%20version%202%20-%20web.pdf]
Clear Communication People. Health Communication Resources.
[http://www.communicationpeople.co.uk/subjects/health/]

5.2.5 Planning for Transition from Paediatric Services to Adult Services

The transfer from paediatric to adult health services for young people with chronic health conditions can be difficult and traumatic for them, as well as their families. Good practice dictates that the handover should be planned and managed as a process which can be conceptualised as a 'transition'.

Such a transition can be defined as:

> …a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems. (Department of Health, 2006, p.14)

Transition takes time. Clinicians and parents should begin the planning process with young people in early adolescence so they are well prepared by the time they need to transfer to adult services, usually between 16 and 18 years. Registered Nurses who work with young people and their families play a leading role in initiating and coordinating transition planning. Contact the ACI Transition Care Network for information and referral.

The NSW Agency for Clinical Innovation (ACI) Transition Care Network aims to improve the continuity of care for young people with chronic health problems as they move from pediatric to adult health services. The Network Manager leads a team of three Transition Care Coordinators based at Westmead, Royal Prince Alfred and John Hunter Hospitals. The Coordinators are also affiliated with the NSW tertiary

children's hospitals in Sydney and Newcastle. The network extends across all local health districts in NSW.

For further information see:
The NSW Agency for Clinical Innovation (ACI) Transition Care Network
[http://www.aci.health.nsw.gov.au/networks/transition-care]
Transition Framework for NSW
[http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0010/155719/final_framework.pdf#zoom=10 0]
References on Transition – a huge reading resource.
[http://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0004/163156/transition_references_dec_200 9.pdf#zoom=100]
Transition Resources[http://www.aci.health.nsw.gov.au/publications#transition]

(Sources used for Sections 3.2 – 3.2.5: Balandin, Hemsley, Sigafoos& Green, 2007; Buzio, Morgan & Blount, 2002; Goddard, Davidson, Daly & Mackey, 2008; Hemsey, Balandin &Togher, 2007& 2008; Hemsleyet al., 2001; Iacono& Davis, 2003; Wallace &Beange, 2008; Webber, Bowers &Bigby, 2010)

5.3 What does this mean for your nursing practice?

> **Practice Points:**
> **PERSON-CENTRED HEALTH CARE ASSESSMENTS**
> **and the DEVELOPMENT of HEALTH CARE PLANS**
>
> - Health care assessment and planning are core components of nursing practice.
> - Systematic, thorough, comprehensive, person-centred health assessment is essential for the development of health care plans.
> - Person-centred health care plans that incorporate person and family goals provide maps for effective health care and management.
> - Regular health assessments are the most effective way of achieving positive health gains for people with an intellectual disability.
> - Health assessment and planning are ongoing processes.
> - Health care plans must be flexible to enable participation in life.
> - All assessment data and health plans must be documented.
> - Every encounter and interaction with people for whom you provide care is an 'assessment moment'. Record changes and act on them when indicated.
> - Collaborative practice is essential – with people with an intellectual disability, families, support networks, health colleagues, direct care staff.
> - Build collaborative relationships with direct care staff. They are your eyes and ears. Encourage staff to observe, document and report all changes. Your role is to interpret such observations and implement any necessary health actions.
> - Health care plans must be reviewed and evaluated against specific goals. Informal review is ongoing. Formal review occurs at specified intervals.
> - Registered Nurses play a central role in GP and Specialist consultations.
> - Registered Nurses anticipate the need for and tests, reviews, referrals, etc. related to health problems.
> - Registered nurses anticipate threats to health for people with an intellectual disability.
> - Detailed planning is required for planned hospital admissions.
> - Emergency hospital admissions require follow-up and support from Registered Nurses.
> - Transitions from paediatric to adult services must be planned well in advance.
> - The role of the Registered Nurse in person-centred health care assessments and the development of health care plans for people with an intellectual disability is complex. Remember, you are the conductor of a large and multifaceted orchestra.

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