Family & Community Services
NSW GOVERNMENT

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Working with People with Chronic and Complex Health Care Needs Practice Package

Summary: This package has been designed to provide information when supporting people with complex health care needs that guides nurses when working with people with disability in order to promote consistent and efficient best practice.

Document approval

Working with People with Chronic & Complex Health Care Needs has been endorsed and approved by:

Signature on file

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Executive Director

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1. INTRODUCTION

1.1 Introduction and purpose

Welcome to the Working with people with Chronic and Complex Health Care Needs practice package. Prior to reading this practice package nurses should have read and understood the other practice packages titled Person Centred Health Care Assessments and the Development of Health Care Plans, Communication & Behaviour Support, and Mealtime Management.

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 information on working with people with complex health care needs that guides nurses when working with people with disability in order to promote consistent and efficient best practice. It outlines current principles around good practice in working with people with complex health care needs by nurses. This practice package is designed to complement organisation's policies and procedures, rather than replace them.

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 some of the information contained in this package is specific to all nurses working with people with a disability in New South Wales, Australia.

This resource was developed by Clinical Innovation and Governance, within Ageing, Disability and Home Care, Department of Family and Community Services, New South Wales, Australia.

1.2 Common core standards

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

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. Practitioners in other workplaces should be guided by the terms and conditions of their employment and current workplace.

Access to this document for 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.

2. 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 disabilitiy 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 people with disability are permanent and conditions which cause disability increase with age (Australian Network on Disability, 2013).

2.1 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)

3. Working with People with Chronic and Complex Health Care Needs: Health Care and Support

The need for chronic and complex health care arises due to the **impact** and **severity** of diagnoses and/or conditions. For example, a diagnosis of cerebral palsy (CP) does not automatically give rise to nursing complexity. However, if a person has severe CP, then nursing complexity is present because of problems such as:

- **the neurological impact** on skeleton, muscles, bowels, bladder, oral cavity, chest, etc., along with
- possible **impaired functional outcomes** such as:
  - deformity
  - impaired muscle co-ordination
  - limited mobility
  - osteoporosis
  - pain
  - dysphagia
  - malnutrition
  - aspiration
  - incontinence
  - bowel blockage
  - chest infections, etc.

The very nature of intellectual disability contributes further to complexity because of the lack of capacity to direct or to be responsible for one's own health care.

The following addresses four domains of nursing practice:
1. Health Care and Support
2. Teaching and Coaching
3. Advocacy and Coordination
4. Education, Research and Evaluation.

Health Care and Support

Healthcare and support (nursing management) will be clustered around threats to health associated with conditions already outlined in Section 2.3: *Threats to Health for People with Intellectual Disability'.*

The cues for management which follow are intended as a guide to nursing practice. Naturally, each person will be different. While the cues for management are separated into particular threats to health, each person will most likely have multiple threats to health. Herein lies the complexity of nursing care with people with chronic and complex health care needs. As you come across more complex healthcare issues in your practice you will be guided by your senior nurses and manager (Australian Government Department of Health and Ageing, 2010).

From these cues, the Nurse will develop a health care plan as outlined in Section 3.2: *Health Planning*. Remember that health care plans are person-centred, goal-directed, and collaborative. They reflect best practice, enable participation in meaningful activities, and can only be implemented with informed consent.

Integral to health care planning is information and education for people with an intellectual disability, their families and carers. This will be addressed in Section 3.2: *Teaching and Coaching*.

A key role for Nurses in developing a health care plan is in locating accessible health practitioners to assist with blood collection, imaging, and general and specialist appointments, including dental. Access is not just about parking and buildings, doorways, hoists, accessible toilets (including ones with trolleys for changing adults), height-adjustable examination beds, imaging machines that suit the person (rather than the person having to conform to the machine) but also about culturally appropriate services. Most importantly, access is about health practitioners who are familiar with working with people with intellectual disability and chronic and complex health care needs (Brehmer-Rinderer *et al*, 2013) or who are prepared to learn.

All nursing care requires advocacy and coordination which will be addressed separately in Section 3.3: *Advocacy and Coordination.* Nurses are required to practise using an evidence base and to constantly evaluate their nursing practice; these issues will be addressed in Section 3.4: *Education, Research and Evaluation.*

For further information see:
Discrimination and Other Barriers to Accessing Health Care: Perspectives of Patients with Mild and Moderate Intellectual Disability and Their Carers
[http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0070855]
Position Statement on the Health of People with an Intellectual Disability[http://www.nswcid.org.au/images/pdfs/Posn_18_1_12.pdf]
Developmental Disabilities Nursing Manual (Oregon)[http://www.oregon.gov/dhs/spd/provtools/nursing/ddmanual/all_sections.pdf]

3.1 Management of Dysphagia

The Nurse works with the multidisciplinary team in the management of dysphagia to prevent threats to health from dysphagia. The multidisciplinary team may include a Speech Pathologist, Dietitian, Physiotherapist, Occupational Therapist, Gastroenterologist and Respiratory Physician. There are also specialist Dysphagia and Nutrition Clinics in some hospitals in NSW.

The Nurse considers:
- completion of the Nutrition and Swallowing Checklist
- referral to specialists
- modified barium swallow/Barium via PEG
- infant feeding
- menus, recipes, portions
- safe storage and handling of food
- textures of food and drink and how to achieve them
- supplements and how to add them
- alternatives to oral eating and drinking – benefits, risks, ethics, family issues
- nasogastric tube feeding
- pre- and post-operative care of gastrostomy tube
- enteral feeding regimes – rate and timing
- maintenance and replacement of enteral feeding tubes
- maintenance and safe handling of enteral feeding equipment
- plan for dislodged tube
- stoma care
- oral care
- positioning
- specialised eating and drinking equipment
- financial assistance for specialised equipment, formula and supplements through FACS's AIDAS program or Enable's Home Enteral Nutrition (HEN) program
- self-feeding programs
- environments for eating and drinking
- coughing and gagging
- aspiration
- sleep patterns
- weight

Further details can be found: Core Standard Mealtime *Management.*

(Burton, Cox & Sandham, 2009; Crawford, 2009; Kenny & Goodman, 2010; Sleigh, 2005; Therapeutic Guidelines, 2012)

For further information see:
Nutrition and Swallowing Checklist
[http://www.FACS.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=N]
Enteral tube feeding: An evidence-based practice protocol.
[http://www.nursingcenter.com/lnc/static?pageid=1001969]
Gastrostomy Information and Support Service (GISS)
[http://www.scopevic.org.au/index.php/site/resources/gastrostomies]
HEN Program
[http://www.enable.health.nsw.gov.au/home/forms-and-guidelines/hen]
AIDAS Program

3.2 Management of Gastrointestinal Problems

Management of gastrointestinal problems in this population usually refers to management of gastro-oesophagus reflex disease (GORD), Helicobacter pylori, gastroenteritis and surgery. The Nurse works with the GP to prevent threats to health from gastrointestinal problems.

3.3 Gastro-oesophageal reflex disease (GORD) and Helicobacter pylori

The Nurse must be alert to the signs of GORD and *Helicobacter pylori* infection, especially in people who cannot relate their symptoms. These signs may include:

- burping
- regurgitation
- vomiting
- weight loss
- loss of appetite
- depleted iron stores
- hand-mouthing
- dental erosion
- challenging behaviour

Given the incidence of GORD and *Helicobacter pylori* in the population of people with intellectual disability, any suspicion should be referred to the GP for investigation. The Nurse considers:

- introduction of, or change to type or dose of, PPI
- iron levels, iron supplementation
- benefits and disadvantages of gastroscopy
- benefits and disadvantages of treatment of helicobacter pylori
- referral to Dietitian
- positioning for and after meals
- portions
- weight
- smoking
- alcohol

3.4 Gastroenteritis

The primary concerns with acute gastroenteritis are aspiration and dehydration. The nurse considers:

- standard precautions
- severity of acute episode, likelihood of dehydration – can be managed at home with/without assistance of GP or requires hospitalisation for IV treatments and/or co-morbidities, e.g. epilepsy medication
- management of vomiting through medication, e.g., IM Maxolon
- management of aspiration through positioning and oral care
- management of dehydration through fluid and electrolyte replacement, e.g., Gastrolyte
- management of pain/fever with cooling methods and/or medication, e.g., paracetamol
- stool sample for culture
- management of diarrhoea with medication, e.g., Immodium (with care)
- perineal care
- slow resumption of low-irritant diet
- slow resumption of formula for a person who receives nutrition and fluids via enteral feeding

3.5 Surgery

The most common surgeries include endoscopy, appendectomy, cholecystectomy, and bowel resection. The Nurse considers pre-and post-operative care.
(Crawford, 2009; Therapeutic Guidelines, 2012)

For further information see:
Top 10 GERD Guidelines
[http://www.medscape.com/viewarticle/802952?src=nl_topic]
Viral Gastroenteritis
[http://www0.health.nsw.gov.au/factsheets/infectious/gastroenteritis.html]
Perioperative Nursing Care
[http://www.slideshare.net/twiggypiggy/perioperative-nursing-care]

3.6 Respiratory Health

Good chest management prevents threats to health and is best done in collaboration with a Physiotherapist who can devise an individualised regime of positioning, movement and exercise for a person with respiratory health problems.

For people with asthma, a GP can assist with an asthma management plan. For people with recurrent chest infections and/or chronic lung disease, regular reviews with a GP or respiratory physician are recommended. They can help develop a chest management plan.

The Nurse considers:

- chest management plan
- annual Fluvax
- Pneumovax (some discussion re adverse effects of second dose)
- how to integrate the Physiotherapy plan into the person's daily activities
- sleep patterns
- exercise tolerance
- smoking
- equipment required, e.g., wedges, electric bed
- oral suction (tracheal suction not recommended)
- percussion and drainage
- oral care
- management of drooling, e.g., Botox
- inhalants – puffer, spacer, nebuliser followed by oral care
- respiratory rate
- pulse oximetry
- oxygen (rate prescribed by doctor)
- maintenance, hygiene and replacement of equipment
- financial assistance for equipment
- triggers for asthma
- safety of heating, e.g. noxious fumes from unflued gas heating
- moisture of air
- household hygiene, e.g., dust, pillows
- pets
- household maintenance, e.g., painting, building
- prophylactic and/or early introduction of antibiotics
- management of acute episodes at home or in hospital

3.7 Management of Acute Asthma

Management of acute asthma depends on the severity of the exacerbation. For mild and moderate attacks, the asthma action plan should indicate the steps to take, e.g., use of Ventolin, oxygen, prednisolone. For severe attacks, transfer the person to hospital.

The Nurse considers:
- coughing
- wheezing
- breathlessness
- distress
- response to medication
- fever
- previous history
- human resources
- follow up, eg, review medications and action plan with GP

The asthma management plan should identify triggers to avoid.

3.8 Management of Chest Infection / Aspiration Pneumonia

This too will depend on the severity of the chest infection. The person may be managed at home with assistance from the GP or transferred to hospital for IV antibiotics.

The Nurse considers:
- respiratory rate
- oxygen saturation
- chest sounds
- coughing
- fever
- response to fever-reducing medication/treatments
- response to suction
- sputum culture
- response to antibiotics (oral or enteral tube)
- co-morbidities, eg, seizures increasing, vomiting with coughing
- previous history
- GP and/or specialist recommendations
- family wishes
- human resources
- follow up, eg, review chest management with respiratory physician

3.9 Management of Tracheostomy, Mechanical ventilation, CPAP (Continuous Positive Airway Pressure), BiPAP (Bi-level Positive Airway Pressure)

Some people are assisted to breathe using invasive (tracheostomy) or non-invasive (CPAP, BiPAP) methods.

The Nurse considers:
- pre- and post-operative care
- maintenance and replacement of tracheostomy tube
- cuff pressure (if cuffed)
- maintenance and safe handling of tracheostomy equipment
- maintenance and replacement of non-invasive equipment
- humidification

- suction
- back up manual ventilation
- stoma care
- oral care
- positioning
- comfort of ties and masks
- plan for dislodged tube
- regular checks of ventilation machines
- settings on ventilation machines
- financial assistance for specialised equipment through FACS's AIDAS program or Enable's Home Respiratory Program

(Clark & Gates, 2006; Davis et al, 2013; Pearce & Prigmore, 2012; Therapeutic Guidelines, 2012; Wallis, 2009)

For further information see:

Home Care of Children and Youth with Complex Health Care Needs and Technology Dependencies
[http://www.pediatricsdigest.mobi/content/129/5/996.full]

Asthma Action Plan
[http://www.asthmafoundation.org.au/asthma_action_plan.aspx]
Tracheostomy Care at Home
[http://www.cdha.nshealth.ca/patientinformation/nshealthnet/0244.pdf]
Tracheostomy Emergency
[http://www.dcdmj.co.uk/articles/7-1/vol%207%20no%201%20pg%2016-21.pdf]
Clinical Consensus Statement: Tracheostomy Care
[http://171.67.121.218/content/148/1/6.full.pdf+html]
Home Mechanical Ventilation: Tensions
[http://www.biomedcentral.com/1472-6963/11/115]
Home Mechanical Ventilation: Equipment
[http://www.ferno.com.au/Portals/0/Brochure/Weinmann%20Homecare%20Catalogue%20part%203.pdf]
Humidification
[http://kidshealth.schn.health.nsw.gov.au/fact-sheets/humidification-cpap-and-bilevel-machines]
Home Respiratory Program
[http://www.enable.health.nsw.gov.au/hrp]
AIDAS Program
[http://www.FACS.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=A]

3.10 Oral Health

The Nurse, in collaboration with the Dentist and the Speech Pathologist, develops oral care plans for people with an intellectual disability to prevent threats to health from oral problems. Such a plan considers:
- regular dental reviews
- benefits and risks of general anaesthetic for those unable to co-operate with dental examination and procedures
- explanation to person responsible and gaining of consent
- post-operative care

- at least twice daily teeth brushing and how to manage that, eg, time, position, place, mouth prop
- dentures
- type of toothbrush
- type of toothpaste
- type of mouthwash and how to use
- how to manage rinsing
- lip balm
- flossing
- two to four hourly oral care (eg, toothettes, Biotene, and lip balm) for people who have nothing by mouth
- management of drooling and bruxism, eg, Botox
- prevention and treatment of mouth ulcers, eg, vitamin supplement, Kenalog
- care of skin around the mouth
- any changes to the mouth, eg, bleeding gums, swelling at jawline
- consultation with Speech Pathologist re texture of food

The Nurse is alert to any signs of oral health problems, for example:
- not eating/drinking
- rubbing or banging at cheeks or other parts of the head
- swelling
- odour
- unusual drooling

(Therapeutic Guidelines, 2012; Watt-Smith, 2009)

For further information see:
Healthy Mouths
[http://www.scopevic.org.au/index.php/cms/frontend/resource/id/131]
Dental Care Considerations for Disabled Adults
[http://paul-burtner.dental.ufl.edu/files/2012/05/Disabled-Adults.pdf]
Oral Care for people with Disabilities
[http://www.adelaide.edu.au/arcpoh/dperu/special/disability/Disabilities%20A3.pdf]

3.11 Nutrition, Hydration and Weight Management
Refer also to core standard : *Mealtime Management* for more detailed information for this section.

The Nurse collaborates with the Dietitian and the Speech Pathologist in the management of nutrition, hydration and weight to prevent threats to health from malnutrition and dehydration. The Dietitian can devise an individualised Nutrition Care Plan and the Speech Pathologist can advise re the textures of food and drink. From there, the Nurse (sometimes the Dietitian) can develop a menu for those who eat and drink orally, or a feeding regime for those who gain their nutrition and/or hydration via an enteral tube. An Occupational Therapist may assist with a self-feeding program and a Psychologist may help with challenging behaviours associated with eating and drinking. The Nurse:
- monitors food and fluid intake and weight
- ensures completion of the Nutrition and Swallowing checklist
- finds ways to assist the person to eat and drink
- monitors intake of supplements

- monitors texture of food and drink

(Burton, Cox & Sandham, 2009; Clark & Gates, 2006; Therapeutic Guidelines, 2012)

> **For further information see:**
> FACS: Nutrition in Practice Manual
> [http://www.FACS.nsw.gov.au/__data/assets/file/0019/228124/Nutrition_Practice_Manual_July2012.pdf]

3.12 Management of Type 2 Diabetes

The Nurse collaborates with the GP, Dietitian and Physiotherapist to prevent or identify Diabetes Type 2 or manage the threats to health from a diagnosis of Diabetes Type 2. The Nurse may consult with the local Diabetes Nurse Educator and a referral to an Endocrinologist and a Podiatrist may be warranted.

The Nurse considers:
- risks, e.g., weight, statins, testosterone deficiency
- possible signs, e.g., excessive drinking, frequent urination
- diet (low glycaemic index)
- exercise
- sleep
- medication and interactions
- blood sugar levels
- foot care
- infection control

(Phillips & Gadsby, 2012; Rey-Conde & Lennox, 2007; Therapeutic Guidelines, 2012)

> **For further information see:**
> ACI NSW Endocrine Network
> [http://www.aci.health.nsw.gov.au/networks/endocrine]
> Diabetes Australia
> [http://www.diabetesaustralia.com.au/]

3.13 Management of Bowel Problems

To prevent threats to health from bowel problems, the Nurse collaborates with the GP, and may consult a Dietitian, Physiotherapist, Incontinence Nurse Advisor or Stomal Therapy Nurse.

3.14 Faecal Incontinence

The management of faecal incontinence in this population is usually with incontinence products. The Nurse may consult with an Incontinence Nurse Advisor and considers:
- diet and fluid intake
- exercise
- impact of medications
- overflow diarrhoea
- haemorrhoids
- care of perineal area

- suitable incontinence products through FACS's AIDAS program, the Federal Government's Continence Aids Payment Scheme (CAPS) and Enable NSW's Aids and Equipment Program
- bowel habit training
- regular enemas
- sacral nerve stimulation

3.15 Constipation

While there is no clear evidence for fibre, fluids and exercise for the management of constipation, this is considered best practice. The Nurse may collaborate with the Dietitian regarding fibre and fluids, with the Physiotherapist regarding exercise, and with the GP regarding suitable medications.

The Nurse considers:
- record of bowel motions
- method of reporting
- strategies to maintain regularity, including toileting times
- frequency, size and consistency of bowel motions
- types of aperients and rectal medications
- impact of other medications
- examination per rectum
- haemorrhoids
- bowel sounds
- abdominal palpation
- abdominal x-ray
- care of perineal area
- suitable incontinence products through FACS's AIDAS program, the Federal Government's Continence Aids Payment Scheme (CAPS) and Enable NSW's Aids and Equipment Program

3.16 Colostomy, Ileostomy, Caecostomy

For a number of reasons, a person may have a stoma to manage bowel function. The Nurse's main concerns are stool management and stoma care. The Nurse may consult with a Stomal Therapy Nurse and considers:
- pre- and post-operative care
- diet and fluid intake
- suitable products through the Stoma Appliance Scheme
- prevention and management of skin breakdown
- Antegrade Continence (Colonic) Enema (ACE)

(Carnaby& Cambridge, 2006; Clark & Gates, 2006; Coleman & Spurling, 2010; Pawlyn & Budd, 2009; Therapeutic Guidelines, 2012)

For further information see:
Continence Information and Advice
[http://www.continence.org.au/pages/professionals.html]
Bristol Stool Chart
[http://www.continence.org.au/pages/bristol-stool-chart.html]
Enable: Continence Aids Application
[http://www.enable.health.nsw.gov.au/home/forms-and-guidelines/continence]
Continence Aids Payment Scheme

[http://www.bladderbowel.gov.au/caps/]
[CH2 Incontinence Products](http://www.ch2.net.au/page/ch2-aged-community-care/welcome-ch2-aged-community-care)
[http://www.ch2.net.au/page/ch2-aged-community-care/welcome-ch2-aged-community-care]
[Stoma Appliance Scheme](http://www.health.gov.au/internet/main/publishing.nsf/Content/Stoma+Appliance+Scheme-3)
[http://www.health.gov.au/internet/main/publishing.nsf/Content/Stoma+Appliance+Scheme-3]
[AIDAS Program](http://www.FACS.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=A)
[http://www.FACS.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=A]
[Australian Association of Stomal Therapy Nurses](http://www.stomaltherapy.com/)
[http://www.stomaltherapy.com/]
[Bowel Wash Out](http://www.stomaltherapy.com/documents/Patient_Education_Pamphlet_Antegrade_Continence_Enema.pdf)
[http://www.stomaltherapy.com/documents/Patient_Education_Pamphlet_Antegrade_Continence_Enema.pdf]
[Management of Stoma Complications](http://www.nursingtimes.net/nursing-practice/clinical-zones/continence/management-of-stoma-complications/5037748.article)
[http://www.nursingtimes.net/nursing-practice/clinical-zones/continence/management-of-stoma-complications/5037748.article]

3.17 Management of Bladder Problems

The Nurse manages bladder problems in collaboration with the GP to prevent threats to health from incontinence and infection and may consult an Incontinence Nurse Advisor, a Urology Nurse or a Behaviour Specialist.

3.18 Urinary Incontinence

The management of urinary incontinence for people with intellectual disability is usually with incontinence products. Some interventions may be useful in the prevention of urinary incontinence.

The Nurse may consult with an Incontinence Nurse Advisor and considers:
- alcohol and caffeine intake
- times of fluid intake
- bladder training, eg, Kegel exercises, toilet timing
- medical treatments, eg, pessary, Botox, collagen, sacral nerve stimulation
- care of perineal area
- suitable incontinence products through FACS's AIDAS program, the Federal Government's Continence Aids Payment Scheme (CAPS) and Enable NSW's Aids and Equipment Program

3.19 Urinary Tract Infections

The role of the Nurse related to urinary tract infections is in prevention, identification and treatment in consultation with the GP.

The Nurse considers:
- training for females on toilet hygiene
- urinary alkanisers, e.g., cranberry, Ural
- prophylactic antibiotics for underlying abnormalities, e.g., vesico-ureteric reflux
- signs such as irritability, crying, going off food, vomiting, frequency, difficulty with micturition, odour, discolouration, fever
- symptoms such as stinging and burning, abdominal pain
- urinalysis
- urine sample for culture
- antibiotics

3.20 Toilet Training

Toilet training may be accomplished using toilet timing and operant conditioning methods. The Azrin-Foxx method and its variants are the most commonly used procedures.

The Nurse may consult with a behaviourist and considers:
- usual times of incontinence (bladder and bowel)
- ability to sit with/without assistance
- equipment required
- human resources

3.21 Uridomes and Catheters

Uridomes, intermittent catheterisation, indwelling catheters, and suprapubic catheters may be used for collection of urine specimens or for the management of incontinence.

The Nurse may consult with a Urological Nurse and considers:
- insertion, maintenance and replacement of catheter and accessories
- plan for dislodged catheter
- fluid intake
- urinary output
- perineal care
- stoma care
- lower abdominal or back pain
- regular reviews with urologist/renal physician
- financial assistance for products

(Carnaby & Cambridge, 2006; Pawlyn & Budd, 2009; Stenson & Danaher, 2005; Therapeutic Guidelines, 2012)

For further information see:
Continence Information and Advice
[http://www.continence.org.au/pages/professionals.html]
Continence Aids Payment Scheme
[http://www.bladderbowel.gov.au/caps/]
Enable: Continence Aids Application
[http://www.enable.health.nsw.gov.au/home/forms-and-guidelines/continence]
AIDAS Program
[http://www.FACS.nsw.gov.au/publications/policies/policies_a-z/?result_237652_result_page=A]
CH2 Incontinence Products
[http://www.ch2.net.au/page/ch2-aged-community-care/welcome-ch2-aged-community-care]
Toilet training
 [http://dcautismparents.org/yahoo_site_admin/assets/docs/ABA_4.9255817.pdf]
Sensory experience of toilet training
[http://cdn.intechopen.com/pdfs/43264/InTech-The_sensory_experience_of_toilet_training_and_its_implications_for_autism_intervention.pdf]
FACS Community Support Teams (CSTs)
[http://www.FACS.nsw.gov.au/individuals/support/everyday_living_support/community_support_teams]
FACS Behaviour Support

[http://www.FACS.nsw.gov.au/individuals/support/behaviour_support]
Catheter Care Guidelines
[http://www.thegaun.org/documents/ANZUNS_catheterisation_document.pdf]
Suprapubic Catheter
[http://www.health.qld.gov.au/qscis/documents/spc-care.pdf]
ACI: Male and Female Catheter Guidelines
[http://www.aci.health.nsw.gov.au/search-results?mode=results&queries_keyword_query=catheter&x=0&y=0]

3.22 Management of Vision Impairment and Eye Problems

The Nurse works with the GP to prevent threats to health from blindness and infection.

3.23 Vision Impairment

It is recommended that eyes are checked at least every three years. The Nurse considers:

- purpose of examination
- ability of person to co-operate with eye examination
- Ophthalmologist or Optometrist?
- advising specialist in advance of particular needs
- safety of eyes and person after pupil dilation

If a person wears glasses, the Nurse considers:

- annual prescription
- Ophthalmologist or Optometrist
- use, cleaning, maintenance, and storage of glasses

It is unlikely that people in this population would be wearing contact lenses but children may require occlusion therapy for correction of amblyopia.

To assist with vision, the Nurse considers:

- removing glare
- increasing light
- providing contrast
- finding the best position
- allowing time
- advice from a low vision clinic

People who are blind may display "blindisms", eg, spinning, eye pressing, head banging, rocking, bouncing. For these behaviours and for those with cortical blindness, the Nurse may consult with other specialists re best management for communication and sensorimotor integration.

See complementary information in the Core Standard Commination and Behaviour Support

3.24 Eye Infection

The Nurse is alert to any signs of eye infection and refers to the GP for treatment. The Nurse considers:

- rubbing eye/s
- avoiding light
- increased blinking
- change in behaviour

- swelling
- tears
- redness
- discharge/crusting
- previous history

3.25 Surgery

The most likely eye surgery for people with disability will be cataract removal. The Nurse considers pre- and post-operative care for the person.
(Levy, 2009; Therapeutic Guidelines, 2012)

For further information see:
Vision Australia
[http://www.visionaustralia.org/]
Royal Institute for Deaf and Blind Children
[http://www.ridbc.org.au/]
Australian DeafBlind Council
[http://www.deafblind.org.au/]
Eye Infections
[http://www.australianprescriber.com/magazine/17/3/66/8]
Occlusion Therapy
[http://kidshealth.schn.health.nsw.gov.au/fact-sheets/your-childs-contact-lenses-and-patching-therapy-0]
Congenital Cataracts
[http://kidshealth.schn.health.nsw.gov.au/fact-sheets/congenital-cataracts]

3.26 Management of Hearing Impairment and Ear Problems

The Nurse works with the GP to prevent threats to health from deafness and ear infections.

3.27 Hearing Impairment

It is recommended that hearing is checked every five years. This will be more frequent for people with hearing aids and people with Down syndrome.

The Nurse considers:
- purpose of examination
- ability of person to co-operate with hearing examination
- Hearing Australia or Audiologist?
- advising specialist in advance of particular needs
- ear wax drops before examination
- otoscopy before examination

If a person uses hearing aids, the Nurse considers:
- use, cleaning, maintenance, and storage of hearing aid/s
- environmental equipment, eg, flashing light for doorbell, soft surfaces, vibrating aids

For those known to have regular build-up of wax in the ears, the Nurse considers:
- ways to clean ears
- frequency of ear wax drops

- frequency of otoscopy

To assist with hearing, the Nurse considers:
- environmental noise levels
- speaking clearly (not shouting)
- good lighting (because deaf people rely more on vision)

People who have hearing impairments may be socially isolated and display repetitive and stereotypical behaviours (similar to autistic behaviours). The Nurse may consult with other specialists re best management for communication and sensorimotor integration.

Refer to Communication and Behaviour Support Practice Package for further complementary information in Section 3.1.5: *Communicating with People with Sensory Impairments.*

3.28 Ear Infection

The Nurse is alert to any signs of ear infection and refers to the GP for treatment. The Nurse considers:
- rubbing of ear/s
- head banging
- crying
- change in behaviour
- not appearing to hear
- discharge (odour)
- fever
- previous history

3.29 Grommets

Some children may have grommets. The Nurse considers pre- and post-operative care for the child. It is unlikely that people in this population would have a cochlear implant.

(Therapeutic Guidelines, 2012; Waite, 2009)

For further information see:
Australian Hearing
[http://www.hearing.com.au/about-us]
Royal Institute for Deaf and Blind Children
[http://www.ridbc.org.au/]
Australian DeafBlind Council
[http://www.deafblind.org.au/]
Otitis media
[http://www.australianprescriber.com/magazine/32/6/article/1062.pdf]
Grommets
[http://kidshealth.schn.health.nsw.gov.au/fact-sheets/glue-ear-and-grommets]

3.30 Seizure Management

The primary aim of treatment is for the person to become seizure-free. Most people in this population will have seen a neurologist. They have most likely had an encephalogram (EEG) and have been prescribed anti-epileptic drugs (AEDs).

The Nurse considers:
- regular review with Neurologist
- record of AEDs used
- record of seizures
- epilepsy management plan
- blood tests required
- regular bone mineral density
- adverse reactions to AEDs, e.g., drowsiness, aggression, gingivitis, drop in Vitamin D, osteoporosis, altered liver function.
- changes in frequency, duration or type of seizures
- Sudden unexpected death in epilepsy (SUDEP)
- triggers, e.g., strobe lights, alcohol, dehydration, pain, fever, menstruation, constipation, other medications (e.g., OCP), sleep disturbance
- safety, e.g., water, falls
- bed seizure alarm
- medical alert bracelet
- first aid
- emergency
- recovery
- follow up of unusual seizure activity, e.g., review with Neurologist, change to epilepsy management plan
- ketogenic diet

Seizures may occur with conditions other than epilepsy, e.g., hypo- or hyper-glycaemia, ventral shunt blockage. If there is no history of epilepsy, it is best to consider other alternative explanations for seizures.
(Codling & MacDonald, 2009; Ilchef, 2013; Therapeutic Guidelines, 2012)

For further information see:
Epilepsy
[http://www.intellectualdisability.info/physical-health/epilepsy#top]
FACS Epilepsy Policy
[http://www.FACS.nsw.gov.au/__data/assets/file/0011/228089/Epilepsy_Policy_April_2012.pdf]
Epilepsy Management Plan (including Seizure Chart)
[http://www.FACS.nsw.gov.au/publications/policies/policies_a-z?result_237652_result_page=E]
AEDs
[https://www.epilepsy.com/epilepsy/newsletter/sept09/aeds]
Epilepsy Action Australia
[http://www.epilepsy.org.au/]
Ketogenic Diet
[http://onlinelibrary.wiley.com/doi/10.1111/j.1528-1167.2008.01765.x/full]
Hydrocephalus shunt malfunction
[http://hydrocephalus.allanach.dk/complications]

3.31 Management of Thyroid Disease

The role of the Nurse related to thyroid disease is in prevention, identification and treatment in consultation with the GP.

The Nurse considers changes to:

- weight
- level of activity
- bowel motions
- menstruation
- mood
- behaviour
- skin

- hair
- nails
- eyes
- bodily comfort
- tolerance to heat and cold
- pulse
- respiration

The Nurse ensures that regular screening occurs (annually is recommended for those with Down Syndrome, the older person or those with existing thyroid disease, 3-5 yearly for others), medication (for hyperthyroidism or hypothyroidism) is administered regularly, and reports any adverse effects to the GP. Referral to an Endocrinologist may be warranted. Thyroidectomy may be considered for hyperthyroidism. The Nurse would consider pre- and post-operative care.

Newborn screening and lifelong treatment with thyroxin has eliminated congenital hypothyroidism in developed countries.

(Centre for Developmental Disability Studies, 2006; Therapeutic Guidelines, 2012)

For further information see:
Thyroid Australia
[http://www.thyroid.org.au/]

3.33 Management of Musculoskeletal Problems

The Nurse collaborates with the Physiotherapist in the management of musculoskeletal problems.

The Nurse considers:

- mobility
- posture
- comfort
- surgery3.34 Mobility

Because immobility causes so many threats to a person's health, the Nurse is concerned with maintaining as much mobility as possible. For people who can or have the potential to walk, maintaining mobility means suitable exercise and the prevention of falls. For those who are unlikely to walk, maintaining mobility refers to activities which enhance movement of the body.

3.35 Exercise

There are various generic and specialist exercise programs for people with disability. The general recommendation is 30 minutes or more of moderate-intensity physical activity (such as brisk walking) on most, if not all days of the week. This amount of activity can be accumulated in shorter bouts, such as three 10-minute walks per day. For children, it's 60 minutes. Walking without purpose can get boring. The Heart Foundation has identified a number of

different activities which can maintain motivation to exercise. There are also specialist camps available to some people with intellectual disability. Professor Roger Stancliffe of the University of Sydney is researching in the area of exercise and people with intellectual disability.

3.36 Falls

The Nurse collaborates with the Physiotherapist, Occupational Therapist, Dietitian, Speech Pathologist, Psychologist, Behaviour Support Practitioner, GP, Optometrist and Audiologist in monitoring and managing mobility in the ageing disability population. The Nurse considers:

- exercise programs, e.g., Tai Chi, yoga, Pilates
- balance training
- muscle strengthening
- gradual introduction of a mix of interventions designed to meet the needs, capabilities and preferences of the person
- home hazard assessment and modification for people with a disability at high risk of falls and/or with severe vision impairment

3.37 Movement

The Nurse collaborates with the Physiotherapist on a movement plan for those who cannot walk and who may be subject to joint contractures. All movement should be slow and gentle, and should occur at least every two hours. The movement plan may include active or passive full range of movement, swimming, games which increase movement, e.g., ball play. It may also include specialised equipment such as side lyers, prone lyers, standers and walkers to encourage movement of the torso and limbs.

3.38 Posture

Many people with intellectual disability have a level of hypotonia which makes good posture difficult to maintain. The Nurse considers:
- body alignment
- frequent exercise or movement

The Nurse collaborates with the Physiotherapist on a positioning plan for those who cannot initiate or control movement, usually as a consequence of hypertonia. The aim of positioning is to maintain body alignment. This may require pillows, wedges or sandbags or specialised equipment such as seating supports and sleeping systems. Specialised equipment, prescribed by a Physiotherapist, may be available through FACS's AIDAS program or Enable's Aids and Equipment Program

3.39 Comfort

Pain and discomfort from musculoskeletal problems may arise from osteoarthritis, spasm, contractures, or problems with toenails. If exercise, gentle and slow movement and positioning are not reducing discomfort, the Nurse considers:
- pain distractors, e.g., music, vibrating mats, engaging activities
- heat pads or cold packs (exercise caution)
- lotions, e.g., deep heat (exercise caution with Voltaren products)
- medication, e.g., Baclofen, pain relief
- referral to a podiatrist (through Medicare's Chronic Disease Management [CDM])
- referral to a rehabilitation physician or pain specialist

See related information in Section 3.43: 3,44: 3,55: 3,56 : *Pain Management*.

3.40 Surgery

There are a number of neurosurgical and orthopaedic surgical interventions for musculoskeletal problems. This could include surgeries for back (scoliosis), neck (atlanto-axial instability), hips (dislocated), knees, hands and feet. The Nurse considers pre- and post-operative care.

(Barks, 2010; Cahill et al, 2013; Cheuk et al, 2013; Clark & Gates, 2006; Claus et al., 2009; Cox et al., 2010; Hanegem et al., 2013; Hill & Goldsmith, 2009; Rimmeretal, 2010; Stancliffe et al., 2011, 2012)

For further information see:

Heart Foundation: Be Active Every Day
[http://www.heartfoundation.org.au/SiteCollectionDocuments/Be-active-everyday.pdf]

A Physical Activity Guide For Older Australians
[http://www.dva.gov.au/aboutDVA/publications/health/Documents/choosehealth.pdf]

Obesity
[http://www.pandda.net/files/2011-Stancliffe-Obesity.pdf]

Exercise Intervention Research and People with Disabilities
[http://www.rectech.org/publications/Rimmer_2010_Ex.%20Intervention%20on%20Persons%20with%20Disabilities.pdf]

Physical Activity and People with Disabilities: Research Protocol
[http://www.controlled-trials.com/ISRCTN77889248/]

Hydration and the Active Child
[http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/hydration-and-active-child.pdf]

Physical Activity and Diabetes
[http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/physical-activity-and-diabetes.pdf]

Physical Activity and Spina Bifida
[http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/be-active-spina-bifida.pdf]

Atlantoaxial instability
[http://www.dsmig.org.uk/library/articles/dsa-medical-series-3.pdf]

NSW Falls Prevention Program
[http://fallsnetwork.neura.edu.au/wordpress/wp-content/uploads/2011/03/Preventing-falls-and-harm-from-falls-in-Community-Care-NSW-June-20121.pdf]

Australian Commission on Safety and Quality in Health Care
[http://www.safetyandquality.gov.au/our-work/falls-prevention/]

ALS: Range of Motion Exercises
[http://www.alsworldwide.org/pdfs/rom_exercises.pdf]

Good Posture: Slide Show
[http://www.mayoclinic.com/health/back-pain/LB00002_D]

Allied Health Services Under Medicare
[http://www.health.gov.au/internet/main/publishing.nsf/Content/health-medicare-health_pro-gp-pdf-allied-cnt.htm]

Hip Dysplasia
[http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/developmental-dysplasia-hip-ddh.pdf]

Hip Abduction Orthosis

http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/hip-abduction-orthosis.pdf
Broomstick Plaster
[http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/broomstick-plaster.pdf]
Plaster Care
[http://kidshealth.schn.health.nsw.gov.au/sites/kidshealth.schn.health.nsw.gov.au/files/fact-sheets/pdf/plaster-cast-or-backslab-care-instructions-patients-and-their-carers.pdf]

3.41 Management of Osteopenia and Osteoporosis

The aim of management is to prevent osteoporosis.

The Nurse, in consultation with the GP, Dietitian and Physiotherapist, considers:

- daily exposure to sunlight
- annual vitamin D and calcium levels
- treatment with vitamin D
- daily intake of calcium
- management of weight
- weight-bearing exercise, eg, Tai Chi, stander, vibration
- gentle movement for those with osteoporosis, eg, warm water exercise
- potential for fracture
- falls prevention
- regular DEXA
- referral to an Endocrinologist
- IV Aclasta (Zometa, Zoledronic acid) (oral bisphosphonates may cause reflux)
- Membership of an association, eg, Osteoporosis NSW

(Rahman& Bhatia, 2007; Therapeutic Guidelines, 2012; Wilson Jones & Morgan, 2010)

For further information see:
Osteoporosis NSW
[http://arthritisnsw.org.au/osteoporosis/]
ACI Musculoskeletal Network
[http://www.aci.health.nsw.gov.au/networks/musculoskeletal]

3.42 Management of Cardiovascular Disease

The Nurse collaborates with the GP to prevent the threats to health associated with cardiovascular disease.

The Nurse considers:

- weight
- diet (low cholesterol)
- BP
- urinalysis (for kidney involvement)
- blood tests for lipids and renal function
- antihypertensives
- statins
- hypotensive effects of other medications, eg, some psychotropics
- exercise tolerance (cardio programs)
- temperature control (poor peripheral circulation)

- prophylactic antibiotics before invasive procedures (ASD, VSD)
- referral to a cardiologist. (Therapeutic Guidelines, 2012)

For further information see:
Heart Foundation[http://www.heartfoundation.org.au/Pages/default.aspx]
ASD[http://www.mayoclinic.com/health/atrial-septal-defect/DS00628]
VSD[http://www.mayoclinic.com/health/ventricular-septal
defect/DS00614/DSECTION=treatments-and-drugs]

3.43 Pain Management

The Nurse collaborates with the multidisciplinary team to prevent and manage threats to health from discomfort and pain.

3.44 Discomfort

Comfort has been addressed in Section 3.39. The Nurse ensures that each person has an individually tailored plan to manage discomfort.

3.45 Acute Pain

Acute pain may arise as a consequence of spasm, incorrectly-fitted splints, reflux, environmental causes, bites and stings, injury or inflammation.

The Nurse assesses the signs and symptoms (including a full body check, if required) and considers:

- re-positioning
- check of clothing and splints
- reduction of noise, light, heat, cold, perfumes, etc
- first aid
- GP assistance
- transfer to hospital

3.46 Chronic Pain

Chronic pain may arise as a consequence of many problems, e.g., spasm, skeletal deformity, arthritis, reflux, oesophagitis, constipation, gall bladder disease, renal stones, occult fractures, hip dislocations, otitis media, sinusitis, pressure sores or skin breakdown, dental decay. The primary aim is to recognise chronic pain and then treat it.

The Nurse consults with the GP, ensures that there is an individually tailored plan to manage chronic pain and considers:

- positioning and re-positioning
- alternatives to medication – heat or cold (with care), music, massage, pet therapy, etc
- importance of staying on top of the pain
- distress checklist
- dangers of Panadol and NSAIDs
- opioids – adverse effects (constipation), patches (skin reactions)
- referral to pain or other specialists
- surgery

(Beacroft & Dodd, 2010, 2011; Bischof & Chirwa, 2011; Breau & Camfield, 2011; Clark & Gates, 2006; Conway & Higgins, 2011; deKnegt et al, 2013; McGuire, Daly & Smyth, 2010; Parkinson et al, 2010; Turk et al., 2012; van Huet, Innes,& Stancliffe, 2013; Wilson Jones & Morgan, 2010).

For further information see:
WHO's pain ladder
[http://www.who.int/cancer/palliative/painladder/en/index.html]
Pain management – adults
[http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Pain_management_adults?open]
Pain management - children
[http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Pain_management_children?open]
WHO: Pain Management Guidelines: Children
[http://whqlibdoc.who.int/publications/2012/9789241548120_Physicians&Nurses.pdf]
Pain Management for all Australians
[http://www.painaustralia.org.au/images/pain_australia/NPS/National%20Pain%20Strategy%202011.pdf]
NSW Health Pain Management Report 2010
[http://www0.health.nsw.gov.au/pubs/2012/pdf/taskforce_report.pdf]
Pain expression
[http://www.tandfonline.com/doi/pdf/10.1080/19315864.2011.603881]
Pain in Cerebral Palsy
[http://research.ncl.ac.uk/sparcle/Publications_files/Published%20article%20Pain.pdf]

3.47 Personal and Intimate Hygiene Management

Much of the area of personal and intimate hygiene management is still taboo in many societies and remains invisible work.

To prevent threats to health, the Nurse considers:
- identification of preferences, eg, shower or bath, morning or evening, which caregiver, shave or not, which side to lie on, etc
- observation, eg, dry skin, pressure areas, rashes, bruises, skin tears
- risk management during bathing
- hair and body cleaning products
- safety of deodorants, creams and powders
- particular attention during bathing and drying to:

  - scalp
  - eyes
  - feet
  - skin folds associated with scoliosis, contractures, obesity
  - perineum – penile hygiene, labial hygiene, peri-anal hygiene

  - ears
  - nose

- menstrual management
- assisting with toileting
- changing continence pads
- changing soiled clothing
- cleaning up vomit, faeces, urine, blood, drool, mucous, nasal secretions, food spills – infection control, presentation and feelings of client, feelings of caregiver
- pressure area care
- dressing – age-appropriate but comfortable, temperature control
- grooming – hair, nails, beauty/hypoallergenic products
- ageing – skill loss
-

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

3.48 Physical Fitness

The Nurse collaborates with the multidisciplinary team to prevent threats to health associated with poor physical fitness.
See Sections 3.11: *Nutrition, Hydration and Weight Management* **and 3.35:** *Exercise.*

3.49 Women's Health

The Nurse works with the GP to prevent threats to health from women's health problems.

The Nurse considers:
- breast check
- mammography
- PAP smear
- pelvis ultrasound - ?internal
- sexuality
- sexually transmitted infection
- abuse
- amenorrhoea
- hormone deficiency – link with osteoporosis
- menstruation-linked symptoms, eg, pain, mood, catamenial epilepsy
- menstrual suppression, contraception – special consent for long acting hormones
- pregnancy
- thrush
- menopause
- iron deficiency
- blood tests
- referral to gynaecologist, endocrinologist

(McCarthy & Cambridge, 2006; Therapeutic Guidelines, 2012)

3.50 Men's Health

The Nurse works with the GP to prevent threats to health from men's health problems.

The Nurse considers:

- testicular problems – undescended, small - surveillance
- androgen deficiency – link with diabetes type 2, osteoporosis
- blood tests
- scrotal ultrasound
- paraphimosis
- prostate
- breast check
- sexuality
- abuse
- erectile dysfunction
- inguinal hernia
- sexually transmitted infection
- referral to endocrinologist, urologis

(Therapeutic Guidelines; Wilson et al, 2009, 2010, 2012)

For further information see:

Andrology Australia
[https://www.andrologyaustralia.org/]
Sexual health and Family Planning Australia[http://www.shfpa.org.au/]
National Male Health Policy
[http://www.health.gov.au/internet/main/publishing.nsf/Content/4F49BF09C90C846ECA2578EF00029963/$File/MainDocument.pdf]

3.51 Management of Mental Health Problems

People with an intellectual disability have an increased incidence of mental health problems then the general population. As we know some have fallen between the cracks. To address this important issue when supporting people with an intellectual disability who have been diagnosed with a mental illness, is currently being addressed at several levels, for example, Universities are reviewing there curriculum to reflect intellectual disabilities and mental health issues, some psychiatrists specialising in the area, have developed an *Intellectual Disability Mental Health First Aid Manual* (Kitchener *et al,* 2010) (an excellent resource for Nurses and other health professionals), and the announcement of the Chair of Intellectual Disability Mental Health and the subsequent Department of Developmental Disability Neuropsychiatry (3DN) at the University of NSW.

Nurses have an understanding of both physical and mental health issues. Nurses always collaborate with the multidisciplinary team in the maintenance of mental health, prevention and early identification of mental health problems, and in the diagnosis and treatment of mental health problems.

3.52 Mental Health

The World Health Organisation has defined mental health as:
"… a state of well-being in which the individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community" (WHO, 2010).

The Nurse includes mental health promotion activities in health care plans. The Nurse considers social, educational and vocational environments and

environmental conditions when assessing and planning care. Meaningful participation in learning, work and play enhances mental health.

3.53 Mental Illness

Mental illness is defined in the WHO Classification of Mental Diseases (ICD-10: Chapter V: Mental and Behavioural Disorders). Psychiatrists use the classification for diagnostic purposes.

> There are a wide range of treatment options available to the general public: however, their availability to people with an intellectual disability may be limited because of:
> - Assumptions that people with an intellectual disability aren't able to benefit from the same interventions and treatments
> - Lack of awareness about services offered by mental health and other providers of treatment and
> - Lack of mental health staff trained and experienced in working with people with an intellectual disability.
>
> Fortunately, there is growing recognition that, within limits, established treatments can be adapted to the circumstances of the person with an intellectual disability and should always be considered (Kitchener *et al*, 2010, p.15).

These treatments include:
- positive behaviour support
- psychotherapy
- counselling
- cognitive behaviour therapy
- psychopharmacology
- complementary therapies (e.g., relaxation, massage)
- lifestyle change
- art therapies (art, music, dance, drama)
- support groups (e.g., SANE, Black Dog Institute, Beyond Blue)

The Nurse implements or assists others to implement the proposed treatments but Nursing also has a particular role to play in interventions, described by Watson (1997, in Taggart and Slevin, 2010, p. 184):

> The artistry of caring draws from the same source as life itself; from human encounter, engaging with indelible stories of people, of caring moments or connecting through eyes, touch, sound, space, spirit itself. Such engaging moments of caring touch the human soul and provide a reflection into human existence.

Kitchener *et al* (2010) expand:

> People recover from mental illness. Mental illness affects people differently and the recovery journey is different for each person. Recovery can progress slowly and it may also take time. Many different factors contribute to recovery. These may include having good support from family and friends, having a meaningful role in society through employment or education opportunities, getting professional help early, getting the best possible treatments and the

person's willingness and ability to take up the opportunities available (Kitchener *et al*, 2010, p.18).

The Nurse considers:
- physical causes of presenting problem, e.g., illness, constipation, epilepsy, drug interactions
- blood tests
- urine culture
- imaging – head scan (CT or MRI), EEG, abdominal X-ray (to rule out constipation)
- pharmacist review
- data collection – nature of the behaviour reported; recent changes in behaviour; mood changes; communication abilities; changes in sleep, appetite, weight; and current accommodation, social, educational and vocational environments
- analysis of data
- ICD-10 classification of diseases (Chapter V)
- decision re cluster of symptoms that indicate a mental health problem
- referral to appropriate specialist/s (Psychologist, Psychiatrist, Mental Health Nurse)
- consent for treatment
- inclusion of proposed medication and therapies in the health care plan
- continuation of physical care
- safety – physical and emotional
- promotion of therapeutic environment, e.g., time and space for the person, noise levels, room temperature, preferred physical and emotional activities
- continuing data collection (for evaluation purposes)
- follow up with specialist
- ongoing management.

3.54 Pica

Pica is treated separately in this section on mental health problems because it presents such high physical health risks to a person. Pica is common among people with developmental disability, and pica can also affect neurological development.

People with pica frequently crave and consume non-food items such as dirt, paint chips, coffee grounds, cigarette butts, garden plants, stones, faeces, paper, soap, coins, paper clips, buttons, and so on. Risks associated with pica include:
- Bowel blockage
- Ulceration and perforation of the GI tract
- Poisoning, toxicity, parasitic infection
- Choking, aspiration
- Nutritional deprivation (by not eating enough food items)

The best way to manage pica is to develop strategies to prevent the swallowing of non-food items. The following may be helpful when caring for a person with pica:

- limit access to environments that are not rigorously monitored for small indigestible items
- ensure close supervision of the person with pica
- develop a plan specific to the person and their support needs
- provide caregiver/staff training in all locations where the person spends time
- consider the need to routine surveillance (pica sweeps) of the areas frequented by the individual to find and remove targeted pica items
- avoid clothing with buttons/bows that can be pulled off
- avoid toys/gifts with small pieces that can be chewed or broken off and swallowed
- avoid access to soaps, creams, shampoos, etc.

A safety plan should be developed with input from health professionals and the people who know the person and their environment best. It should include details of the Poisons Information Centre – Phone 13 11 26, Australia wide, 24 hours per day, 7 days per week. It is important to remember that pica presents a serious risk to a person's health and should not be disregarded or taken lightly. It can result in serious illness, surgery and even death. Knowledge of the condition and its specific manifestation in an individual and implementation of a well-developed safety plan will give family/caregivers the information that they need to assist individuals to live safe, happy and healthy lives.

(Cooper et al, 2007; Hermans, 2012; Kitchener et al, 2010; McBrien, 2003; Royal College of Nursing, 2010; Taggart &Slevin, 2006; Therapeutic Guidelines, 2012; WHO 2010)

For further information see:
Intellectual Disability Mental Health First Aid Manual
[http://www.mhfa.com.au/cms/wp-content/uploads/2011/02/2nd_edition_id_manual_dec10.pdf]
Uni of NSW: Department of Developmental Disability Neuropsychiatry
[http://3dn.unsw.edu.au/content/about-us]
World Health Organization: ICD-10
[http://apps.who.int/classifications/icd10/browse/2010/en]
Classification and Assessment of Psychiatric Disorders in Adults with Learning [Intellectual] Disabilities
[http://www.intellectualdisability.info/mental-health/classification-and-assessment-of-psychiatric-disorders-in-adults-with-learning-intellectual-disabilities]
Fourth National Mental Health Plan 2009–2014
[http://www.health.gov.au/internet/main/publishing.nsf/content/360EB322114EC906CA2576700014A817/$File/plan09v2.pdf]
NSW Health Program Information
[http://www0.health.nsw.gov.au/mhdao/program_information.asp]
Australian College of Mental Health Nurses
[http://www.acmhn.org/]
SANE Australia
[https://www.sane.org/]
SANE: Life without Stigma
[http://www.sane.org/images/stories/media/ALifeWithoutStigma_A_SANE_Report.pdf]
Beyond Blue
[http://www.beyondblue.org.au/]
Black Dog Institute

3.55 Medication Management

The Nurse collaborates with the GP and the Pharmacist to prevent threats to health from polypharmacy and administration by multiple caregivers.

The Nurse considers:
- legislation
- consent
- objection
- special consent for psychotropic and long-acting medication
- Guardianship Tribunal and Office of the Children's Guardian (OCG)
- NSW Health guidelines
- policy for your organisation
- delegation
- duty of care
- allergies
- prescription and 'over the counter' (OTC) medication
- complementary and alternative medication
- interactions with other medications and food
- adverse effects, including effects on swallowing and decreased appetite
- overdose
- missed medications
- medication errors
- swallowing
- crushing and dissolving
- medications via enteral feeding tube
- types of medication and uses
- system of administration, eg, packed
- system for correcting errors, eg, re-packing
- the '5 rights' of administration
- creative ways to administer medication
- storage
- disposal
- documentation and reporting
- regular review by GP
- pharmacist's review
- relationship with GP
- relationship with pharmacist
- connecting GP and pharmacist
- compounding pharmacist

Nurses who work for FACS have access to MIMS online and Mealtime Management Module 6.

(Carl & Johnson, 2006; Coleman, 2002, 2009; Williams, 2008)

> **For further information see:**
> Medication Guidelines
> [http://www0.health.nsw.gov.au/policies/PD/2005/pdf/PD2005_105.pdf]
> FACS Medication Management Plan and Charts
> [http://www.FACS.nsw.gov.au/__data/assets/file/0006/251619/Medication_Management_Plan_and_Charts_Dec2012.pdf]
> Don't Rush to Crush
> [http://www.shpa.org.au/scripts/cgiip.exe/WService=SHPA/ccms.r?PageId=10243]
> Don't Rush to Crush Option with MIMS Online
> [http://www.mims.com.au/newsletter/201302/ManagingEditorFeb13.pdf]
> Medication via enteral feeding tube
> [http://www.medscape.com/viewarticle/585397]
> Compounding Pharmacist
> [http://www.pccarx.com.au/]

3.56 Lifespan Considerations

Most of the management described in Section 5.1 applies equally to children, adolescents, adults and older people with intellectual disability and chronic and complex health care needs. The setting and the focus may be different.

Nurses more commonly come into contact with children and often adolescents when they are living with their parents (or guardians), when they come to respite accommodation or when they come to hospital, rather than in residential settings. Nurses may have contact with early intervention programs or schools which children attend, as well as the GP, Paediatrician, other specialists and allied health professionals who may be involved with children at home, in early intervention programs or at school. Children's health services in NSW are, in the main, excellent.

The primary concern of parents has been that hospital staff do not listen to them well enough, especially with regard to early identification of a health problem. The focus for nursing with children is identifying signs and symptoms which aid with diagnosis of conditions associated with intellectual disability, and the focus for nursing with adolescents is transition to adult services. For both children and adolescents, the focus of nursing is growth and development, physically, emotionally, socially and spiritually.

There are more adults than younger people in residential care, albeit still a smaller proportion than those living in the family home. Residential care includes the large residential centres (which are slowly closing) and community alternatives. Many adults with chronic and complex health care needs utilise hospital services. Nurses may have contact with day options programs as well as the usual GP, adult specialist and allied health services. Adult health services in NSW for people with intellectual disability and chronic and complex health care needs are far more disjointed at the time of writing this document than younger people's services. The focus of nursing is co-ordinating the health support required by individuals and their families. This will be further discussed in Section 5.3: *Advocacy and Co-ordination.*

Ageing is still a relatively new concept in disability services because it has not been for very long that people with chronic and complex health care needs survived until old age. Research has indicated an increase in conditions associated with ageing. The focus of nursing is alertness to changing health

care needs related to ageing, modifications to address any health care issues, referrals to a Geriatrician or specialists for specific health issues, consideration of needs while in hospital, and suitability of activities and accommodation.
(Evenhuis, 2000; Therapetic Guidelines, 2012)

For further information see:
[Transition from Child to Adult Services](http://www.aaiddjournals.org/doi/abs/10.1352/1934-9556-51.3.176)
[http://www.aaiddjournals.org/doi/abs/10.1352/1934-9556-51.3.176]
[Hospitalised patients with ASD](http://cpj.sagepub.com/content/52/7/652.short)
[http://cpj.sagepub.com/content/52/7/652.short]
[Hospital Experiences of Older People](http://informahealthcare.com/doi/abs/10.3109/13668250.2010.491071)
[http://informahealthcare.com/doi/abs/10.3109/13668250.2010.491071]

3.57 End of Life Care

It is important to reflect on definitions of palliation, palliative care and end of life care as described by Palliative Care Australia. Such reflection assists with understanding nursing practice with people with chronic and complex health care needs.

- ▪ **Palliation** is alleviation of symptoms without curing the underlying medical condition. (Most of the work done by Nurses who work with people with chronic and complex health care needs throughout the lifespan is palliation.)
- ▪ **End of life** refers to that part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.
- ▪ **An eventually fatal condition** means a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant illness and ageing.
- ▪ **End of life care** combines the broad set of health and community services that care for the population at the end of their life.
- ▪ **Palliative care** is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.

Discussions about end of life care are best done way before there is any expectation of death. Discussions should include reviewable deaths, funeral arrangements, financial matters, food and fluids, treatments, resuscitation, place for care, cultural and spiritual issues, replacement person responsible or Guardianship, activities during end of life, and so on.

While there is promotion of Advance Care Directives (ACD) in Australia, most people with intellectual disability do not have the capacity to make an ACD and there is no room in law in NSW for the person responsible to make one on their behalf. Not everyone needs a palliative care plan. When taken to A&E or when there is planned surgery, the hospital asks what treatment the person wants should there be an adverse event. Most organisations have a policy of resuscitation unless a person has a palliative care plan. So, there is a gap. Kearney *et al* (2010) are trialling a future care planning process in an attempt to close this gap.

Few people with chronic and complex health care needs die unexpectedly and most have the opportunity to anticipate death. Little can be done if people do die unexpectedly but there is a huge area of research and literature on expected death.

The commencement of end of life care or palliative care is contentious and difficult to determine with anyone, let alone those with little communication and chronic and complex health care needs. This moment is really a process and requires ongoing discussion among all interested parties when a person seems to have used up all available treatments and quality of life becomes more important than quantity of life. Considering trajectories of illness can be helpful, as can reading the Ombudsman's reports on reviewable deaths. Palliative care teams are an excellent source of advice in this area.

The aims of palliative care are to:
- provide relief from pain and other distressing symptoms
- affirm life and regard dying as a normal process
- intend neither to hasten or postpone death
- integrate the psychological and spiritual aspects of care
- offer a support system to help people live as actively as possible until death
- offer a support system to help the family cope during the person's illness and in their own bereavement
- use a team approach to address the needs of patients and their families, including bereavement counselling if indicated
- enhance quality of life, and also positively influence the course of the illness
- begin early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO, accessed 26.8.13).

"Palliative care is generally provided to people of all ages whose condition has progressed beyond the stage where curative treatment is effective and/or a cure is attainable, or to those who choose not to pursue curative treatment" (FACS Palliative Care Policy).

The Nurse collaborates with the multidisciplinary team and considers:
- the wishes of the person with a disability and their family regarding end of life care and death
- care in the home of the person with a disability, in the family home, in respite, hospice or hospital
- living the end of life – school, day program, suitable activities
- involvement of a palliative care team
- communication of situation to the person who is at the end of life
- continuation or withdrawal of medications
- non-oral alternatives for nutrition and hydration
- personal and intimate hygiene (see Section 5.1.17)
- comfort
- pain management (see Section 5.1.16)
- medication management (see Section 5.1.22)
- palliative care plan including resuscitation orders

- age-appropriateness
- cultural appropriateness
- grief management – client, others living with the client, families, staff
- notification to the coroner
- records for the Ombudsman
- notification to FACS (for FACS and FACS-funded services)

(Capizzi, 1998; Senate Affairs Reference Committee, 2012; Department of Health and Ageing, 2011; Hynson et al, 2003; Kearney *et al*, 2010; Marlow & Martin, 2008; Palliative Care Australia, 2003, 2008; Radbruch& Downing, 2010; Todd, 2013; Tuffrey-Wijne*et al*, 2013; Wagemans*et al*, 2013; Wiese *et al*, 2012; World Health Organisation [accessed 26.8.13].)

For further information see:

Future Care Planning
[http://www.pandda.net/files/2010-Kearney.pdf]
Trajectories at End of Life
[http://www.uq.edu.au/primarypallcare/documents/Concept%20of%20Trajections%20Scott%20Murray%200610.pdf
Illness Trajectories and Palliative Care
[http://www.ncbi.nlm.nih.gov/pmc/articles/PMC557152/]
NSW Ombudsman: Report of Reviewable Deaths 2010-2011
[http://www.ombo.nsw.gov.au/__data/assets/pdf_file/0007/9448/Reviewable-Deaths-Disability-Death.pdf]

NSW Plans
NSW Government Plan Palliative Care 2012-2016
[http://www.health.nsw.gov.au/publications/Publications/Palliative%20Care%20Plan%202012-2016.pdf
ACI: Framework for the Statewide Model for Palliative and End of Life Care Service Provision

[http://www.aci.health.nsw.gov.au/models-of-care]

Policies – FACS and Health

FACS: Palliative Care Policy
[http://www.FACS.nsw.gov.au/__data/assets/file/0003/228126/Palliative_Care_Policy_April_2012.pdf]

End of life care and people under guardianship

[http://www.publicguardian.lawlink.nsw.gov.au/agdbasev7wr/publicguardian/documents/pdf/12_end_of_life_care_sep2011.pdf]
Client Death Policy (FACS)
[http://www.FACS.nsw.gov.au/__data/assets/file/0005/228065/Client_death_Policy_and_Procedures_April_2012.pdf]
Advanced Care Planning
[http://www.archi.net.au/documents/resources/models/acp/advance-planning.pdf]
Decisions Related to No CPR: NSW Health
[http://www0.health.nsw.gov.au/policies/gl/2008/pdf/GL2008_018.pdf]
End-of-Life Care and Decision-Making – Guidelines: NSW Health

[http://www0.health.nsw.gov.au/policies/gl/2005/pdf/GL2005_057.pdf]

Intellectual Disability

[Palliative Care in People With Congenital or Acquired Intellectual Disability and High Nursing Support Needs: A Literature Review](http://www.FACS.nsw.gov.au/__data/assets/file/0010/228187/34_PalliativeCareAliteraturereview.pdf)

[http://www.FACS.nsw.gov.au/__data/assets/file/0010/228187/34_PalliativeCareAliteraturereview.pdf]

[Cancer, Palliative Care and Intellectual Disabilities](http://www.intellectualdisability.info/physical-health/cancer-palliative-care-and-intellectual-disabilities)

[http://www.intellectualdisability.info/physical-health/cancer-palliative-care-and-intellectual-disabilities]

[Disability Residential Services Palliative Care guide (Vic)](http://docs.health.vic.gov.au/docs/doc/4758F8FEB4320819CA25796C00084A6D/$FILE/disability_palliative_care_guide.pdf)

[http://docs.health.vic.gov.au/docs/doc/4758F8FEB4320819CA25796C00084A6D/$FILE/disability_palliative_care_guide.pdf]

[NSW Council for Intellectual Disability-End of Life Care](http://www.nswcid.org.au/health/se-health-pages/end-of-life-care.html)

[http://www.nswcid.org.au/health/se-health-pages/end-of-life-care.html]

[Managing Grief Better: People With Intellectual Disabilities](http://www.intellectualdisability.info/mental-health/managing-grief-better-people-with-intellectual-disabilities)

[http://www.intellectualdisability.info/mental-health/managing-grief-better-people-with-intellectual-disabilities]

Special Groups

[Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander people](http://www.health.gov.au/internet/main/publishing.nsf/Content/58F4F2A90927FEBBCA256F4100153AFA/$File/principles.pdf)

[http://www.health.gov.au/internet/main/publishing.nsf/Content/58F4F2A90927FEBBCA256F4100153AFA/$File/principles.pdf]

[Challenges for Aboriginal Palliative Care Models](http://www.rrh.org.au/publishedarticles/article_print_2339.pdf)

[http://www.rrh.org.au/publishedarticles/article_print_2339.pdf]

[Multicultural Palliative Care Guidelines](http://www.palliativecare.org.au/Portals/46/resources/MulticulturalGuidelines.pdf)

[http://www.palliativecare.org.au/Portals/46/resources/MulticulturalGuidelines.pdf]

[Paediatric Palliative Care Planning Framework 2011-2014](http://www0.health.nsw.gov.au/policies/gl/2011/pdf/GL2011_014.pdf)

[http://www0.health.nsw.gov.au/policies/gl/2011/pdf/GL2011_014.pdf]

Palliative Care

[Standards for Providing Quality Palliative Care for all Australians](http://www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf)

[http://www.palliativecare.org.au/Portals/46/Standards%20for%20providing%20quality%20palliative%20care%20for%20all%20Australians.pdf]

[Supporting Australians to Live Well at the End of Life](http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/NationalPalliativeCareStrategy.pdf)

[http://www.health.gov.au/internet/main/publishing.nsf/Content/533C02453771A951CA256F190013683B/$File/NationalPalliativeCareStrategy.pdf]

[WHO: Palliative Care – Symptom Management and End-of-Life Care](http://www.who.int/hiv/pub/imai/genericpalliativecare082004.pdf)

[http://www.who.int/hiv/pub/imai/genericpalliativecare082004.pdf]

[The Role of the Nurse in Palliative Care](http://www.rcna.org.au/WCM/Images/RCNA_website/Files%20for%20upload%20and%20link/policy/documentation/review/role_of_the_nurse_in_palliative_care.pdf)

[http://www.rcna.org.au/WCM/Images/RCNA_website/Files%20for%20upload%20and%20link/policy/documentation/review/role_of_the_nurse_in_palliative_care.pdf]

[Hospice and Palliative Nurses Association: Patient/Family Teaching Sheets](http://www.hpna.org/DisplayPage.aspx?Title=Patient/Family%20Teaching%20sheets)

http://www.hpna.org/DisplayPage.aspx?Title=Patient/Family%20Teaching%20sheets

[List of Helpful Websites-Palliative Care](http://palliativecarensw.org.au/site/about-palliative-care/helpful-websites/)

[http://palliativecarensw.org.au/site/about-palliative-care/helpful-websites/]

3.58 Teaching and Coaching

One of the National Competency Standards for Registered Nurses in Australia (Standard 7.7: Nursing and Midwifery Board, 2010) is teaching.

The Nurse:
- educates individuals/groups to promote independence and control over their health
- identifies and documents specific educational requirements and requests of individuals/groups
- undertakes formal and informal education sessions with individuals/groups as necessary, and
- identifies appropriate educational resources, including other health professionals.

The Nurse should be familiar with this role that is integral to all nursing practice. The following highlights some points associated with teaching and coaching people with intellectual disability, their families and those who work with them.

The Nurse teaches and coaches people with intellectual disability, families, support workers, school teachers and health professionals unfamiliar with intellectual disability about health and health interventions for people with intellectual disability. Such teaching is a reciprocal arrangement where, in partnership, the Nurse and all these people learn from each another.

The Nurse is particularly involved in the interpretation of specialist health reports for others, and in teaching health procedures that, until recently, were the domain of nursing. Clinical areas of particular concern include:
- intimate hygiene
- movement and exercise
- medication
- nutrition
- mealtime management
- sexuality – client and carer feelings, time and place for expression, illegal for someone who cannot consent to have intercourse
- death and dying and grief, including chronic sorrow

Each of these areas may be the subject of formal teaching sessions but the Nurse also recognises 'teaching moments' (Nigolian & Miller, 2011) every day. The Nurse uses evidence to teach knowledge and skills, and locates resources for others.

For further information see:
Note: Some of the resources under each of the above areas of health care and support may be useful for teaching and coaching in particular circumstances.
Supporting Family Caregivers: Teaching Essential Skills to Family Caregivers[http://journals.lww.com/ajnonline/Fulltext/2011/11000/Supporting_Family_Caregivers__Teaching_Essential.28.aspx]
Guide for Nurses Teaching Healthcare
[http://www.healthcareersjournal.com/a-guide-for-nurses-teaching-healthcare-effectively-to-patients/]
Guide to Learning New Clinical Skills

[http://suite101.com/article/a-nurses-guide-to-the-theory-of-learning-new-clinical-skills-a361180]
Johanna Briggs Institute[
http://joannabriggs.org/]
Patient Education: A Guide for Nurses[
http://www.nursetogether.com/patient-education-a-guide-for-nurses]
Clinical Nursing Skills Videos
[http://www.youtube.com/watch?v=qrBNFTv-CVE]

3.59 Advocacy and Co-ordination
3.59.1 Advocacy

Inherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect. Nursing care is respectful of and unrestricted by considerations of age, colour, creed, culture, disability or illness, gender, sexual orientation, nationality, politics, race or social status. The Nurse advocates for a safe and healthy environment, equity and social justice in resource allocation, access to health care and other social and economic services (International Council of Nurses, 2012).

One of the National Competency Standards for Registered Nurses in Australia (Standard 2.4: Nursing and Midwifery Board, 2010) is advocacy. It states that the Nurse advocates for individuals/groups and their rights for nursing and health care within organisational and management structures. This means that the Nurse:

- identifies when resources are insufficient to meet care needs of individuals/groups
- communicates skill mix requirements to meet care needs of individuals/groups to management
- protects the rights of individuals and groups and facilitates informed decisions
- identifies and explains policies/practices which infringe on the rights of individuals or groups
- clarifies policies, procedures and guidelines when rights of individuals or groups are compromised, and
- recommends changes to policies, procedures and guidelines when rights are compromised.

Nursing's Code of Professional Conduct Australia states: "In situations where a person is unable or unwilling to decide or speak independently, nurses endeavour to ensure their perspective is represented by an appropriate advocate, including when the person is a child."

The Nurse should be familiar with this role. The following highlights some points associated with advocacy in nursing and advocacy with people with intellectual disability.

The Professional Association of Nurses in Developmental Disability Australia (PANDDA) has developed Standards for Developmental Disability Nursing which include health advocacy. Equity of access to resources for the promotion of health and wellness is a nursing concern. Developmental Disability Nursing practice will include strategies to minimise differences and

maximise equity in the distribution and utilisation of health care resources so that all people within the community can achieve their full health potential.

Despite Nurses promoting advocacy as one of their roles, there is a discussion in the literature regarding what advocacy in nursing actually means (Gray & Jackson, 2002; Turnbull, 2004; Winslow, 1984). If one uses the usual understanding of advocacy (to assist a person to do as they wish), one can find oneself in conflict with one's own personal and professional moral/ethical code. Ethical principles can guide moral decision making and moral actions.

In trying to find a definition, Vaartia *et al* (2006) found that advocacy is not a single event, but a process of analysing, counselling, responding, shielding and whistleblowing activities in clinical nursing practice. Given the political nature of advocacy, one might also find oneself in conflict with employers. There is little protection for whistle blowers in NSW but the guidelines from the NSW Nurses and Midwives Association may be useful.

In a recent study of advocacy and people with intellectual disability, Brolan *et al* (2012) found a number of themes:

> The first underscored how advocacy to 'speak up' for the person with ID is integral to both parent and support worker roles. The second and third themes considered the contexts for advocacy efforts. Access to quality health care was a core concern, along with advocacy across other areas and sectors to address the person's wider psychosocial needs. The remaining themes highlighted the many dimensions to advocacy, including differences between parent and support worker views, with parental advocacy being an expression of 'caring' and support workers motivated by a 'duty of care' to protect the individual's 'rights'.

British Learning Disability Nurses have long been interested in clarifying nursing's advocacy role (Blackmore, 2001; Gates, 2006; Jenkins, 2012; Llewellyn & Northway, 2002, 2007). Given the move from a social to a health focus for Nurses (Atkinson, 2010), it is recommended that Nurses respond to health inequity using a two-pronged approach: providing excellent health care to individuals, and being socially active in challenging health inequalities (Sheerin, 2012).

Using this approach, the Nurse provides evidence-based clinical health care and is involved in the direction of policies both within and external to the workplace. At the very least, the Nurse is an active member of their professional organisation, and may extend their activities to include professional and political activities that facilitate the best health outcomes for people with intellectual disabilitiy.

Given the complications of competing agendas and conflicts, Atherton (2006) suggests that it is not desirable for a person who is close to another person to be an advocate. Nevertheless the Nurse will continue to have a role in advocacy, ensuring that a person has an advocate, and challenging health inequity at every level. The Nurse of the future will no doubt refer people with disability to the many disability advocacy groups and, with the emergence of

the health advocate as an occupation in NSW, refer people to health advocates.

3.59.2 Coordination

Because of the chronic and complex health care needs of this group, it usually falls to the Nurse to co-ordinate health care. The Nurse collaborates with the person with a disability, their person responsible, their carers, their school or day program, and the multidisciplinary health team, including hospitals, to ensure that all the activities of the health care plan occur in a timely fashion.

One way to do this is to have a regular health audit, say every six weeks (preferably in conjunction with regular reviews with the GP), to ensure that all recommendations have been followed up and that all recommended appointments have been made. The Nurse must anticipate the guidance that is needed by all involved, for example:

- information about health status and recommended health care for the person with a disability, their person responsible, and carers;
- consent from the person with a disability and/or their person responsible for health care changes;
- information for school or day programs about health care and any changes to protocols;
- collaboration with allied health about changes in health status and health care so that they can adjust their plans accordingly;
- questions for the GP about health status and requests for referrals, pathology and imaging for regular reviews with specialists (so that the person with a disability does not have to make two trips to the specialist for the same thing);
- information for specialists about the usual health status and presentation of the person with a disability and any changes.

The Nurse also decides the most appropriate person to accompany the person with a disability to any appointments. It is important to note that, in a recent study (Lennox *et al*, 2012) of the utilisation of the CHAP, matters associated with support worker engagement emerged as an area of concern, in particular the lack follow up of GP recommendations.

In a review of multidisciplinary continuity of care, Haggerty *et al* (2003) found that,

>…for continuity to exist, care must be experienced as connected and coherent. For patients and their families, the experience of continuity is the perception that providers know what has happened before, that different providers agree on a management plan, and that a provider who knows them will care for them in the future. For providers, the experience of continuity relates to their perception that they have sufficient knowledge and information about a patient to best apply their professional competence and the confidence that their care inputs will be recognised and pursued by other providers.

(Betz & Nehring, 2010; Gates, 2006; Haggerty et al, 2003; Lennox et al, 2012)

For further information see:

Rights of People with Intellectual Disabilities in Australia
[http://www.nswcid.org.au/images/pdfs/legislation%20fact%20sheet.pdf]

The involvement of parents in healthcare decisions where adult children are at risk of lacking decision-making capacity: a qualitative study of treatment decisions in epilepsy
[http://www.clahrc-cp.nihr.ac.uk/wp-content/uploads/2013/06/Redley-et-al-2013.pdf]

ICN Code of Ethics
[http://www.icn.ch/images/stories/documents/about/icncode_english.pdf]

Nursing and Midwifery Board of Australia: Codes and Guidelines
[http://www.nursingmidwiferyboard.gov.au/Codes-Guidelines-Statements]

Ethics in Nursing
[http://nursingstandard.rcnpublishing.co.uk/archive/article-an-introduction-to-ethics-in-nursing]

Guidelines on Whistleblowing and Nursing
[http://www.nswnurses.asn.au/multiattachments/40208/DocumentName/Whistleblowing.pdf]

Protection of Whistleblowers Australia
[http://www.australiancollaboration.com.au/pdf/Democracy/Protection-of-whistleblowers.pdf]

Disability Advocacy Groups NSW
[http://www.fahcsia.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program/models-of-disability-advocacy/national-disability-advocacy-agencies-funded-by-the-commonwealth-by-state-or-territory/disability-0]

Continuity of Care[http://www.ncbi.nlm.nih.gov/pmc/articles/PMC274066/]

3.60 Education, Research and Evaluation

Evidence based practice is concerned with the ability to question the knowledge underpinning approaches to nursing work. Again the Nurse should be familiar already with the areas of education, research and evaluation. The following makes some refresher points with particular reference to the health of people with intellectual disability.

3.60.1 Education

Annual registration of the Nurse is dependent on engaging in continuing professional development (CPD) activities with evidence provided in the accrual of CPD points. PANDDA holds an annual conference which, along with others, such as ASID and AADDM, provide excellent opportunities for professional development regarding the latest research, current issues and best practice related to health and people with intellectual disability. Nurses may also actively participate by presenting their own work.

Postgraduate courses in disability related areas are available by attendance at university and online. Many RTOs are now providing online short courses for Nurses in areas that may be useful to the health of people with intellectual disability; a few are free, most are user-pays. Many companies providing products used by people with disability also have an education arm, usually for no cost to Nurses.

3.60.2 Research

Historically, nursing research has been poor but this is improving. While British Nurses who work with people with intellectual disability have taken on the challenge, there is little research by Nurses who work with people with intellectual disability in Australia.

Nurses participate in research activities in a number of ways:
- read and utilise research in clinical practice
- participate in research projects
- lead research projects when they identify a gap in practice. The latter is best done in collaboration with Nurse academics who have access to all that is needed to complete research.

Nurses employed by FACS or NSW Health have access to free online databases and there are many free databases now on the internet, e.g., the Cochrane Library, Medscape, Google Scholar. Members of the Australian College of Nursing have access to a free online database. University students have access to free databases. Other free sources of information and education can be found in specialist websites, such as CDS, CDDHV, QCIDD, 3DN, PANDDA, Johanna Briggs, Medicare Locals, Think GP, ACI, ICN, WHO, Mayo Clinic, NCID, NSW CID.
See Kearney (2011) for an overview of the utilisation of research in your nursing practice.

3.60.3 Evaluation
Evaluation refers to the health goals of the individual, clinical governance, and reflective practice.

3.60.4 Evaluation of Health Goals
The identification of measurable goals with the person with a disability, their person responsible, their carers and the multidisciplinary health team is the first step in the process of evaluation. Evaluation may be both ongoing and final. Ongoing evaluation of health care plans should occur at least every three months. A formal evaluation involves the person with a disability and all people with an interest and should occur every year. The Nurse considers:
- the accuracy and the completeness of the initial assessment
- whether the set goals are realistic and achievable
- the suitability of any agreed actions
- changes in health status
- the reports and opinions of all involved (Gates, 2006).

3.60.5 Clinical Governance
The concept of clinical governance integrates clinical decision-making in a management and organisational framework and requires clinicians and administrators to take joint responsibility for the quality of clinical care delivered by the organisation. Clinical governance can be considered as "the responsibility of governing bodies to:
- demonstrate sound strategic and policy leadership in clinical safety and quality
- ensure appropriate safety and quality systems are in place
- ensure organisational accountability for safety and quality" (NSW Health, 2005, p.4).

Both FACS and NSW Health work within a Safety and Quality Framework. The Nurse is familiar with these frameworks and assists in their development and monitoring.

3.60.6 Reflective Practice

Reflective practice should not be a new concept to Nurses. This is essentially an ongoing critical evaluation of nursing practice. It can be done alone, using such techniques as journal writing and research articles, or it can be done with a clinical supervisor who can assist with feedback on reflections and practice. While there is no clear definition of reflective practice, its engagement is associated with improvement of the quality of care, stimulating personal and professional growth and closing the gap between theory and practice. Somerville & Keeling (2004) provide some practical tips on how to be a reflective practitioner.

For further information see:

3DN
[http://3dn.unsw.edu.au/]
AADDM
[http://ausaddm.wordpress.com/home/]
ACI
[http://www.aci.health.nsw.gov.au/]
ACN
[http://www.acn.edu.au/]
FACS: Updated NSW Disability Services Standards and the Quality Framework
[http://www.FACS.nsw.gov.au/__data/assets/file/0016/262132/Factsheet6_Updated_NSW_Standards.pdf]
ASID
[http://www.asid.asn.au/]
CDDHV
[http://www.cddh.monash.org/]
CDS
[http://www.cds.med.usyd.edu.au/]
Cochrane Library
[http://www.thecochranelibrary.com/view/0/FreeAccess.html]
Doing Research
[http://www.pandda.net/files/2011-Wilson-LicenceToResearch.pdf]
ICN
[http://www.icn.ch/]
Johanna Briggs Institute
[http://joannabriggs.org/]
Mayo Clinic
[http://www.mayoclinic.com/]
Medscape[http://www.medscape.org/multispecialty]
NCID
[http://www.ncid.org.au/]
NSW CID
[http://www.nswcid.org.au/]
NSW Health: NSW Clinical Governance Directions Statement
[http://www0.health.nsw.gov.au/resources/quality/pdf/cgudirstat.pdf]
NSW Medicare Locals
[http://www.gpnsw.com.au/about-us/nsw-medicare-locals.html]
Nurse IT
[http://www.nurseit.com.au/education-journals.php]
Nurse Training Online
[http://www.nursetrainingonline.com.au/]
Nurses for Nurses
[http://www.nursesfornurses.com.au/index.aspx?page=121]
PANDDA

[http://www.pandda.net/PANDDA/Home.html]
Practical Tips on Reflective Practice
[http://www.nursingtimes.net/nursing-practice/clinical-zones/educators/a-practical-approach-to-promote-reflective-practice-within-nursing/204502.article]
QCIDD
[http://www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability.aspx]
Think GP
[http://thinkgp.com.au/education]
Utilising Research
[http://www.pandda.net/files/2011-Kearney-Research.pdf]
WHOhttp://www.who.int/en/][

3.61 *What does this mean for your nursing practice?*

Practice Points: **WORKING WITH PEOPLE WITH CHRONIC and** **COMPLEX HEALTH CARE NEEDS**

- The need for chronic and complex health care arises due to the **impact** and **severity** of diagnoses and/or conditions.
- Health threats associated with chronic and complex health care needs may be physiological or functional.
- Be familiar with threats to health associated with people with intellectual disability
- Be familiar with threats to health for individuals.
- Anticipate threats to health and employ nursing interventions to prevent them.
- Nursing management of multiple health threats for any individual comprises thoughtful analysis of the situation, along with the integration of recommendations of all health professionals to prevent health breakdown.
- Nursing interventions are evidence based.
- Nursing interventions reflect the goals of the individual.
- Nursing interventions enable meaningful participation in life activities.
- Collaborate with the multidisciplinary health team.
- Develop partnerships with people with chronic and complex health care needs and their significant others.
- Network with health, education and disability services.
- Teaching, coaching, access, coordination and ongoing evaluation are integral to health care and support.
- Anticipate guidance that others may need.
- The person with an intellectual disability is unlikely to have the capacity to consent to health interventions.
- The person responsible consents to health interventions.
- If the person with an intellectual disability objects to a health intervention, the Nurse has a duty of care to ensure that the health intervention is performed.
- If the person responsible withholds consent for a health intervention despite negotiation, the Nurse may seek a Guardianship hearing (through their employer).
- Identify and use specialist resources to promote the health and well-being of the person with chronic and complex health care needs.
- Utilise equipment resources such as Enable and AIDAS.
- Teach and coach people with chronic and complex health care needs, their families, and support workers in schools and day programs about health.
- Advocate for the individual, and for people with chronic and complex health care needs generally, to gain equitable access to health services.
- Stay current in nursing practice and health interventions for people with intellectual disability and chronic and complex health care needs.
- Utilise research to validate nursing practice.

3.62 References and Resources for Working with People with Chronic and Complex Health Care Needs

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