Practice Package
Nursing and Health Care
Document approval

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Table of contents

INTRODUCTION........................................................................................................... 7

1. Introduction .............................................................................................................. 7

1.1 The Core Standards for Practice ........................................................................ 7
  1.1.1 Nursing and Health Care Core Standards for Nurses .................................. 7
  1.1.2 Contexts of Disability Nursing Practice ....................................................... 8

1.2 Using this Practice Package .................................................................................. 8
  1.2.1 Organisation and Rationale ......................................................................... 8
  1.2.2 Hyperlinks .................................................................................................. 9
  1.2.3 Practice Package Updates ........................................................................... 9
  1.2.4 Copyright .................................................................................................... 10

DISABILITY and HEALTH ........................................................................................... 11

2. Disability and Health ............................................................................................... 11

2.1 Background .......................................................................................................... 11

2.2 Medical Diagnoses Commonly Associated with Developmental and Intellectual
Disability ....................................................................................................................... 12
  2.2.1 Autism Spectrum Disorders ........................................................................ 13
  2.2.2 Cerebral Palsy ............................................................................................ 14
  2.2.3 Genetic Disorders ....................................................................................... 14
     2.2.3.1 Down Syndrome .................................................................................. 15
     2.2.3.2 Fragile X Syndrome .......................................................................... 15
     2.2.3.3 Prader-Willi Syndrome ..................................................................... 16
     2.2.3.4 Tuberous Sclerosis Complex .............................................................. 16
     2.2.3.5 Inborn Errors of Metabolism ............................................................... 17
  2.2.4 Adverse Environmental Influences ................................................................ 18
     2.2.4.1 Prenatal ............................................................................................... 18
     2.2.4.2 Perinatal .............................................................................................. 18
     2.2.4.3 Postnatal – Infancy and Childhood ..................................................... 19
  2.2.5 Epilepsy ......................................................................................................... 19

2.3 Threats to Health for People with Intellectual Disability .................................. 21
  2.3.1 Dysphagia .................................................................................................... 21
  2.3.2 Gastrointestinal Problems .......................................................................... 22
  2.3.3 Respiratory Illness ...................................................................................... 22
  2.3.4 Oral Health Problems .................................................................................. 23
  2.3.5 Problems with Nutrition and Hydration ....................................................... 23
  2.3.6 Type 2 Diabetes .......................................................................................... 24
  2.3.7 Bowel Problems .......................................................................................... 24
  2.3.8 Bladder Problems ....................................................................................... 25
  2.3.9 Vision Impairment and Eye Problems .......................................................... 25
  2.3.10 Hearing Impairment and Ear Problems ..................................................... 26
  2.3.11 Seizures ..................................................................................................... 27
  2.3.12 Thyroid Disease ........................................................................................ 27
  2.3.13 Musculoskeletal Problems ......................................................................... 27
  2.3.14 Osteopaenia and Osteoporosis .................................................................. 28
  2.3.15 Cardiovascular Disease ............................................................................. 28
  2.3.16 Pain ............................................................................................................ 29
  2.3.17 Problems Related to Hygiene .................................................................... 29
  2.3.18 Poor Physical Fitness ................................................................................ 29
  2.3.19 Women’s Health Problems ....................................................................... 30
  2.3.20 Men’s Health Problems ............................................................................. 31
  2.3.21 Mental Health Problems .......................................................................... 31
  2.3.22 Polypharmacy ............................................................................................ 32
<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.4 Disability and Health: Lifespan Considerations</td>
<td>33</td>
</tr>
<tr>
<td>2.4.1 Children with Disabilities – Health Considerations</td>
<td>34</td>
</tr>
<tr>
<td>2.4.2 Adolescents with Disabilities – Health Considerations</td>
<td>35</td>
</tr>
<tr>
<td>2.4.3 Adults with Disabilities – Health Considerations</td>
<td>36</td>
</tr>
<tr>
<td>2.4.4 Older Adults with Disabilities – Health Considerations</td>
<td>36</td>
</tr>
<tr>
<td>2.5 Disability and Causes of Death</td>
<td>38</td>
</tr>
<tr>
<td>2.6 People with Disabilities, their Families and Carers</td>
<td>39</td>
</tr>
<tr>
<td>2.6.1 Lifelong Impact of Disability on Families</td>
<td>40</td>
</tr>
<tr>
<td>2.7 What does this mean for your nursing practice?</td>
<td>41</td>
</tr>
<tr>
<td>2.8 Readings and Resources for Disability and Health</td>
<td>42</td>
</tr>
<tr>
<td><strong>CORE STANDARDS</strong></td>
<td>44</td>
</tr>
<tr>
<td>3, 4, 5 &amp; 6 Nursing and Health Care Core Standards</td>
<td>44</td>
</tr>
<tr>
<td>3. Person-Centred Health Care Assessments and the Development of Health</td>
<td>44</td>
</tr>
<tr>
<td><strong>Care Plans</strong></td>
<td>46</td>
</tr>
<tr>
<td>3.1 Health Assessment</td>
<td>46</td>
</tr>
<tr>
<td>3.1.1 Assessment Data</td>
<td>47</td>
</tr>
<tr>
<td>3.1.2 Types of Health Assessment</td>
<td>48</td>
</tr>
<tr>
<td>3.1.3 Health Care Assessment Tools</td>
<td>48</td>
</tr>
<tr>
<td>3.1.4 Doing Health Assessments</td>
<td>48</td>
</tr>
<tr>
<td>3.2 Health Planning</td>
<td>59</td>
</tr>
<tr>
<td>3.2.1 Health Care Plans and Nurses</td>
<td>59</td>
</tr>
<tr>
<td>3.2.2 Comprehensive Health Care Plans: Development, Review and Evaluation</td>
<td>60</td>
</tr>
<tr>
<td>3.2.3 Planning for Consultations with GPs and Specialists</td>
<td>63</td>
</tr>
<tr>
<td>3.2.4 Planning for Hospitalisation</td>
<td>66</td>
</tr>
<tr>
<td>3.2.5 Planning for Transition from Paediatric Services to Adult Services</td>
<td>68</td>
</tr>
<tr>
<td>3.3 What does this mean for your nursing practice?</td>
<td>70</td>
</tr>
<tr>
<td>3.4 Readings and Resources for Person Centred Health Care Assessments and the Development of Health Plans</td>
<td>71</td>
</tr>
<tr>
<td><strong>4. Communication and Behaviour Support</strong></td>
<td>73</td>
</tr>
<tr>
<td>4.1 Communication</td>
<td>73</td>
</tr>
<tr>
<td>4.1.1 Language Development</td>
<td>74</td>
</tr>
<tr>
<td>4.1.1.1 Levels of Communication</td>
<td>74</td>
</tr>
<tr>
<td>4.1.2 Communication Plans and Profiles</td>
<td>75</td>
</tr>
<tr>
<td>4.1.3 Augmentative and Alternative Communication (AAC)</td>
<td>75</td>
</tr>
<tr>
<td>4.1.4 Communicating with People with Intellectual Disabilities</td>
<td>76</td>
</tr>
<tr>
<td>4.1.5 Communicating with People with Sensory Impairments</td>
<td>76</td>
</tr>
<tr>
<td>4.1.6 Communication Between Health Professionals, People with Disabilities, their Families and Carers, Schools, Day Options</td>
<td>79</td>
</tr>
<tr>
<td>4.1.7 Communicating with Families of People with Disabilities</td>
<td>79</td>
</tr>
<tr>
<td>4.1.8 Communication and Behaviour</td>
<td>80</td>
</tr>
<tr>
<td>4.2 Behaviour Support</td>
<td>81</td>
</tr>
<tr>
<td>4.2.1 Challenging Behaviour</td>
<td>81</td>
</tr>
<tr>
<td>4.2.1.1 Links between Communication, Challenging Behaviour and Ageing</td>
<td>82</td>
</tr>
<tr>
<td>4.2.1.2 Some Causes of Challenging Behaviour</td>
<td>82</td>
</tr>
<tr>
<td>4.2.1.3 Examples of Challenging Behaviour</td>
<td>83</td>
</tr>
<tr>
<td>4.2.1.4 Impact of Challenging Behaviour</td>
<td>83</td>
</tr>
<tr>
<td>4.2.2 Positive Behaviour Support</td>
<td>84</td>
</tr>
<tr>
<td>4.2.2.1 Assessment of Behaviour</td>
<td>85</td>
</tr>
<tr>
<td>4.2.2.2 Behaviour Support Plan</td>
<td>85</td>
</tr>
</tbody>
</table>
5. Working with People with Chronic and Complex Health Care Needs ................. 92

5.1 Health Care and Support ............................................................................. 92
  5.1.1 Management of Dysphagia ................................................................. 93
  5.1.2 Management of Gastrointestinal Problems ......................................... 94
    5.1.2.1 GORD and Helicobacter pylori .................................................. 94
    5.1.2.2 Gastroenteritis ............................................................................. 95
    5.1.2.3 Surgery ....................................................................................... 95
  5.1.3 Respiratory Health ................................................................................ 96
    5.1.3.1 Management of Acute Asthma .................................................... 96
    5.1.3.2 Management of Chest Infection/Aspiration Pneumonia ............... 97
    5.1.3.3 Management of Tracheostomy, Mechanical ventilation, CPAP (Continuous Positive Airway Pressure), BiPAP (Bi-level Positive Airway Pressure) ................................................. 97
  5.1.4 Oral Health ........................................................................................... 98
  5.1.5 Nutrition, Hydration and Weight Management ...................................... 99
  5.1.6 Management of Type 2 Diabetes ........................................................ 100
  5.1.7 Management of Bowel Problems ........................................................ 100
    5.1.7.1 Faecal Incontinence ................................................................... 100
    5.1.7.2 Constipation ............................................................................... 101
    5.1.7.3 Colostomy, Ileostomy, Caecostomy ............................................. 101
  5.1.8 Management of Bladder Problems ...................................................... 102
    5.1.8.1 Urinary Incontinence .................................................................. 102
    5.1.8.2 Urinary Tract Infections .............................................................. 102
    5.1.8.3 Toilet Training ............................................................................ 103
    5.1.8.4 Uridomes and Catheters ............................................................. 103
  5.1.9 Management of Vision Impairment and Eye Problems ....................... 104
    5.1.9.1 Vision Impairment ...................................................................... 104
    5.1.9.2 Eye Infection ............................................................................... 104
    5.1.9.3 Surgery ....................................................................................... 105
  5.1.10 Management of Hearing Impairment and Ear Problems .................... 105
    5.1.10.1 Hearing Impairment .................................................................. 105
    5.1.10.2 Ear Infection ............................................................................. 106
    5.1.10.3 Grommets ............................................................................... 106
  5.1.11 Seizure Management ........................................................................... 106
  5.1.12 Management of Thyroid Disease ....................................................... 107
  5.1.13 Management of Musculoskeletal Problems ........................................ 108
    5.1.13.1 Mobility .................................................................................... 108
    5.1.13.2 Posture ..................................................................................... 109
    5.1.13.3 Comfort ................................................................................... 109
    5.1.13.4 Surgery ..................................................................................... 110
  5.1.14 Management of Osteopenia and Osteoporosis .................................... 111
  5.1.15 Management of Cardiovascular Disease ........................................... 112
  5.1.16 Pain Management ................................................................................ 112
    5.1.16.1 Discomfort ............................................................................... 112
    5.1.16.2 Acute Pain ............................................................................... 112
    5.1.16.3 Chronic Pain ............................................................................ 113
  5.1.17 Personal and Intimate Hygiene Management ..................................... 113
  5.1.18 Physical Fitness .................................................................................... 113
  5.1.19 Women’s Health ................................................................................ 114
  5.1.20 Men’s Health ...................................................................................... 115
  5.1.21 Management of Mental Health Problems ......................................... 116
    5.1.21.1 Mental Health .......................................................................... 116
    5.1.21.2 Mental Illness .......................................................................... 116
    5.1.21.2 Pica .......................................................................................... 118
  5.1.22 Medication Management .................................................................... 119
  5.1.23 Lifespan Considerations ..................................................................... 120
5.1.24 End of Life Care ........................................................................................................ 121
5.2 Teaching and Coaching ............................................................................................... 125
5.3 Advocacy and Co-ordination ..................................................................................... 126
  5.3.1 Advocacy .................................................................................................................. 126
  5.3.2 Coordination ............................................................................................................. 128
5.4 Education, Research and Evaluation .......................................................................... 129
  5.4.1 Education ................................................................................................................. 130
  5.4.2 Research .................................................................................................................. 130
  5.4.3 Evaluation ................................................................................................................ 130
    5.4.3.1 Evaluation of Health Goals ................................................................................. 130
    5.4.3.2 Clinical Governance ......................................................................................... 131
    5.4.3.3 Reflective Practice ............................................................................................ 131
5.5 What does this mean for your nursing practice? ....................................................... 133
5.6 Readings and Resources for Working with People with Chronic and Complex Health Care Needs .................................................................................................................. 134
6. Mealtime Management ................................................................................................. 136
6.1 Nutrition for Health and Wellbeing .......................................................................... 136
  6.1.1 Nutritional Risks for People with Disabilities ......................................................... 136
  6.1.2 Outcomes of Poor Nutrition .................................................................................. 139
  6.1.3 Assessment of Nutrition ....................................................................................... 139
  6.1.4 Nutrition for Health and Wellbeing ..................................................................... 139
  6.1.5 Healthy Nutrition .................................................................................................. 140
  6.1.6 Nurses and Nutrition ............................................................................................. 140
6.2 Managing Dysphagia .................................................................................................. 142
  6.2.1 Dysphagia ............................................................................................................... 142
  6.2.2 Screening for Dysphagia ....................................................................................... 143
  6.2.3 Assessing Dysphagia ............................................................................................. 144
  6.2.4 Hydration ................................................................................................................ 144
  6.2.5 Medications and Dysphagia .................................................................................. 145
  6.2.6 Oral Health and Dysphagia .................................................................................. 145
6.3 Enteral Nutrition .......................................................................................................... 149
  6.3.1 Reasons for Enteral Nutrition ................................................................................. 150
  6.3.2 Making Decisions about Enteral Nutrition ............................................................ 150
  6.3.3 Delivering Enteral Nutrition .................................................................................. 151
  6.3.4 Enteral Nutrition – Some Practical Considerations .............................................. 151
6.4 What does this mean for your nursing practice? ....................................................... 154
6.5 Readings and Resources for Mealtime Management ................................................ 156
REFERENCES ...................................................................................................................... 158
7. References ....................................................................................................................... 158
INTRODUCTION

1. Introduction
Welcome to the Nursing and Health Care Practice Package (the Practice Package) which has been developed for Nurses who provide person centred health support for people with disabilities.

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

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

1.1 The Core Standards for Practice
ADHC has developed Core Standards for Practice for practitioners who provide support to people with a disability. These include generic common core standards and discipline-specific core standards. The Common Core Standards for Practice cover the following areas for all practitioners:
- Professional Supervision
- The Working Alliance
- Intellectual Disability: Philosophy, Values and Beliefs
- Service Delivery

Information about these standards, along with information necessary for staff working in ADHC services, is available in the Community Support Teams Practice Package. Nurses working within ADHC are expected to be familiar with this document (available on the ADHC intranet only).

Interactive learning modules are currently being developed around these generic core standards and will be available on the ADHC intranet for staff, and on the internet for all nurses.

1.1.1 Nursing and Health Care Core Standards for Nurses
This Nursing and Health Care Practice Package focuses on the four core standards for nursing developed by regional senior practitioners and the Practice Leader – Nursing and Health Care. The Nursing and Health Care Core Standards address:
- Person-Centred Health Care Assessments and the Development of Health Care Plans
- Communication and Behaviour Support
- Working with People with Chronic and Complex Health Care Needs
- Mealtime Management.
These core standards represent fundamental areas of knowledge, skills and attitudes required by Registered and Enrolled Nurses when supporting people with disabilities, their families and carers. The standards are not intended to restrict practice nor imply boundaries. Rather, they are intended to enhance core nursing skills that underpin practice. Information presented in this Practice Package provides access to key information and resources thus contributing to ADHC’s knowledge translation programme.

1.1.2 Contexts of Disability Nursing Practice
With changes in philosophies, approaches, community participation, and service delivery for people with disabilities, their families and supporters, it is essential for Nurses in all contexts to provide effective nursing support.

It is assumed Registered and Enrolled Nurses are competent in comprehensive nursing practice and meet all the relevant National Competency Standards according to the Nursing and Midwifery Board of Australia. This Practice Package builds on those standards and is intended to provide information that is particularly useful to Registered and Enrolled Nurses new to practice in disability. These may include:

- ADHC 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 practitioners’ surgeries (GPs)
- residential/accommodation services
- community health services
- specialist teams
- hospitals
- nursing homes

1.2 Using this Practice Package
1.2.1 Organisation and Rationale
The Practice package is organised into the following sections:

- Section 1 – Disability and Health
- Section 2 – Person-Centred Health Care Assessments and the Development of Health Care Plans
- Section 3 – Communication and Behaviour Support
- Section 4 – Working with People with Chronic and Complex Health Care Needs
- Section 5 – Mealtime Management.
Section 1, Disability and Health, provides background information about the health of people with disabilities and their families. It is designed to build knowledge essential to the understanding of nursing and health care practice. This understanding is necessary to promote proactive, as well as responsive, health care and management when supporting people with disabilities. Sections 2-5 address the Nursing and Health Care Core Standards and provide information and guidance for practice.

All sections provide introductory information, along with resources that may be useful for further exploration of a topic. It is important to remember that the information here is not exhaustive and that knowledge changes constantly. This package is grounded in evidence available at the time of writing, but it is your responsibility as a professional practitioner to ensure you are up to date with current best practice.

The greatest benefit will be derived by reading the Practice Package in its entirety as knowledge is built from section to section. However, this may not always be possible. Therefore, it is recommended that Section 1, Disability and Health, be read thoroughly first. The sections that follow are linked to the information in Section 1 and follow the order of presentation, e.g. management strategies in Sections 2-5 link back to ‘threats to health for people with disabilities’ in Section 1.

Sections include identification of resources specific to information in sub-sections, and finish with more general resources useful to the practice standard. Each of the Nursing and Health Care Practice Standards sections includes a box of practice points: ‘What does this mean for your nursing practice?’

The Practice Package concludes with an extensive Reference List that identifies the sources of evidence used in the development of the package.

1.2.2 Hyperlinks
Where documents or further resources are available on the internet, hyperlinks and web addresses are available. Because this Practice Package is available to nurses outside ADHC, every endeavour has been made to include links to the internet (open access). However, occasionally a document is available to ADHC staff only on the ADHC intranet (internal system restricted to ADHC staff). These are included because they are useful for ADHC staff.

Hyperlinks, followed by web addresses, are often included so that addresses are visible to people using a printed version of the Practice Package. Hyperlinks work with an electronic copy when the computer mouse is pointed to activate.

Every effort has been made to include active and reliable web addresses. However, sometimes these change. If the document is not available try a web search.

1.2.3 Practice Package Updates
The Practice Package will be updated regularly by the Practice Leader at Clinical Innovation and Governance. Be mindful that policies and practice change, particularly in the current climate of massive systemic changes in service provision for people with disabilities and their families. Should you identify significant
omissions or information that is incorrect, contact the Practice Leader – Nursing and Health Care.

1.2.4 Copyright
A comprehensive range of resources has been drawn upon in the development of this package. Every endeavour has been made to acknowledge sources of information. It is important to be aware of copyright laws when utilising information provided in references and websites. Generally, appropriate acknowledgement of the source suffices. However, always remember to check any constraints regarding use of information or materials from the internet; sometimes, written consent is required.
DISABILITY and HEALTH

2. Disability and Health
This section sets the scene for nursing and health care practice addressed within the Nursing and Health Care Core Standards. It provides background information about the health of people with disabilities and their families organised under the following headings:
- Background
- Medical Diagnoses Commonly Associated with Developmental and Intellectual Disability
- Threats to Health for People with Intellectual Disability
- Disability and Health: Lifespan Considerations
- Disability and Causes of Death
- People with Disabilities, their Families and Carers

The overview of health conditions experienced by people with disabilities highlights the particular problems associated with developmental and intellectual disability (sometimes referred to in this section collectively as ‘intellectual disability’). Understanding of aetiologies and diagnoses associated with intellectual disabilities, along with the family impact of disability, provide essential awareness of health risks, along with cues for assessment and monitoring. Such understanding promotes proactive, as well as responsive, health care and management which are addressed in the sections that present the Nursing and Health Care Core Standards:
- Person-Centred Health Care Assessments and the Development of Health Care Plans
- Communication and Behaviour Support
- Working with People with Chronic and Complex Health Care Needs
- Mealtime Management.

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

People with disabilities experience the same health problems as others in the general community. With increasing life spans, disease patterns and risk factors are also increasing in line with the general population. These include rates of cancer, diabetes, arthritis, cardiovascular disease, falls, and dementia. The risks for these conditions in people with disabilities increase due to barriers to health care. People with intellectual disabilities are less likely to be involved in preventative health care and thus are at further risk for ‘lifestyle’ diseases such as diabetes, cardiovascular disease, smoking-related respiratory disease, and some cancers (Dossetor, 2013;
People whose main disabling condition is intellectual disability require assistance with daily living activities. They experience limitations in communication, mobility and self-care and need lifelong support and assistance which ranges through intermittent, limited, high and pervasive. Many of these people have complex health needs.

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

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

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

### 2.2 Medical Diagnoses Commonly Associated with Developmental and Intellectual Disability

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

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

(Carnaby, 2009; CDDS, 2006)

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

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

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

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

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

2.2.1.2 Health issues associated with autism include:

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

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

For further information see:

- Autism [http://www.intellectualdisability.info/diagnosis/autism]
- Autism Spectrum Disorder – DSM 5
- Autismhelp [http://www.autismhelp.info/default.aspx]
- Australian Advisory Board on Autism Spectrum Disorders [http://www.autismadvisoryboard.org.au/]
2.2.2 Cerebral Palsy

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

Cerebral palsy is classified according to:
- **type** of motor disorder (the way the body is affected) – hypertonic (spastic), hypotonic, athetoid, dyskinetic, ataxic, mixed
- **distribution** of motor disorder (where the body is affected) – quadriplegic, diplegic, hemiplegic
- **severity** of motor disorder – categorised on a scale of GMFCS I-V by using the Gross Motor Function Classification System (GMFCS).

2.2.2.1 Health issues associated with cerebral palsy include:
- Sensory impairments (visual, hearing, touch)
- Epilepsy
- Neuromuscular problems
- Skeletal deformities
- Osteoporosis
- Incontinence
- Voiding dysfunction
- Constipation
- Skin breakdown
- Pain
- Depression
- Dysphagia
- Eating and drinking difficulties
- Main nutrition
- Recurrent aspiration
- Gastro-oesophageal reflux disease (GORD)
- Barrett’s oesophagus
- Gastric bleeding/anaemia
- Poor peripheral circulation
- Recurrent chest infections
- Chronic lung disease
- Dental problems

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

For further information see:
- Cerebral Palsy Alliance [https://www.cerebralpalsy.org.au/]
- Cerebral Palsy Fact Sheet CDDH [http://www.cddh.monash.org/assets/fs-cerebralp.pdf]

2.2.3 Genetic Disorders

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

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

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

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

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

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

2.2.3.1.1 Health issues associated with Down syndrome include:

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

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

For further information see:

Down Syndrome Australia

Down Syndrome Association NSW

2.2.3.2 Fragile X Syndrome

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

Fragile X syndrome is characterised by particular physical characteristics, general developmental delay, intellectual disability (100% in males), and behavioural and emotional problems.
2.2.3.2.2 Health issues associated with Fragile X syndrome include:

- visual impairments
- hearing impairment
- recurrent ear infections
- epilepsy
- cardiac defects
- scoliosis
- congenital hip dislocation
- hypotonia
- connective tissue dysplasia (loose joints)
- attention deficit/hyperactivity (ADHD)

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

**For further information see:**
- Fragile X Association of Australia  
- Fragile X Syndrome Research Today  
  [http://www.fragilexsyndrome.researchtoday.net/](http://www.fragilexsyndrome.researchtoday.net/)

2.2.3.3 Prader-Willi Syndrome

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

2.2.3.3.1 Health issues associated with Prader-Willi syndrome include:

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

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

**For further information see:**
- Prader-Willi Syndrome Association of Australia  
- Prader-Willi Syndrome – Information Sheets 1 & 2. CDDS Monash University  

2.2.3.4 Tuberous Sclerosis Complex

Tuberous sclerosis (also known as *epiloia*) is a multisystem genetic condition that varies widely in severity. It is characterised by benign growths (tumours or lesions) in various parts of the body. Skin, brain, eyes, heart, kidneys and lungs are most commonly affected, though tumours may be found in other organs. ~50% of people with tuberous sclerosis have normal intelligence, while others will have developmental delay and some have severe intellectual disability. It is strongly associated with epilepsy and autism.
2.2.3.4.1 Health issues associated with tuberous sclerosis include:
Health problems are related to where tumours are located in the body.
- retinal tumours
- rhabdomyomata – eye, bone, heart, lung, liver
- hypertension
- cerebral astrocytoma
- epilepsy
- sleep problems
- hamartomata – kidney, lung
- polycystic kidneys
- dental abnormalities
- skin lesions – may be disfiguring and interfere with function
- behavioural difficulties
(CDDS, 2006; Centre for Genetics Education, 2013; Leung & Robson, 2007; Therapeutic Guidelines, 2012)

For further information see:
The Australasian Tuberous Sclerosis Society
http://www.atss.org.au
Tuberous Sclerosis Complex. Fact Sheet 61

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

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

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

2.2.3.5.1 Health issues associated with inborn errors of metabolism include:
Health problems are related to and vary according to the nature of the metabolic error. The range includes:
- epilepsy
- CNS symptoms – pyramidal and extrapyramidal syndromes
- cardiac problems
- connective tissues problems
- skin problems, including eczema
- respiratory problems
- nutritional problems
- visual problems – damage to cornea
- CNS problems
- hyperactivity
- phobic anxiety
(CDDS, 2006; Centre for Genetics Education, 2013)

For further information see:
Australasian Society for Inborn Errors of Metabolism
http://www.hgsa.org.au/asiem
The PKU (Phenylketonuria) Association of NSW Inc.
2.2.4 Adverse Environmental Influences
Numerous factors have an influence on the development of the foetus and infant. Many environmental factors have an adverse impact on foetal and infant development, but particularly the developing brain which is highly susceptible to insult. Such factors may result in childhood developmental delay and intellectual disability in adulthood. These adverse environmental influences will generally result in cerebral palsy (neurological damage due to an insult to the developing brain).

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

2.2.4.1 Prenatal
Factors during intrauterine life that may have an adverse effect on foetal development and result in developmental disability include:

- maternal substance abuse – alcohol (foetal alcohol syndrome), nicotine and other drugs
- harmful chemicals – pollutants, heavy metals, phenytoin
- severe maternal malnutrition
- deficiencies – iodine, folic acid
- maternal infections – rubella, cytomegalovirus, toxoplasmosis, HIV
- intrauterine cerebral infarction
- Rh incompatibility
- hyperbilirubinaemia
- complications of pregnancy – placental dysfunction, maternal disease (diabetes, heart and kidney disease).

2.2.4.2 Perinatal
Factors occurring during labour, delivery, and immediate post-delivery that may have an adverse effect on infant development and result in developmental disability include:

- severe prematurity
- very low birth weight (VLBW)
- prolonged birth hypoxia
- cerebral haemorrhage or infarct
- cerebral oedema
- birth injury
- infant jaundice (hyperbilirubinaemia causing kernicterus), septicaemia, hypoglycaemia, hyperglycaemia

It is important to note that birth hypoxia as indicated in a low Apgar score, is rarely the primary cause of neurological damage. It is more often a manifestation of a brain already vulnerable due to a pre-existing abnormality (Therapeutic Guidelines, 2012).
2.2.4.3 Postnatal – Infancy and Childhood
Factors occurring in infancy and early childhood that may have an adverse effect on development and result in developmental disability include:
- CNS infections – meningitis, encephalitis
- head injury – shaken baby syndrome, traumatic brain injury
- chronic lead exposure
- severe, prolonged malnutrition
- severe, prolonged understimulation.

2.2.4.4 Health issues associated with disability caused by adverse environmental influences include:
- failure to thrive
- sensory impairments (visual, hearing, touch)
- epilepsy
- neuromuscular problems
- skeletal deformities
- osteoporosis
- incontinence
- constipation
- pain
- depression
- dysphagia
- eating and drinking difficulties
- recurrent aspiration
- gastro-oesophageal reflux disease (GORD)
- gastric bleeding/anaemia
- recurrent chest infections
- chronic lung disease
- dental problems

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

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

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

1. Focal (partial) seizures
Seizure activity starts in one area of the brain and may spread to other areas. These seizures may be subtle or unusual, and may be mistaken for something else, e.g. daydreaming. Types of focal (partial) seizures are:
- focal seizure – awareness is retained (simple partial seizures)
- focal dyscognitive seizure – awareness altered (complex partial seizure)
- focal seizure evolving to a bilateral convulsive seizure (secondarily generalised tonic-clonic seizure).
2. Generalised seizures
Seizures arise in both hemispheres of the brain at the same time. Consciousness is lost from the outset of the seizure. Types of generalised seizures are:
- absence (*petit mal*):
  - typical
  - atypical
  - absence with special features
    - myoclonic absence
    - eyelid myoclonia
- tonic-clonic
- tonic
- clonic
- atonic
- myoclonic
  - myoclonic
  - myoclonic atonic
  - myoclonic tonic

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

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

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

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

2.2.5.1 Health issues associated with epilepsy
- status epilepticus
- risk of SUDEP
- further cognitive decline
- risk of injury during seizure
- risk of choking during seizure
- adverse effects of AEDs — neurological, GI, haematological, vertigo, sedation, drowsiness, mood, periodontal disease, skin rashes
- irritability, confusion, depression,
risk of drowning during seizure
social difficulties
sleep disturbances
(Bernal, 2003; Chapman et al., 2005; Epilepsy Action Australia, 2013; Prasher & Kerr, 2008; Therapeutic Guidelines, 2012)

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

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

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

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

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

- aspiration
- chest infections
- chronic lung disease
- malnutrition
- obstructive sleep apnoea
- hypoxaemia during oral feeding
- asphyxia
- death

(Crawford, 2009)

2.3.2 Gastrointestinal Problems

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

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

2.3.2.1 Threats to health from gastrointestinal problems include:

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

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

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

2.3.3 Respiratory Illness

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

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

Chronic lung disease is a common outcome of pulmonary limitations and recurrent infections.
2.3.3.1 Threats to health from respiratory illness include:

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

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

2.3.4 Oral Health Problems

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

2.3.4.1 Threats to health from oral problems include:

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

(CDDS, 2006; Watt-Smith, 2009)

2.3.5 Problems with Nutrition and Hydration

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

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

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

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

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

In **type 2 diabetes**, the pancreas either does not make enough insulin, or the body’s cells become resistant to insulin, thus impairing glucose metabolism. Although there is a familial tendency for type 2 diabetes, it is strongly associated with lifestyle factors such as:
- high blood pressure
- poor diet
- overweight and obesity
- lack of exercise, and
- an ‘apple’ shaped body where excess weight is carried around the middle.

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

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

2.3.6.1 Threats to health from type 2 diabetes include:
- visual problems – retinopathy, glaucoma, cataracts, blindness
- cardiovascular problems – stroke, heart attack
- peripheral vascular disease – ulcers, gangrene, amputation
- poor wound healing
- nerve damage including peripheral and autonomic neuropathies
- kidney disease
- infections – candida
- impotence
- pregnancy complications
- death

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

2.3.7 Bowel Problems

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

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

Death may result from complications of constipation because the symptoms are not always recognised.
2.3.7.1 Threats to health from bowel problems include:

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

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

2.3.8 Bladder Problems

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

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

2.3.8.1 Threats to health from bladder problems include:

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

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

2.3.9 Vision Impairment and Eye Problems

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

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

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

2.3.9.1 Threats to health from vision impairment and eye problems include:

- developmental delay
- reduced function
- potential for accidents
- social isolation
- impaired communication
- poor coordination and balance
- inflammation, infections
- discomfort and pain
- anxiety and depression
- challenging behaviour
- blindness
- sleep disturbance (circadian rhythm disturbance associated with blindness)

(CDDS, 2006; Levy, 2009)
For further information see:
Sight Problems in People with Intellectual Disabilities
Visual Impairment: Its Effect on Cognitive Development and Behaviour

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

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

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

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

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

2.3.10.1 Threats to health from hearing impairment and ear problems include:
- developmental delay
- language impairment
- dizziness, poor coordination and balance
- social isolation
- reduced function
- potential for accidents

(CDDS, 2006; Waite, 2009)

For further information see:
Hearing Impairment and Down Syndrome.
[http://www.intellectualdisability.info/physical-health/hearing-impairment-downs-syndrome]
2.3.11 Seizures
See Section 2.2.5 ‘Epilepsy’ for information about seizures. Seizures are repeated in this section because, apart from being a medical diagnosis, they represent a major threat to health for people with intellectual disabilities. Below are repeated the threats to health.

2.3.11.1 Threats to health from seizures include:
- status epilepticus
- risk of SUDEP
- further cognitive decline
- risk of injury during seizure
- risk of choking during seizure
- risk of drowning during seizure
- social difficulties
- adverse effects of AEDs – neurological, GI, haematological, vertigo, sedation, drowsiness, mood, periodontal disease, skin rashes
- sleep disturbance
- irritability, confusion, depression, anxiety

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

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

2.3.12.1 Threats to health from thyroid disease include:

**Hypothyroidism:**
- weight gain
- hypoactivity, lethargy
- hair loss
- skin problems
- high cholesterol
- muscle and joint pain
- constipation
- menstrual problems
- anxiety and depression

**Hyperthyroidism:**
- weight loss
- hyperactivity
- low cholesterol
- neck discomfort
- diarrhoea, irritable bowel
- osteoporosis
- anxiety

(Beange et al, 1999; CDDS, 2006; Therapeutic Guidelines, 2004)

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

2.3.13.1 Threats to health from musculoskeletal problems include:
- impaired movement and mobility
- spasm
- tight tendons
- compression and distortion of organs, especially lungs
- respiratory problems
- fatigue
- acute and chronic pain
- osteopaenia and osteoporosis
- arthritis
- sleeping difficulties
- poor saliva control
- eating and drinking problems
- elimination problems
- pressure areas

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

2.3.14 Osteopaenia and Osteoporosis

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

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

2.3.14.1 Threats to health from osteopaenia and osteoporosis include:
- fractures
- bone and muscle pain
- muscle weakness
- skeletal deformity
- decreasing mobility
- decreasing activity
- increased falls risk

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

2.3.15 Cardiovascular Disease

With the increase in life expectancy of people with intellectual disabilities, the prevalence of cardiovascular disease is increasing along with the general population. People with Down syndrome have a higher risk of cardiac problems while others experience similar risk factors to the general community, e.g., hypertension, diabetes, overweight (especially abdominal), and hypercholesterolemia. However, people with intellectual disabilities are often at higher risk due to congenital defects along with barriers related to their disability, e.g., impaired understanding and communication, poor access to preventative health care.

2.3.15.1 Threats to health from cardiovascular disease include:
- cardiomyopathy
- pulmonary hypertension
- oedema
- poor peripheral circulation
- breathlessness
- fatigue
- reduced exercise tolerance
- chest pain
- heart attack
- stroke
- death

(deWinter et al, 2009; NSW Ombudsman, 2013)
2.3.16 Pain
People with intellectual disabilities are at high risk of experiencing pain and for having more frequent and severe pain related to conditions identified in this section. Pain may be acute or chronic, but identification and assessment are complex due to impaired capacity to self-report. Undertreatment and lack of treatment of pain in people with intellectual disabilities is common. Pain should always be considered whenever there is a change in behaviour or any self-injurious behaviour.

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

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

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

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

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

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

(Carnaby & Cambridge, 2006; Wilson et al., 2009)
2.3.18 Poor Physical Fitness
Many people with intellectual disability have low levels of physical activity. This may be related to physical impairments affecting mobility, or environmental and lifestyle factors. Obesity is up to three times higher than the level in the general population. Life expectancy is related to activity in those with severe intellectual disability, and immobility is a predictor for mortality.

2.3.18.1 Threats to health from poor physical fitness include:
- overweight and obesity
- poor circulation
- hypothermia
- diabetes
- cardiovascular disease
- poor musculoskeletal development
- tight tendons, contractures
- osteoporosis
- reduced function
- lethargy and fatigue
- depression
- death

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

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

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

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

2.3.19.1 Threats to health from problems with women’s health include:
- menstrual management
- menstrual control
- infections – candida, cystitis, UTIs
- sexually transmitted infections
- contraception
- exploitation and abuse
- premenstrual syndrome (PMS)
- dysmenorrhoea (painful period)
- menorrhagia (heavy period)
- amenorrhea (no period)
- catamenial epilepsy (increased seizures before or during period)
(Noonan & Heller, 2002; Therapeutic Guidelines, 2004 & 2012)
2.3.20 Men’s Health Problems
Approaches to men’s health are the same as for the general community, viz., an awareness of and need for screening for testicular, prostate and breast cancers. However, some boys have hormone deficiencies that delay or prevent puberty. This is usually treatable. Testicular problems are more prevalent than in the general population and sometimes testicles fail to descend which increases the risk of testicular cancer tenfold. These problems are associated with low androgens (testosterone) which carry further health risks. Undescended testicles require regular monitoring.

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

2.3.20.1 Threats to health from problems with men’s health include:
- testosterone deficiency
- infertility
- lack of secondary sexual characteristics
- erectile dysfunction
- poor self-image
- increased fat mass
- inguinal hernia
- poor muscle development
- low energy
- mood swings, irritability
- osteoporosis
- infections – STIs, bacterial, fungal
- testicular cancer
- breast cancer
- prostate cancer

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

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

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

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

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

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


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

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

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

- drug interactions
- overdose
- ineffective dose
- poor compliance
- adverse reactions
- medication administration errors
- difficulties in identifying medication-related problems (what drug caused what?)

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

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

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

2.4 Disability and Health: Lifespan Considerations

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

When providing health care for people with intellectual disabilities, it is important to adopt a lifespan approach that recognises the progression or consequences of specific health problems and therapeutic interventions. The following practice examples illustrate this concept:

- In the general population gastro-oesophageal reflux disease (GORD) does not usually manifest until adulthood. However, there is a high incidence of childhood onset GORD in children with cerebral palsy. If this is not identified and treated, it can lead to oesophageal stricture or cancer in adulthood.
- The long term use of some anticonvulsants may lead to loss of bone density and result in osteoporosis.

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

The following sections outline some specific age-related health conditions and risk factors for people with intellectual disabilities. Knowledge of these factors enables prevention or early diagnosis of further potential impairments thus possibly increasing life expectancy.

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

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

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

2.4.1 Children with Disabilities – Health Considerations

Health care for children with intellectual/developmental disabilities is associated with:
- assessment of developmental status and its implications
- identification of impairments
- diagnosis of health conditions
- minimising the impact of the above problems.

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

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

2.4.1.2 Specific health conditions and risks of children with disabilities include:

- hearing impairments (sensorineural or middle ear)
- vision impairments (cortical, cataracts, refractory and acuity defects)
- epilepsy
- musculoskeletal problems
- poor oral health
- endocrine disorders (hypothyroidism, etc.)
- behaviour disturbances (may indicate underlying health problem)
- congenital heart disease
- recurrent chest infections
- oropharyngeal dysfunction (dysphagia, etc.)
- gastro oesophageal dysfunction
- malnutrition (undernutrition and obesity)
- incontinence
- constipation
- polypharmacy

These health conditions require specialised formal assessment. (Therapeutic Guidelines, 2012)
2.4.2 Adolescents with Disabilities – Health Considerations

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

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

Adolescents with disabilities require access to the same health promotion and disease prevention education and strategies as others, e.g., healthy diet, exercise and weight management; smoking, alcohol and drug use; sexual activity, safe sex and contraception; immunisation.

Note: Information needs to be provided in formats that can be understood.

2.4.2.1 Specific health conditions and risks of adolescents with disabilities include:

- mental ill health (depression, anxiety, psychosis, etc.)
- precocious puberty (tuberous sclerosis, post-infection syndromes, TBA, hydrocephalus)
- absent or delayed puberty (Prader-Willi, Klinefelter, Turner, Noonan syndromes)
- small or ambiguous genitalia (Prader-Willi, Klinefelter, Down syndromes)
- problems associated with impaired mobility (osteoporosis, spasticity, pain, deformity, dislocations, foot problems)
- malnutrition (undernutrition, obesity)
- poor strength and fitness
- problems associated with poor personal hygiene (incontinence, menstrual management, skin care)
- vision and hearing impairments
- epilepsy (seizure patterns may change during adolescence)
- substance misuse
- abuse

Adolescence is a time to build resilience by encouraging to:

- develop trusting relationships
- focus on strengths and abilities and develop further
- explore ways to experience independence and success.

(Therapeutic Guidelines, 2012)

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

Adults with intellectual disabilities experience the same range of health problems as the general community. The major differences relate to problems being more prevalent and often unrecognised or poorly managed. There may be also be additional health problems related to the cause of a person’s disability.

*It is important to understand that the burden of illness is greater in people who cannot effectively express symptoms such as pain.* Pain and infection are often not recognised and may only be expressed by a change in behaviour.

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

2.4.3.1 Specific health conditions and risks of adults with disabilities include:
- vision and hearing impairments
- dental disease
- dysphagia
- GORD
- *Helicobacter pylori* infection
- constipation
- bowel obstruction
- incontinence
- respiratory conditions (infections, especially related to aspiration; foreign bodies in lungs)
- musculoskeletal and joint problems (unrecognised fractures, sublaxed hips, chronic pain)
- women’s and men’s health issues
  (Therapeutic Guidelines, 2012)

2.4.4 Older Adults with Disabilities – Health Considerations

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

It is important to recognise that older people with disabilities carry the dual health burdens of lifelong health problems associated with their disabling impairments, as well as health conditions associated with normal ageing and lifestyle factors. These include: musculoskeletal disorders, cardiovascular disease, cancers, endocrine disorders, cognitive decline, mental health problems. Age-related health conditions sometimes occur earlier than expected in people with disabilities and are sometimes associated with specific diagnoses or syndromes, e.g., early dementia is associated with Down syndrome. Age-related disability exacerbates the underlying problems of people with intellectual disabilities from health, functional and social perspectives.
Frailty results when people are subjected to a number of physiological problems because reserve capacities diminish. The concept applies to people with disabilities in whom frailty increases with age. Common medical problems may have a bigger impact on health and function than in others and there is an increased risk of further disability and death from relatively minor stressors.

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

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

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

2.4.4.1 Specific health conditions and risks of older adults with disabilities include:

- sensory decline (vision and hearing deteriorate, cataracts, glaucoma)
- neurological decline and disorders (balance, co-ordination, gait, dexterity, effects of long-term medications, Parkinson’s disease)
- dementia (depression and seizures sometimes seen as a lead up)
- cognitive decline
- mental health problems (depression, anxiety, delirium, psychosis)
- bereavement and grief (losses more common with ageing – often overlooked)
- cardiovascular problems (hypertension, dyslipidaemia, cerebrovascular disorders)
- respiratory deterioration (decreased pulmonary function, infections)
- gastrointestinal problems (GORD, dysphagia, chronic constipation)
- dental problems (gingivitis, unrecognised pathology)
- pain (often goes unrecognised)
- musculoskeletal problems (arthritis, contractures, impaired mobility, falls and fractures, osteoporosis)
- falls
- endocrine disorders (thyroid, diabetes, impact of oestrogen and testosterone reduction)
- malnutrition (undernutrition, high incidence of obesity, nutrient deficiencies, e.g., calcium)
- genitourinary problems (urinary incontinence, increase in UTIs)
- skin deterioration (skin thins and becomes paler, increased sunburn risk, wound healing slows, pressure area risk increases)
- thermoregulation deterioration (thinning skin, reduced sweat glands, usually more susceptible to cold)
- polypharmacy (long term medication use, unnecessary medications, medication reactions different in elderly people)

(Evenhuis et al, 2000; Therapeutic Guidelines, 2012).
In summary, a lifespan approach to health care for people with disabilities enables a proactive approach to the prevention, diagnosis and management of conditions that may exacerbate disability and ill health. Such an approach promotes longevity and enhances healthy living and ageing.

For further information see:

NSW CID. Adults – Signs of Illness

NSW CID. Ageing and Health

NSW Chronic Disease Management Program (Connecting Care in the Community)
[http://www0.health.nsw.gov.au/cdm/severe_chronic_disease_management_program.asp]

Community Packages (CommPacks)

Rehabilitation Research and Training Center on Ageing with Developmental Disabilities – Lifespan Health and Function
[http://www.rrtcadd.org/]

IASSID. Ageing and Intellectual Disabilities – Fact Sheet.

Therapeutic Guidelines (2012)

2.5 Disability and Causes of Death

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

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

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

The main causes of death include:
- respiratory diseases – mainly aspiration pneumonia and chronic lower respiratory diseases such as chronic lung disease
- heart diseases – mainly ischaemic heart disease
- cancers – mainly lung and bowel cancer
- digestive system diseases – includes volvulus, megacolon, and acute vascular intestinal disorders
- choking on food.

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

(NSW Ombudsman, 2013).

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

### 2.6 People with Disabilities, their Families and Carers

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

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

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

2.6.1 Lifelong Impact of Disability on Families

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

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

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

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


Department of Developmental Disability Neuropsychiatry, Faculty of Medicine, University of NSW. http://3dn.unsw.edu.au/


Supporting the Mental Health of Children and Adolescents with an Intellectual Disability.
http://www.schoollink.chw.edu.au/mh-id/


3, 4, 5 & 6 Nursing and Health Care Core Standards

The following sections are organised according to the four Nursing and Health Care Core Standards developed by regional senior practitioners and the Practice Leader – Nursing and Health Care. 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**
  - Health Assessment
  - Health Planning

- **Communication and Behaviour Support**
  - Communication
  - Behaviour Support

- **Working with People with Chronic and Complex Health Care Needs**
  - Health Care and Support
  - Teaching and Coaching
  - Advocacy and Co-ordination
  - Education, Research and Evaluation

- **Mealtime Management**
  - 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 disabilities, 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 ADHC’s knowledge translation programme.

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:

- ADHC 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 practitioners’ surgeries (GPs)
- residential/accommodation services
- community health services
- specialist teams
- hospitals
- nursing homes.
3. Person-Centred Health Care Assessments and the Development of Health Care Plans

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

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

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

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

(Adapted from National Ageing Research Institute, 2006).

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

3.1 Health Assessment

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

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

Assessment is considered the most important part of health care planning and delivery. If not undertaken comprehensively and thoroughly, or if the information is inaccurate, the health of people with intellectual disabilities will be further compromised.
Regular health assessments (sometimes called ‘health checks’) have been identified as the most effective way of achieving positive health gains. They are the key to the early detection and treatment of a wide range of actual health problems and threats to health. Research evidence supports annual health checks for people with intellectual disabilities for the following reasons:

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

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

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

3.1.1 Assessment Data

Health data may be broadly classified according to their source.

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

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

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

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

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

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

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

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

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

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

3.1.3 Health Care Assessment Tools

Numerous **assessment tools** are available to enable the systematic gathering and documentation of data for comprehensive or targeted assessment.
Some tools are **standardised** so that comparisons can be made between an individual and the population, e.g., developmental and cognitive assessment tools such as the Bayley Scales of Infant Development, the Griffiths Mental Developmental Scales, Wechsler Intelligence Scales, Stanford Binet Intelligence Scales.

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

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

Some accommodation and community services may have different health care planning processes or use different comprehensive health assessment tools. However, it is important that all processes and tools used address the areas of health concern set out in the CHAP and MBS tools. These areas of health concern are presented in the preceding Section 2 ‘Disability and Health’. You need good working familiarity with the health problems and threats in order to use an assessment tool effectively.
<table>
<thead>
<tr>
<th>Name</th>
<th>Description</th>
<th>Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare Benefits Schedule (MBS): Health Assessment for People with an Intellectual Disability</td>
<td>Time based (Items 701, 703, 705, 707)MBS assessments may be used with a person with intellectual disability. However, it is recommended that a long (705) or prolonged assessment (707) is used due to difficulties with recognising and reporting symptoms. The MBS assessment tool was designed for use with people with intellectual disability who require assistance with daily living activities. This tool allows GPs and Practice Nurses to comprehensively assess the physical, psychological and social functions of patients with intellectual disability and identify any medical intervention and preventive health care required.</td>
<td>MBS Health Assessment. DoHA Fact Sheet MBS Q&amp;A Annual Health Assessment NSW Council for Intellectual Disability Fact Sheet</td>
</tr>
<tr>
<td>The Comprehensive Health Assessment Program (CHAP)</td>
<td>CHAP was developed by the University of Queensland’s Centre for Intellectual and Developmental Disability. The assessment tool was designed to allow for improved identification and documentation of health status and needs of adults with an intellectual disability. CHAP is a two part assessment. The first section creates a comprehensive health history and is completed by the person and/or support people. The second part is completed by a health professional, i.e., the person’s GP or a Registered Nurse. ADHC has purchased the right under a licensing agreement to implement the CHAP in NGO and ADHC operated services. The CHAP is endorsed by ADHC as it was developed, tested and demonstrated to improve healthcare delivery to people with a disability in Australia. It has been validated in Australian studies. Use of CHAP is limited to services who pay for the licence. Research with GPs indicates that CHAP enhances diagnosis and communication. However, structural barriers related to: time, lack of support worker skills and lack of organisational comprehensive assessment and follow-up create problems (Lennox et al, 2013)</td>
<td>The Comprehensive Health Assessment Program. CHAP Brochure The Comprehensive Health Assessment Program-Version 11(ADHC intranet) New Medicare items to help you to provide health assessment for people with intellectual disability(ADHC intranet) NSW Council for Intellectual Disability Fact Sheet CHAP Report</td>
</tr>
<tr>
<td>Target or Problem Area</td>
<td>Assessment Tool</td>
<td>Description</td>
</tr>
<tr>
<td>------------------------</td>
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</tr>
<tr>
<td>PAIN</td>
<td>Pain Assessment Nursing Tool (PANT)</td>
<td>This tool was developed by disability nurses working at Hunter Residences (Stockton) and is designed to assist nurses in the identification, intervention and monitoring of pain experiences for people with intellectual disability who are not adequately served by existing pain assessment systems. The package consists of three sections: 1. Clinical Indicators of Pain Checklist 2. Nursing Physical Assessment 3. Behaviour Monitoring/Intervention Tool</td>
</tr>
<tr>
<td>Abbey Pain Scale</td>
<td>Abbey Pain Scale</td>
<td>The Abbey Pain Scale was developed to allow for the measurement of pain in people with dementia who cannot verbalise. It is an assessment tool employed as part of an overall pain management plan. It is used to assess pain in people who have with severe cognitive impairment and difficulties communicating. It can be used by people with no nursing training.</td>
</tr>
<tr>
<td>PAINAD</td>
<td>The Pain Assessment in Advanced Dementia (PAINAD) was developed to assess pain in people who are cognitively impaired, non-communicative, or suffering from dementia and unable to use self report methods to describe pain. Variables recorded include: breathing, vocalisation, facial expression and body language.</td>
<td>Pain Assessment in Advanced Dementia (PAINAD) Scale Pain Assessment Tool Guidelines for use: PAINAD PAINAD Instructions</td>
</tr>
<tr>
<td>Target or Problem Area</td>
<td>Assessment Tool</td>
<td>Description</td>
</tr>
<tr>
<td>--------------------------------</td>
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<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>DISTRESS</td>
<td>DisDAT</td>
<td>Disability distress assessment tool. Identifies distress cues in people with severe communication impairments. Website includes background information, instructions and tool.</td>
</tr>
</tbody>
</table>
| NEUROLOGICAL                   | Glasgow Coma Scale (GCS) | Tool to assess and quantify the level of consciousness of a person. Three types of responses are assessed and recorded to achieve a maximum GCS score of 15  
  1. Eye opening response  
  2. Verbal response  
  3. Motor response  
The Paediatric Glasgow Coma Scale is a modified version that may be useful for people with intellectual disabilities. | Glasgow Coma Scale  
Rainbow Rehabilitation Center-Glasgow Coma Scales (Adult & Paediatric)  
Modified Glasgow Coma Scale for Infants and Children  
RPA ICU GCS Procedure                                                                                                           |
| RESPIRATORY                    | Various Respiratory Assessment Guides | Respiratory assessment addresses respiratory status and also provides information related to other systems, e.g., cardiovascular, neurological systems. Alteration in breathing is often the first vital sign observed when a person's health is deteriorating. | Quick Respiratory Assessment & Documentation Guide  
Respiratory Status & Perfusion Assessment  
Respiratory Systems Case Study  
Nursing Times Respiratory Assessment                                                                                           |
<p>| NUTRITION and SWALLOWING       | Nutrition and Swallowing Risk | The Nutrition and Swallowing Risk Checklist screens people for difficulties related to nutrition and swallowing. It was developed to                                                                 | Nutrition &amp; Swallowing Checklist (ADHC intranet)                                                                         |</p>
<table>
<thead>
<tr>
<th>Target or Problem Area</th>
<th>Assessment Tool</th>
<th>Description</th>
<th>References and Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>BOWELS</td>
<td>The Bristol Stool Chart classifies stool form into seven categories to indicate a range from constipation to diarrhoea. Stool type is affected by bowel transit time, so the classification can be an indicator of digestive health.</td>
<td>ADHC Bowel Chart (ADHC intranet) Bristol Stool Chart</td>
<td></td>
</tr>
<tr>
<td>Various – Bowel Screening, Assessment &amp; Management</td>
<td>Documents identifying and evaluating many useful bowel screening and assessment tools.</td>
<td>Bowel Screening, Assessment &amp; Management Refining Continence Measurement Tools</td>
<td></td>
</tr>
<tr>
<td>Community Nursing Bowel Assessment</td>
<td>Enable NSW bowel assessment tool.</td>
<td>Community Nursing Bowel Assessment, Enable NSW</td>
<td></td>
</tr>
<tr>
<td>WEIGHT</td>
<td>ADHC weight chart is designed to keep an ongoing record of a person’s weight. Weight fluctuations are noted on the chart and the reasons for weight changes are assessed.</td>
<td>ADHC Weight Chart Included in ADHC Health Care: Policy &amp; Procedures</td>
<td></td>
</tr>
<tr>
<td>BMI Calculator</td>
<td>Body Mass Index (BMI) provides an estimate of total body fat.</td>
<td>BMI Calculator BMI Calculator, NSW Health</td>
<td></td>
</tr>
<tr>
<td>SLEEP</td>
<td>The BEARS assessment tool assesses children from 2 to 18 years old for major sleep disorders. The assessment focuses</td>
<td>The Bears Sleep Screening Tool</td>
<td></td>
</tr>
<tr>
<td>Target or Problem Area</td>
<td>Assessment Tool</td>
<td>Description</td>
<td>References and Additional Information</td>
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</tr>
<tr>
<td><strong>Sleep Basics Information</strong></td>
<td>Sleep Basics for Health Promotion</td>
<td>Presentation highlighting sleep hygiene and assessment.</td>
<td></td>
</tr>
<tr>
<td><strong>Sleep Assessment Resources</strong></td>
<td>Sleep Assessment &amp; Management</td>
<td>Website that links to various sleep assessment information and tools.</td>
<td></td>
</tr>
<tr>
<td><strong>The Epworth Sleepiness Scale (ESS)</strong></td>
<td>The Epworth Sleepiness Scale</td>
<td>The Epworth Sleepiness Scale is an assessment used to determine a person’s level of daytime sleepiness.</td>
<td></td>
</tr>
<tr>
<td><strong>Sleep Apnoea Screening Tool</strong></td>
<td>Sleep Apnoea Screening Tool</td>
<td>Uses ESS to screen for obstructive sleep apnoea.</td>
<td></td>
</tr>
<tr>
<td><strong>SUPPORT NEEDS</strong></td>
<td>Productivity Commission, Disability Care and Support, Appendix B</td>
<td>Excellent summaries and descriptions of numerous assessments for support in Appendix B. Includes FIM, D-</td>
<td></td>
</tr>
<tr>
<td><strong>Service Need Assessment Profile (SNAP)</strong></td>
<td>SNAP tool information</td>
<td>SNAP was designed in Australia to measure the support needs of a person with a disability. The output of this assessment is an individual support plan which outlines the level of support the person will need e.g. in home support services or overnight care.</td>
<td></td>
</tr>
<tr>
<td><strong>I-CAN</strong></td>
<td>Productivity Commission, Disability Care and Support, Appendix B I-CAN tool information</td>
<td>I-CAN is an Australian system for identifying and classifying a person’s support needs based on the ICF framework.</td>
<td></td>
</tr>
<tr>
<td><strong>Productivity Commission</strong></td>
<td>Productivity Commission, Disability Care and Support, Appendix B</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Target or Problem Area</td>
<td>Assessment Tool</td>
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<td>References and Additional Information</td>
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</tr>
<tr>
<td><strong>FAMILIES</strong></td>
<td>Report No. 54</td>
<td>START, I-CAN, SIS, ICAP, SNAP, as well as sample forms.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>CPCHILD©</td>
<td>Caregiver Priorities &amp; Child Health Index of Life with Disabilities Questionnaire, CPCHILD is a reliable and valid measure of caregivers’ perspectives on the health status, comfort, wellbeing, and ease of caregiving of children with severe developmental disabilities. It is also a useful proxy measure of the health related quality of life of these children</td>
<td>CPCHILD® Questionnaire</td>
</tr>
<tr>
<td><strong>URINARY INCONTINENCE</strong></td>
<td>Revised Urinary Incontinence Scale (RUIS)</td>
<td>The RUIS is a reliable five step assessment scale used to measure urinary incontinence in a person and monitor outcomes following treatment. Its use for people with intellectual disability is limited.</td>
<td>Tools for Assessing and Monitoring Urinary Incontinence: The Revised Urinary Incontinence Scale (RUIS) Refining Continence Measurement Tools</td>
</tr>
<tr>
<td><strong>EPILEPSY</strong></td>
<td>Epilepsy Management Plan</td>
<td>The purpose of this document is to minimise risk to the person and to plan a response to a critical event e.g. a prolonged seizure. Includes assessment processes.</td>
<td>Epilepsy Management Plan Epilepsy Policy and Procedures</td>
</tr>
<tr>
<td></td>
<td>Epilepsy Self-Assessment Tool for Service Providers</td>
<td>Brief assessment that addresses epilepsy management is services.</td>
<td>Epilepsy Self-Assessment Tool for Service Providers</td>
</tr>
<tr>
<td></td>
<td>Nursing Management of Seizures</td>
<td>Guidelines that include nursing assessment.</td>
<td>Nursing Management of Seizures</td>
</tr>
<tr>
<td>Target or Problem Area</td>
<td>Assessment Tool</td>
<td>Description</td>
<td>References and Additional Information</td>
</tr>
<tr>
<td>------------------------</td>
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<td>----------------------------------------</td>
</tr>
</tbody>
</table>
| **Epilepsy Risk Assessments** | Risk assessment tools for people with epilepsy:  
- Individual  
- Safety at home  
- Safety outside home | Three Epilepsy Risk Assessment Tools |
| **FUNCTION** | Mobility & Functional Assessment Tools | Summaries of various tools to assess mobility and function | Functional & Mobility Tools Overview |
| **PRESSURE AREA RISK** | The Waterlow Scale | The Waterlow Scale estimates the risk of pressure sore development. | Waterlow Pressure Sore Prevention/Treatment Policy  
The Waterlow Scale Information and Tools |
| | The Braden Scale | The Braden Scale assesses the risk of pressure sore development. | Braden Scale for Predicting Pressure Sore Risk |
| **DEVELOPMENT** | Developmental Milestones | Developmental Milestones and the Early years Learning Framework is a useful source of information regarding expected development from birth – 5 years | Developmental Milestones |
| | Developmental Checklist | Developmental Checklist. Birth – 13+ years  
*Note:* Knowledge of developmental milestones allows a quick developmental screen. | Developmental Checklist |
<p>| | Developmental Screening and Consultation | Document that provides detailed information about the range | Developmental Screening and Consultation |</p>
<table>
<thead>
<tr>
<th>Target or Problem Area</th>
<th>Assessment Tool</th>
<th>Description</th>
<th>References and Additional Information</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MENTAL HEALTH</strong></td>
<td>Anxiety and Depression Checklist (K10)</td>
<td><em>beyondblue</em> Depression and Anxiety Checklist is a quick and simple screening tool. It has limited application with people with intellectual disabilities but its use can be facilitated for people with milder levels of ID.</td>
<td><em>Anxiety and Depression Checklist (K10), beyondblue</em></td>
</tr>
<tr>
<td></td>
<td>Mental Health Nursing of Adults with Learning Disability</td>
<td>RCN (UK) Guidance document that has information regarding mental health and intellectual disability, including extensive information about assessment and suitable tools.</td>
<td><em>Mental Health Assessment Information</em></td>
</tr>
<tr>
<td></td>
<td>Mental State Examination (MSE)</td>
<td>A MSE is a systematic appraisal of appearance, behaviour, mental functioning, and overall appearance of a person. It provides a ‘snapshot’ of a person’s psychological functioning.</td>
<td><em>Mental State Examination (MSE) Also included in RCN document; Mental Health Assessment Information</em></td>
</tr>
<tr>
<td></td>
<td>Assessment Instruments</td>
<td>of screening and assessment instruments available.</td>
<td><em>Assessment Instruments</em></td>
</tr>
</tbody>
</table>
3.1.4 Doing Health Assessments

Using health assessment tools involves many techniques for gathering information:
- interview, observation, examination, tests, research
- and with input from many sources:
  - individuals, families, carers, support staff, teachers, health professionals

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

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

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

**Important Message**

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

It is also important to work collaboratively with support staff who are your eyes and ears because they work closely with people with intellectual disabilities and often know them well. Encourage support staff to observe carefully and to document and report all changes in the people for whom you are responsible. Although, as a Registered Nurse, you will interpret the observations of support staff, such observations are essential for effective health care.
3.2 Health Planning

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

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

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

- assessment
- diagnosis
- planning
- implementing
- evaluating

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

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

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

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

3.2.1 Health Care Plans and Nurses

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

Traditionally, nurses working in direct care with people with intellectual disabilities have been responsible for care plans that consider whole of life and all daily living issues. However, with changing philosophies and models of service that emphasise social models of disability and person-centred approaches, nurses now focus on health issues.

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

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

It is important that the health care plan considers and reflects multiple specialised assessments, the person’s life, and living and activity contexts. The health care plan must be flexible enough for people with disabilities to participate in and ‘live life’, rather than focusing only on health problems. The health care plan should enhance living and wellbeing.

3.2.2 Comprehensive Health Care Plans: Development, Review and Evaluation

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

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

Comprehensive health care plans are developed to reflect information gathered by comprehensive health assessment in the categories presented in Section 3.1.2.
A comprehensive health care plan includes the following components:

<table>
<thead>
<tr>
<th>Component</th>
<th>Comments and Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>INFORMATION about the PERSON</td>
<td>Name, date of birth, address, religion, ethnicity, significant others, person responsible and contact details (when relevant), Medicare number, health care card number, pension number (when relevant), GP details</td>
</tr>
<tr>
<td>ALLERGIES</td>
<td>Examples: Chlorhexidine – severe contact dermatitis.</td>
</tr>
<tr>
<td>RISKS and ALERTS</td>
<td>Examples: Seizures – never to be alone near water. Pressure – prone to pressure sores on feet. Protect feet, limit pressure (use blanket cradle). Include any potential for injury to self or others.</td>
</tr>
<tr>
<td>PEOPLE INVOLVED</td>
<td>Might include health professionals, key worker, service manager, school, teachers, lifestyle educators</td>
</tr>
<tr>
<td>MEDICATIONS</td>
<td>Dose. Intended action. Common adverse effects.</td>
</tr>
<tr>
<td>HEALTH ISSUES</td>
<td>Actual and potential (health problems and threats to health). Examples: 1. All physical and psychological problems, e.g., pain; anxiety 2. Functional problems, e.g., immobility 3. Growth &amp; development, e.g., underweight (156cm X 44kg = BMI 18) 4. Social and lifestyle problems and threats, e.g., becomes anxious in new situations</td>
</tr>
<tr>
<td>GOALS</td>
<td>For each health issue. Examples: 1. Pain will be controlled. Anxiety will be decreased. 2. Contractures will be prevented 3. Goal weight of 46kg will be achieved (by ‘date’) 4. Anxiety in new situations will be reduced</td>
</tr>
<tr>
<td>RESPONSIBILITY</td>
<td>Who is responsible for actions</td>
</tr>
<tr>
<td>EVALUATION</td>
<td>Specify when (date) and who is responsible for evaluation</td>
</tr>
<tr>
<td>COMMENTS</td>
<td>Provides area for extra instructions, updating, reviews for specific health problems, etc.</td>
</tr>
<tr>
<td>APPOINTMENTS, TESTS, etc.</td>
<td>Include: Identify when regular appointments with GP, specialists, etc. are due. Dates of regular blood tests, e.g., AED levels, etc. Minimise radiation and venipuncture.</td>
</tr>
</tbody>
</table>
**ATTACHMENTS**
Attach all relevant assessments, plans and protocols.  
* Might include: assessments by Psychologist, Physiotherapist, Speech Pathologist, Dietitian, OT  
* Might include: Plans/protocols related to epilepsy, diabetes, communication, positive behaviour support, foot care, eating and drinking, nutrition, positioning, exercise, risks (and many more).

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

**Example:**
**EXTRACT from a SAMPLE COMPREHENSIVE HEALTH CARE PLAN for Person in Supported Accommodation**

<table>
<thead>
<tr>
<th>HEALTH ISSUE</th>
<th>GOAL</th>
<th>ACTION</th>
<th>RESPONSIBILITY</th>
<th>EVALUATION</th>
<th>COMMENTS</th>
</tr>
</thead>
<tbody>
<tr>
<td>WEIGHT</td>
<td>Goal weight 46kg will be achieved</td>
<td>Follow Nutrition Plan. Include supplements.</td>
<td>Support staff. House manager</td>
<td>Dietitian – review 6 months (date)</td>
<td>Monitor with fortnightly weighs. Report any weight loss to RN.</td>
</tr>
<tr>
<td>ANXIETY</td>
<td>Anxiety in new situations will be reduced</td>
<td>Prepare for new social situations gently. Introduce people one at a time. Keep noise levels down.</td>
<td>Support staff. House manager</td>
<td>Psychologist – review 12 months (date)</td>
<td>Report increased anxiety to RN.</td>
</tr>
</tbody>
</table>

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

Formal review and evaluation should occur at regular intervals, at least annually, unless warranted more frequently. It is a good idea to link this review with the annual GP assessment and person-centred planning processes.
Health problems must be evaluated against person’s health goals. If goals are not met, then interventions must be reviewed. For example: if hypertension is an identified health problem, and the goal of BP being maintained below 130/85 is not being met, then interventions must be reviewed. This might include an appointment with GP to review medication, a review of weight goals and management, and a review of exercise goals and activity.

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

This document may be useful for staff in other services and is openly available.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

<table>
<thead>
<tr>
<th><strong>Example:</strong> PLANNING FOR AN APPOINTMENT WITH A NEUROLOGIST</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neurologist will want:</td>
</tr>
<tr>
<td>Referral</td>
</tr>
<tr>
<td>Payment (unless bulk billed)</td>
</tr>
<tr>
<td>Cards – Medicare, Pension or Health Care Card</td>
</tr>
<tr>
<td><em>My Health Record</em> (red book) if available</td>
</tr>
<tr>
<td>Current medications, and history of all previous AEDs (anti-epileptic drugs)</td>
</tr>
<tr>
<td>Previous Neurologist’s reports (if not regular)</td>
</tr>
<tr>
<td>Person with disability may need (will depend on level of support required)</td>
</tr>
<tr>
<td>Transport</td>
</tr>
<tr>
<td>Money – parking, drinks, etc.</td>
</tr>
<tr>
<td>Food, drinks, eating and drinking requirements (supplements, thickener, utensils, etc.)</td>
</tr>
<tr>
<td>Change of clothing</td>
</tr>
</tbody>
</table>
Because of the interplay of epilepsy with female hormones, osteoporosis (2° to AEDs), liver function (2° to AEDs) and electrolytes (2° to AEDs), the following will also be required:

- gynaecologist reports ( &/or menstruation charts)
- endocrinologist reports
- recent DEXA (performed every two years)
- recent pathology results (vitamin D, LFTs, electrolytes)
- AED results (sometimes)

- Reason for current visit.

**For further information see:**

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

**Better Start for Children with Disability**

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

*The Appendix includes a list of specialist clinics and services.*

**Centre for Disability Studies – Clinical Services.**

**NSW Council for Intellectual Disability – Fact Sheets**
Including:

**Personal Health Records**

**Going to the Doctor**

**Finding the Right Doctor**

**Annual Health Assessments**

**Specialised Intellectual Disability Health Services**
3.2.4 Planning for Hospitalisation

NSW Health and ADHC have endorsed the following joint guideline:

**NSW Health and Ageing Disability and Home Care Joint Guideline: supporting residents of ADHC operated and funded accommodation supported services who present to a NSW Public Hospital**


The Joint Guideline incorporates the NSW Health policy:

and ADHC’s:

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

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

Useful comprehensive **Hospital Support Plans** are included in the Appendix of the Joint Guideline.
Following is an example that highlights issues nurses need to consider when planning for hospital admission of a person with intellectual disability.

**Example: PLANNING for HOSPITAL ADMISSION**

- **Talk with hospital staff** (try to include family member) BEFORE the admission – preferably NUM of intended ward (this can change!). **Discuss:**
  - health plans – including any palliative or future care plans, communication plans, hospital support plan, etc.
  - equipment requirements – manual handling, electric bed, bed cradle, air mattress, hoist and sling, etc.
  - management – pressure, feeding regimes, eating and drinking, etc.
  - responsibilities – personal care, medications, etc.
  - any risks and safety issues.
- Leave copies of all **plans**. Also take another set at admission.
- **Attend Pre-Admission Clinic** (preferably with person responsible). All of the above might be addressed at this time. Discuss issues related to induction of anaesthesia, recovery ward, risks, signing of consents. Clarify fasting requirements, cessation of any meds prior (e.g., blood thinners), what meds to take, etc.
- Prepare all necessary **personal items** and clothing needed in hospital. **Examples:** medications, communication aids, continence aids, AFOs, sleep inserts, hearing aids, glasses, formula, thickener, specialised utensils, significant possessions (for security and distraction).
- **Escort** person with disability to hospital (or meet there).
- **Take relevant files, Medicare and Health Care cards, My Health Record** (when available)
- Go to **ward** with person with disability. Try to see the Nurse Manager (often NUM). You may have to go through all this again!
- Identify **unique management strategies** that can be implemented by hospital staff to work effectively with person with disability. **Examples:** Joe needs the framed photo of his mother with him to settle. Always introduce yourself and smile before saying anything to Susan.
- Negotiate **support** for person during hospital stay.
- Ascertain how often you need to **visit**.
- Assess need for a **case conference** prior to discharge. Arrange to take place a couple days before discharge with all key people. Ensure person with a disability is at centre of decision-making.
- Ensure person with a disability **NEVER leaves without a completed discharge summary**.
- **Follow up** discharge summary and any changes to medications and health care plans. Ensure recommendations and changes are documented.

**Note:**
For an **emergency hospital admission**, services generally have relevant hospital transfer documentation. If the person is to stay in the hospital, then the above points apply (with the exception of the pre-admission clinic).

See the **Joint Guideline** for detail.

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

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

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

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

Many services have developed strategies and protocols to make the hospital experience less stressful for people with intellectual disabilities and staff who work with them.

For example: Northern Sydney Central Coast Health has developed the ‘Top 5’ protocol [http://www.nscchealth.nsw.gov.au/carersupport/cc/Top5.shtml] to support residents of Central Coast group homes. The protocol identifies five strategies that will help settle, calm, and care for a person with cognitive impairment. These are recorded on form and included in hospital documentation. See website for resources.

Identify any strategies or protocols used in your work environment.

For further information see:

Good to Great eLearning Program ELMO. Hospitalisation Guideline Module

Login details:
Username: adhc
Password: goodtogreat

The Hospital Communication Book

Clear Communication People. Health Communication Resources.
[http://www.communicationpeople.co.uk/subjects/health/]

3.2.5 Planning for Transition from Paediatric Services to Adult Services

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

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

(Department of Health, 2006, p.14)

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

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

For further information see:

The NSW Agency for Clinical Innovation (ACI) Transition Care Network

Transition Framework for NSW

References on Transition – a huge reading resource.


(Sources used for Sections 3.2 – 3.2.5: Balandin, Hemsley, Sigafoos & Green, 2007; Buzio, Morgan & Blount, 2002; Goddard, Davidson, Daly & Mackey, 2008; Hemsey, Balandin & Togher, 2007 & 2008; Hemsley et al., 2001; Iacono & Davis, 2003; Wallace & Beange, 2008; Webber, Bowers & Bigby, 2010)
### 3.3 What does this mean for your nursing practice?

**Practice Points:**
**PERSON-CENTRED HEALTH CARE ASSESSMENTS**
and the **DEVELOPMENT of HEALTH CARE PLANS**

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


4. Communication and Behaviour Support

Communication and behaviour support are addressed together as a Nursing Core Standard because of the links between communication and people’s behaviour. There is ample evidence to support a significant link between communication difficulties and challenging behaviour.

4.1 Communication

Communication is an interactive process between two or more people. It is usually described as the exchange of information, ideas or meanings between people. For this exchange to occur, we need to be able to **express** (send) and **receive** messages using a shared system of symbols, signs and behaviour.

Information and ideas are usually exchanged in language which may be in:
- words – spoken, written, signed
- pictures

These are symbols for the actual information and ideas. For example, the word ‘truck’ is not a truck. A picture of a truck is not a truck. They are symbols for a truck that convey a shared meaning.

Words alone (or pictures) do not always convey full meaning, but are added to by:
- context
- bodily movements
- gestures
- facial expressions
- tone of voice
- behaviour.

**Expressive communication** refers to the ways we send messages to other people. Usually we do this by putting words together in speech, writing or signing to convey information, thoughts and feelings – this is called expressive language. It also includes body language, voice and face expressions and the use of augmentative and alternative communication (AAC) systems such as symbol boards and voice output communication devices.

**Receptive communication (comprehension)** refers to receiving and understanding messages from others. Receptive language refers to the ability to receive, process, comprehend and integrate spoken language. Understanding may be enhanced when words are accompanied by body language and other cues such as pictures.

It is important not to reduce communication simply to messages sent and received. Rather, communication is an **interactive process** that is the primary means for people doing things together. Meanings evolve and change according to interpretations (and misinterpretations), changed circumstances and because of individuals involved. We all bring different views and experiences to any interaction.
and therefore individuals might interpret things very differently. We also read things into what people say based on our knowledge of them.

4.1.1 Language Development

Language and communication are extremely complex processes involving the senses and brain. Not only do we need to see, hear and feel messages, but also interpret and process the messages so they may be understood. This processing occurs in the brain and develops from infancy. Such brain development involves the processing and interpretation of massive amounts of sensory input from the body and the environment. As infants develop, reflexive, disorganised and haphazard movements and sounds become more organised and purposeful.

Many brain impairments interfere with this processing and integration, so input is not perceived normally. For such people, input does not make sense and may cause confusion and distress. People with intellectual disabilities have brain impairments and many have accompanying sensory impairments (vision, hearing, touch, proprioceptive) that interfere with language development. People with profound and multiple disabilities have obvious problems with language. However, many people with milder levels of disability also experience problems with the understanding and expression of language.

It is vital to understand that people with intellectual disabilities have impaired communication – this ranges from mild and subtle to severe and obvious.

4.1.1.1 Levels of Communication

Communication development goes through many stages that can be broadly broken down to three levels: unintentional, intentional, and symbolic.

Unintentional (or preintentional) communication has the following characteristics:
- the person is not deliberately communicating
- facial expressions, eye movements, body movements, vocalisations are non-specific means of communication
- person does not use communication as a tool to obtain a goal
- communication is not directed at a listener
- listener needs to figure out what the message is
- in normal development, occurs from birth – 6 months.

Intentional communication has the following characteristics:
- the person is deliberately communicating to a listener
- communication becomes more specific – pointing, eye contact, guiding
- the person uses communication as a tool to obtain a goal
- more people can understand the message, but it still needs some familiarity and interpretation
- in normal development, occurs around 6 – 12 months.

Symbolic communication has the following characteristics:
- the person is deliberately communicating a message to a listener
• the person uses a formal symbol system (language) to communicate their message – speech, words, signing, pictures, etc.
• the message is readily understood by those familiar with the language
• in normal development, begins around 12 months. (After Bloomberg & West, 2009)

As children acquire language, they are able to say firstly, what they want, and later, what they mean. Many people with severe and profound intellectual disabilities may never develop the ability to even signal their intentions. Even those who have some capacity for intentional communication may have difficulties because of physical or sensory problems that make their signals hard to recognise. For example, intentional eye gaze or nodding the head for yes might be beyond the motor control of someone with cerebral palsy.

The classification is useful when considering the communication capacities of people with disabilities you work with. A Speech Pathologist may break down these basic levels for further identification of communication competencies during assessment. In this way communication strategies can be targeted specifically for individuals.

People with profound and complex disabilities are dependent on others to interpret their needs and choices through observation, assessment and getting to know them. Their communication is expressed on their faces, and through vocal sounds, body movements and behaviour. By getting to know people with profound disabilities, we can develop some effective ways to respond and communicate.

4.1.2 Communication Plans and Profiles
Following assessment Speech Pathologists develop Communication Plans that identify strategies and systems to support individuals. These plans need to be implemented in a consistent manner by all people working with people with disabilities. Communication Plans should be reviewed annually for children and every second year for adults. Review should be considered if there is significant change in a person’s behaviour.

Communication Profiles are useful tools to provide quick snapshots of individuals’ communication such as levels of understanding and the expression of pain and emotional states. A communication profile can be particularly convenient when support is provided in an unfamiliar environment, e.g., during hospitalisation. For a useful example the template below.


4.1.3 Augmentative and Alternative Communication (AAC)
Augmentative and Alternative Communication (AAC) strategies provide communication options and support for people with complex communication needs. AAC may be used to support an individual’s understanding of communication, as well as to promote expressive communication.
Augmentative Communication strategies support existing speech. Strategies include gestures, eye pointing (gaze) and body language.

Alternative Communication strategies are designed to replace speech when normal speech is not possible. Strategies include pointing to symbols, signing and spelling.

AAC devices range from simple communication boards to symbolic picture systems to electronic devices. Technology is rapidly evolving to support AAC with apps for smart phones and tablet computers. Speech Pathologists assess and formulate appropriate systems for individuals.

For further information see:
Novita AAC
Speech Pathology Australia Position Paper AAC
The Hospital Communication Book
The Clear Communication People, Health Communication Resources
[http://www.communicationpeople.co.uk/subjects/health/]
ADHC (2013) Speech Pathology Practice Package
[Available to ADHC staff on intranet.]

4.1.4 Communicating with People with Intellectual Disabilities
The person with a disability must remain the primary focus of the communication even when accompanied by a communication partner such as family member, carer, support worker, or advocate. Following are some useful strategies.

To enhance receptive communication:
- speak slowly and use pauses to allow person to process words
- try and present only one concept at a time – too many concepts are muddling
- ask one question at a time – provide time for reply
- use short, clear sentences – avoid complex and technical words and jargon
- if necessary to obtain history from a carer, maintain focus on the person through eye contact, touch and body language
- use visual cues, such as objects, pictures, diagrams, to get you message across
- if a communication devise is used, ensure access, read the instructions, and use jointly with the person

To enhance expressive communication:
- provide adequate time for person to formulate responses and questions
- explore statements and questions to ensure you understand the person’s meaning
- use visual cues, such as objects, pictures, diagrams, to enhance meaning
- note expression and body language to interpret meaning and explore if necessary

Never pretend to understand. Use exploratory techniques clarify meanings. If you still don’t understand, then apologise.

When working with people who cannot communicate intentionally, observe facial expression, body language and behaviour. Even though it is necessary to communicate with accompanying carer, the person with a disability must retain a central place in the conversation through eye contact, body language and touch.

**For further information see:**
idmh e-Learning. ID and Mental Health UNSW. Communication Module

### 4.1.5 Communicating with People with Sensory Impairments

Many people with intellectual disabilities have sensory impairments related to **vision** and/or **hearing**. These range from total loss or lack of development of the senses, such as in cortical blindness or sensorineural hearing loss, through a continuum of problems that reduce hearing or visual acuity and result in low hearing or vision.

Vision and hearing impairments have a major impact on communication. Impairments that inhibit the development of sight and/or hearing, such as congenital cortical visual impairment or congenital sensorineural hearing loss, cause the greatest problems with the development of communication.

Some vision and hearing impairments are responsive to correction with glasses or hearing aids, but many are not. Intellectual disability compounds the impact of sensory impairments on communication development and ability. Cochlear implant technology is not available to people with intellectual disabilities due to lack of cognitive capacity to adapt.

**Deafblindness** is the term used when people have combined hearing and vision loss or impairment. It very isolating because it significantly affects communication, socialisation and daily living.

**Sensory integration disorders** are an outcome of developmental sensory impairments. These may result in:
- sensory seeking
- under responsiveness to sensory stimulation
- over responsiveness to sensory stimulation (e.g., tactile defensiveness).

Such responses may be interpreted as stereotypic and/or challenging behaviour. The interpretation of these responses is particularly challenging when
communicating. For example, withdrawal from touch might be interpreted as ‘go away’ or ‘I don’t want that’. However, such withdrawal may be tactile defensiveness. Various communication strategies are used with people with vision or hearing impairments or who are Deafblind. These include:

- speech
- oral/aural communication
- various forms of sign language, including tactile
- Deafblind fingerspelling
- alternative and augmentative communication (AAC)
- print/Braille
- sensory integration therapy

However, the use of some strategies is limited with people with intellectual disability.

Sensory integration activities are the most effective strategies when communicating with people with severe disabilities and sensory impairments. In general, deeper touch is more acceptable than light touch. Getting to know the person is vital – families and carers (including support staff) are the best sources for the interpretation of communication.

Speech Pathologists and Occupational Therapists assess and develop plans for people with sensory impairments.

For further information see:

Royal Institute for Deaf and Blind Children
[http://www.ridbc.org.au/]

DeafBlind Association (NSW)
[http://www.dbansw.org.au/]

Australian DeafBlind Council (ADBC)

Cortical Visual Impairment
[http://www.childrenshospital.org/az/Site2100/mainpageS2100P1.html]

Australian Hearing

Sensory Integration Activities
[http://www.ot-mom-learning-activities.com/sensory-integration-activities.html]

Sensory Integration and Sensory Motor Activities (Texas School for the Blind and Visually Impaired)

Sensory Integration (National Consortium on Deaf-Blindness)
[http://old.nationaldb.org/ISSelectedTopics.php?topicCatID=864]

ADHC (2013) Speech Pathology Practice Package
[Available to ADHC staff on intranet]
4.1.6 Communication Between Health Professionals, People with Disabilities, their Families and Carers, Schools, Day Options

Effective communication between health professionals, people with disabilities, their families and carers, schools and day options is essential. Communication should always be supported by written information that is evidence-based and tailored to an individual’s needs. All support, and the information that accompanies it, should be culturally appropriate. It should also be provided in formats accessible to people with specific needs such as sensory and cognitive impairments.

The notion of **partnerships** is essential to effective communication between all parties. This means that people with disabilities and their families share power, knowledge, and information. Professionals recognise that people with disabilities and their families hold important knowledge about their own needs, and about how best to meet them. With constructive communication, working alliances are created at both interpersonal and practical levels.

Nurses play an important role in:
- facilitating partnerships
- interpreting health information for people with disabilities, their families, carers, support workers, teachers and program co-ordinators
- co-ordinating health information, advice and recommendations
- liaising with GPs, specialists, dentists, and allied health professionals about complex health issues
- following up on health actions recommended by GPs and other health professionals
- providing support to people with disabilities, their families, carers, and support workers during complex medical consultations. This includes interpreting information and seeking further explanations and advice when necessary.

For further information see:

4.1.7 Communicating with Families of People with Disabilities

Families of people with disabilities, especially parents, have often experienced negativity when dealing with health professionals and health systems. They often experience ongoing grief, stress and anxiety related to practical and emotional difficulties encountered because of their child’s disability. Communication may be affected because of negative experiences, misunderstandings, and ongoing anxiety and distress. Many families struggle to cope. When communicating with families, it is important to remember that they know their child better than other people and are the experts in care and support.

Older parents with adult children have likely experienced a lifetime of distress. Many experience anxiety related to the future wellbeing of their adult children.
When working with families, nursing roles include:

- recognition of the impact of disability on parents and families
- active and non-judgemental listening, openness and honesty, open-ended questions
- working with families as partners
- promoting family-centred support
- referral to relevant services, including counselling if necessary
- advocacy for people with disabilities and their families
- enabling others to understand patterns of ability and difficulty, along with implications for learning and living.

For further information see:

Raising Children Network: Children with Disability

Raising Children Network: Communicating with Parents
[http://raisingchildren.net.au/articles/communicating_with_parents_the Basics.html/context/531]

Parent Line 1300 1300 52 Parent Line: Special Needs

ADHC: Older Parent Carers

4.1.8 Communication and Behaviour

Communication is the way we learn, make choices and become independent. It is the way we express our feelings, thoughts and emotions. It is the way we make sense of the world around us. Communication is the means by which we relate to others, make friends, live meaningful lives and develop as people.

Shared communication is fundamental to being included in a society. Our society expects everyone to speak, understand, read and write as the main forms of communication. Lack of common language leads to misunderstanding, mistrust and segregation. People with intellectual disabilities have problems with communication because of cognitive impairments. Sensory impairments further complicate the situation. People with profound and complex disabilities are not able to communicate in the usual manner.

Lack of effective communication leads to frustration. Frustration leads to withdrawal or anger and aggression against self or others. This is seen as ‘challenging behaviour’ and may lead to further exclusion. People with profound disabilities are dependent on others to interpret their needs and choices through observing and responding to their communicative behaviour.

(Sources used for Sections 4.1 – 4.1.8: ADHC, 2012; Balandin, 2002; Baladinet al, 2007; Ballin & Baladin, 2007; Bloomberg & West, 2009; Buzio, Morgan & Blount, 2002; CDDH, 2008; Ellis, Sherwin & van Dam, 2011; Grove et al, 2000; Hemsleyet al, 2001; Iacano et al, 2009; Kearney & Griffin, 2002; King et al, 1999; Mencap, undated; Tadema & Vsalcamp, 2010; Therapeutic Guidelines, 2012; Whittington et al, 2013).
4.2 Behaviour Support

Behaviour is a form of communication. For example, crying behaviour might be a way of communicating hunger, loneliness, pain, discomfort, frustration, grief, sadness. Reaching for a cup might be a way of communicating “I'm thirsty” or “I want to see how this object feels” or “I like the bright colour of this thing” or “I want to throw this cup”. Behaviours perceived as challenging also serve a communicative function. In this section, we look at the relationship between challenging behaviour and communication, and our role as nurses in the assessment and management of challenging behavior.

4.2.1 Challenging Behaviour

Emerson and Einfeld (2011, p.7) define challenging behaviour as:

\[ \text{...culturally abnormal behaviour...} \]
\[ \text{of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or} \]
\[ \text{behaviour that is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities.} \]

The ADHC Behaviour Support Policy (revised 2012) states the following:

Any behaviour displayed by a person which is considered challenging or inappropriate by others, or which gives rise to reasonable concern, may be considered as challenging. However, the use of the term challenging should be understood in terms of the social context in which behaviour occurs, rather than a symptom of individual pathology.

Often the Service User who presents with challenging behaviour is considered to be challenging as a result of their behaviour. However, challenging behaviour is a social construct which is a product of an interaction between an individual and others in their environment. Challenging behaviour should not be interpreted automatically as an expression of deviance or abnormality inherent in the individual, but viewed rather with reference to much wider contextual factors (ADHC, 2012, p.5).

Perceptions of challenging behaviour are partly governed by rules of what is considered appropriate behaviour in various social contexts. For example, the behaviour of fans at a football match would be considered inappropriate (and therefore ‘challenging’) at a funeral.

It is important to remember that challenging behaviour challenges not only the person, but also families, carers, people in a person’s support network and service providers. Responses to challenging behaviour often:

- prevent a person from participating fully in life and the community
- undermine the individual’s rights, as well as others’
- threaten dignity
- reduce quality of life
- pose safety risks to the person and others.
Challenging behaviour often has a significant impact on the person’s health, lifestyle and wellbeing, and on relationships with families, carers, friends and the wider community. Negative perceptions and non-acceptance of people with challenging behaviors are common.

4.2.1.1 Links between Communication, Challenging Behaviour and Ageing
The links between communication difficulties and challenging behaviour are well established. If persons with an intellectual disability do not have a formal way of communicating their wants, needs, likes and dislikes, they may use other behaviours to get their message across.

Evidence suggests that problems with receptive communication (comprehension of information) are more closely associated with challenging behaviours than expressive communication skills. When language is too complex to be understood, people may engage in challenging behaviours because they are scared, confused or frustrated. When carers overestimate people’s receptive language skills, they inadvertently create potential situations for challenging behaviour. Therefore, it is essential to adapt communication and use techniques to enhance understanding (as outlined in Section 4.1.4.)

When people age, the possibility of advancing cognitive decline or dementia may also affect their ability to communicate and further influence behaviours.

For further information see:
Dementia and People with Learning Disabilities
[http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf]
Down Syndrome and Alzheimer’s Disease

4.2.1.2 Some Causes of Challenging Behaviour
Although not necessarily deliberate and planned, behaviour occurs for a reason and serves a function. Identifying reasons for behaviour is necessary if we are to work effectively with people with disabilities. Many factors contribute to challenging behaviour, but sometimes they cannot be identified. Challenging behaviour is more likely to occur in people with limited or no verbal skills.

Broadly speaking, the causes of challenging behaviour are classified into four areas:
1. physical causes – health problems causing pain and discomfort
2. environmental causes – interactions with family, staff and others; lack of control over environment; changes to routines; loss and grief
3. psychiatric causes – psychiatric disorders more prevalent in people with intellectual disability
4. behavioural phenotype – some behaviours may be associated with specific syndromes, e.g., skin picking and Prader-Willi syndrome

Common contributors to challenging behaviour include (but are not limited to):
- health problems, e.g., psychiatric illness, substance abuse, medication, pain, discomfort, epilepsy, GORD, dental problems, osteoporosis, pneumonia, constipation, ear infection, urinary tract infection – it is important to rule out
any underlying health problem before looking for other causes of challenging behaviour

- abuse – physical, sexual and psychological
- life and environmental changes, e.g., school or accommodation changes, change in house mates, changes in routine, death in the family, staff changes, siblings leaving home, divorce
- communicating needs and wants, e.g., food, drink, activity
- communicating need for social interaction – sometimes negatively referred to as ‘attention-seeking’
- communicating avoidance and escape, e.g., avoiding situations that are unpleasant or disliked
- a need for sensory stimulation
- difficulties with regulating emotions
- boredom
- anxiety
- frustration
- confusion

Some apparently negative behaviours may be a positive coping strategy. For example, if Joe is anxious in social situations, rocking and humming provide sensory comfort and distraction from the disliked situation.

4.2.1.3 Examples of Challenging Behaviour

Challenging behaviours may be self-directed or outward-directed.

1. **Self-directed behaviours** include:
   - self-injury
   - withdrawal
   - repetitive (stereotyped) behaviour

2. **Outward-directed behaviours** include:
   - agitation (e.g., pacing)
   - aggression (e.g., hitting out, destruction of property)
   - socially inappropriate behaviour (e.g., sexualised behaviour in a public place)
   - noncompliance (e.g., refusing to follow directions)

Some examples of common challenging behaviours include:

- a person hitting himself about the face and head causing bruises and wounds
- ingestion or inhalation of foreign objects, e.g., pica
- lack of cooperation and abuse towards support staff
- running away in public places
- withdrawal and lethargy that might be accompanied by complaints of stomach pain and nausea

(Therapeutic Guidelines, 2013)

4.2.1.4 Impact of Challenging Behaviour

It is important to understand that it is the **impact** of the behaviours that makes them challenging, rather than judgements about appropriateness of the behaviours.

Challenging behaviours have a wide range of impacts on:

1. the quality of life of persons with the behaviours, and
2. the people who live and work with them.
Challenging behaviours may:
- cause danger to self and others
- cause stress and distress to self and others
- result in social exclusion that may lead to loneliness and depression
- interfere with learning and social development
- have negative effects on social, domestic and employment opportunities.

There is a risk that challenging behaviours may lead to exclusionary and restrictive practices.

For further information see:
- Finding the Causes of Challenging Behaviour
- CDDH Challenging Behaviour Information Sheet
  [http://www.cddh.monash.org/assets/chabev.pdf]
- CDDH Challenging Behaviour
  [http://www.cddh.monash.org/assets/fs-challengbev.pdf]
- Challenging Behaviour and Disability
- Pain, Low Mood and Challenging Behaviour

4.2.2 Positive Behaviour Support

Positive Behaviour Support is both a philosophy of practice and a comprehensive approach to assessment, planning and intervention that focuses on addressing a person’s needs, environments, and quality of life. It is an evidence-based approach that includes families and carers to develop shared understandings about why a person uses challenging behaviors. It has:
- a primary goal – to enhance a person’s quality of life, and
- a secondary goal – to decrease the frequency and intensity of a person’s challenging behaviors (DSC, 2012).

Positive Behaviour Support has four core components.
1. Ensuring the person is living the best life that he or she is able to – sometimes this is all that is required. However, if the person is leading a good life and challenging behaviour continues, then the following strategies should be used.
2. Understand why the person uses challenging behaviour.
3. Find causes for the challenging behaviour and modify them.
4. Teach the person new skills to meet needs. The new skill should be more functional than the challenging behaviour (Centre of Excellence for Behaviour Support, 2012).

Positive Behaviour Support employs the following strategies and approaches:
- person-centred approaches
- inclusion of relevant stakeholders
- assessment based intervention
- behaviour support plans
- reduction in aversive, restrictive and punishment approaches
- skill building
- staff development
- environmental redesign
- systems change (DSC, 2012).

4.2.2.1 Assessment of Behaviour
Before intervention can occur, assessment of behaviour considered to be challenging must be conducted. This is in order to identify its function and any variables that elicit, maintain and reduce the behaviour. Once factors such as triggers, setting events and consequences are understood, a Behaviour Support Plan can be developed with the aim of eliminating the behaviour and replacing it with a more functional way of achieving the goal. See ADHC Behaviour Support Policy (2012). This is usually prepared by a Behaviour Support Practitioner.

4.2.2.2 Behaviour Support Plan
A Behaviour Support Plan (BSP) is designed to eliminate challenging behaviour and replace it with more adaptive alternatives. It reflects the components and strategies of Positive Behaviour Support approaches outlined in the preceding section.

Behaviour Support Plans consider biological, social, psychological, and environmental variables as interrelated and ecological factors.

All aspects of interventions must be described in a BSP to ensure a consistent approach to behaviour support.

Behaviour support must take account of the following:
- Is there an underlying medical diagnosis? For example, consider pain, tooth abscess, constipation, urinary tract infection, itch, gastro-oesophageal reflux disease (GORD), painful menstrual periods, or a broken bone. Pain is a major contributor to challenging behaviour
- Is there a psychiatric diagnosis? Consider depression, psychosis, etc.
- Are there emotional issues? Consider grief and loss, anxiety, distress, relationship problems.
- Have environmental or other triggers been identified and addressed? What is happening in the person’s environment? Have there been changes?
- What is happening in the person’s relationship circles? Have there been changes?
- Does the behaviour constitute a serious risk to the person or to others?
- Are medications causing adverse effects? Are there medication interactions? Assess polypharmacy, side effects or not working well together? Medications for the primary management of challenging behaviours should be considered only after the exclusion of underlying diagnoses and any environmental or other relevant triggers. They may be considered in situations where the behaviour presents a significant danger to the person or others or for the management of diagnosed depression and other disorders.
- Has the GP reviewed all medications, including those currently used to manage behaviour? Have medical specialists been consulted, e.g. a neurologist, if the GP suspects that the person has epilepsy or a psychiatrist for a mental disorder?
- Consider early dementia in people who become less cooperative and whose functional levels decline, e.g., particularly significant in people with Down syndrome.
- Has there been collaboration with the behaviour support specialists regarding other interventions that might be effective in place of medications?
- Would the person benefit from a Behaviour Support Specialist review?

4.2.2.3 Restrictive and Restricted Practice

Where a documented Behaviour Support Plan recommends the use of certain practices or strategies that impose restrictions on a person’s rights or freedoms, these must be justifiable and may be considered for implementation only with legal consent. Such strategies may be wide-ranging and are referred to by ADHC as **Restrictive Practices**.

A number of practices have additional safeguards and are called **Restricted Practices**. These include:
- exclusionary time-out
- physical restraint
- psychotropic medication (for prn use)
- response cost – the withholding of valued items or activities
- restricted access
- seclusion

Such practices are informed by strict guidelines which provide clear conditions and limitations for use (ADHC, 2012). It is essential that you have a clear understanding of issues related to restrictive and restricted practices.


For further information see:
- [The Challenging Behaviour Foundation](http://www.challengingbehaviour.org.uk/)
- [What is Positive Behaviour Support? CEBS](http://www.centreofexcellenceforbehavioursupport.com.au/Portals/0/Practice%20Leadership/Practice%20Guides/No1b.pdf)
(Sources used for Sections 4.2 – 4.2.2.3: ADHC, 2012; ADHC, 2009; Balandin, 2002; Ballin & Balandin, 2007; Bott, Farmer & Rhode, 1997; DSC, 2012; Emerson & Einfeld, 2011; Kevan, 2003; McClintock, Hall & Oliver, 2003; Sigafoos, 2000; Therapeutic Guidelines, 2012)
### Practice Points: COMMUNICATION and BEHAVIOUR SUPPORT

- Effective communication and behaviour support are core components of nursing practice.
- There are significant links between communication difficulties and challenging behaviour.
- Communication is an interactive process. Communication meanings are not static – they evolve and change.
- Sensory impairments interfere with language development.
- People with intellectual disabilities have impaired communication – this ranges from subtle (and difficult to identify) to severe and obvious. Nurses must be aware of potential problems.
- Knowledge of levels of communication – unintentional, intentional, symbolic – enhances understanding of communication capacities and the development of appropriate strategies.
- People with profound and multiple disabilities are dependent on others to interpret their needs and choices through observation, assessment and getting to know them.
- Communication Plans must be implemented in a consistent manner. They must be reviewed by a Speech Pathologist regularly or according to need.
- Communication Profiles are useful snapshots of individuals’ essential communication. They are convenient for unfamiliar environments such as during hospitalisation.
- The person with a disability must be the primary focus of communication.
- Use strategies to enhance both receptive and expressive communication.
- When working with people who cannot communicate intentionally, observe facial expression, body language and behaviour.
- The notion of partnerships is essential to effective communication between health professionals, people with disabilities, their families and carers, schools and day options programs.
- Nurses play an important role in facilitating partnerships, interpreting health information, co-ordinating health practice, and liaising with other health professionals.
- Nurses support families by using family-centred and partnership approaches, and through advocacy of people with disabilities and their families.
- Lack of effective communication leads to frustration. This may result in challenging behaviour.
- Behaviour is a form of communication that serves a function.
- Perceptions of behaviour are governed by social contexts.
- Challenging behaviour challenges not only the person, but also families, carers, people in a person’s support network and service providers.
- Problems with receptive communication are more closely linked with challenging behaviour than expressive communication skills.
- Carers often overestimate people’s language skills. Nurses must assess and educate families, carers and support staff.
- Nurses are responsible for initial assessment of causes of challenging behaviour.
Always consider pain and health conditions first. Assess for other causes. Refer for further assessment when indicated.

- Adopt the principles of Positive Behaviour Support into your nursing practice.
- Advocate for the best possible life for people you work with.
- Refer to Behaviour Support Practitioners when indicated.
- Ensure consistent implementation of Behaviour Support Plans (BSP). Educate families, carers and staff.
- Ensure avoidance of any restrictive and restricted practices unless included in a documented and approved BSP.
- Ensure familiarity with organisational and service behaviour support policies and practices.
4.4 Readings and Resources for Communication and Behaviour Support


ADHC (undated). Building a communication profile template.  


Department of Human Services (DHS) (undated) Supporting people who have complex communication needs. Victoria: DHS.  


5. 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. 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

5.1 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 5.2: *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 5.3: *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 5.4: *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](http://www.plosone.org/article/info%3Adoi%2F10.1371%2Fjournal.pone.0070855)

### 5.1.1 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 ADHC’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 in Section 6: Mealtime Management.

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

For further information see:

5.1.2 Management of Gastrointestinal Problems
Management of gastrointestinal problems in this population usually refers to management of GORD, Helicobacter pylori, gastroenteritis and surgery. The Nurse works with the GP to prevent threats to health from gastrointestinal problems.

5.1.2.1 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
- hand-mouthing
- dental erosion
- loss of appetite
- weight loss
- depleted iron stores
- 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

**5.1.2.2 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, eg epilepsy medication
- management of vomiting through medication, eg, IM Maxolon
- management of aspiration through positioning and oral care
- management of dehydration through fluid and electrolyte replacement, eg, Gastrolyte
- management of pain/fever with cooling methods and/or medication, eg, Panadol
- stool sample for culture
- management of diarrhoea with medication, eg, Imodium (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

**5.1.2.3 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
Viral Gastroenteritis
Perioperative Nursing Care
[http://www.slideshare.net/twiggypiggy/perioperative-nursing-care]

5.1.3 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, eg, wedges, electric bed
- oral suction (tracheal suction not recommended)
- percussion and drainage
- oral care
- management of drooling, eg, 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, eg noxious fumes from unflued gas heating
- moisture of air
- household hygiene, eg, dust, pillows
- pets
- household maintenance, eg, painting, building
- prophylactic and/or early introduction of antibiotics
- management of acute episodes at home or in hospital

5.1.3.1 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.

5.1.3.2 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

5.1.3.3 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 ADHC'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 Dependancies**
[http://www.pediatricsdigest.mobi/content/129/5/996.full]

**Asthma Action Plan**

**Tracheostomy Care at Home**

**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**

**Humidification**

**Home Respiratory Program**

**AIDAS Program**

5.1.4 Oral Health

The Nurse, in collaboration with the Dentist and the Speech Pathologist, develops oral care plans for people with 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

Dental Care Considerations for Disabled Adults
[http://paul-burtner.dental.ufl.edu/files/2012/05/Disabled-Adults.pdf]

Oral Care for people with Disabilities

5.1.5 Nutrition, Hydration and Weight Management
Refer also to Section 6: 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
5.1.6 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, eg, weight, statins, testosterone deficiency
- possible signs, eg, 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)

5.1.7 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.

5.1.7.1 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 ADHC’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

5.1.7.2 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 and consistency of bowel motions
- types of aperients and rectal medications
- impact of other medications
- examination per rectum
- haemorrhoids
- bowel sounds
- abdominal palpation
- abdominal xray
- care of perineal area
- suitable incontinence products through ADHC’s AIDAS program, the Federal Government’s Continence Aids Payment Scheme (CAPS) and Enable NSW’s Aids and Equipment Program

5.1.7.3 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

Bristol Stool Chart

Enable: Continence Aids Application

Continence Aids Payment Scheme

CH2 Incontinence Products
5.1.8 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.

5.1.8.1 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 ADHC’s AIDAS program, the Federal Government’s Continence Aids Payment Scheme (CAPS) and Enable NSW’s Aids and Equipment Program

5.1.8.2 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, eg, cranberry, Ural
- prophylactic antibiotics for underlying abnormalities, eg, 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
5.1.8.3 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

5.1.8.4 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
Continence Aids Payment Scheme
Enable: Continence Aids Application
AIDAS Program
CH2 Incontinence Products
Toilet training
[http://dcautismparents.org/yahoo_site_admin/assets/docs/ABA_4.9255817.pdf]
Sensory experience of toilet training
ADHC Community Support Teams (CSTs)
ADHC Behaviour Support
5.1.9 Management of Vision Impairment and Eye Problems
The Nurse works with the GP to prevent threats to health from blindness and infection.

5.1.9.1 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 Section 4.1.5: Communicating with People with Sensory Impairments.

5.1.9.2 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

5.1.9.3 Surgery
The most likely eye surgery for people with disabilities 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
- Occlusion Therapy
- Congenital Cataracts

5.1.10 Management of Hearing Impairment and Ear Problems
The Nurse works with the GP to prevent threats to health from deafness and ear infections.

5.1.10.1 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.

**See complementary information in Section 4.1.5: Communicating with People with Sensory Impairments.**

**5.1.10.2 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

**5.1.10.3 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)

**5.1.11 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, eg, 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, eg, strobe lights, alcohol, dehydration, pain, fever, menstruation, constipation, other medications (eg, OCP), sleep disturbance
- safety, eg, water, falls
- bed seizure alarm
- medical alert bracelet
- first aid
- emergency
- recovery
- follow up of unusual seizure activity, eg, review with Neurologist, change to epilepsy management plan
- ketogenic diet

Seizures may occur with conditions other than epilepsy, eg, 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]
- AEDs [https://www.epilepsy.com/epilepsy/newsletter/sept09/aeds]
- Epilepsy Action Australia [http://www.epilepsy.org.au/]
- Hydrocephalus shunt malfunction [http://hydrocephalus.allanach.dk/complications]

5.1.12 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/]

5.1.13 Management of Musculoskeletal Problems
The Nurse collaborates with the Physiotherapist in the management of musculoskeletal problems.

The Nurse considers:
- mobility
- posture
- comfort
- surgery

5.1.13.1 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.
5.1.13.1.1 Exercise
There are various generic and specialist exercise programs for people with intellectual disabilities. 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 disabilities. Professor Roger Stancliffe of the University of Sydney is researching in the area of exercise and people with intellectual disabilities.

5.1.13.1.2 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, eg, 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

5.1.13.1.3 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, eg, 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.

5.1.13.2 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 ADHC’s AIDAS program or Enable’s Aids and Equipment Program.

5.1.13.3 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, eg, music, vibrating mats, engaging activities
- heat pads or cold packs (exercise caution)
- lotions, eg, deep heat (exercise caution with Voltaren products)
- medication, eg, 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 5.1.16: Pain Management.

5.1.13.4 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

A Physical Activity Guide For Older Australians

Obesity

Exercise Intervention Research and People with Disabilities

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

Hydration and the Active Child

Physical Activity and Diabetes

Physical Activity and Spina Bifida

Atlantoaxial instability

NSW Falls Prevention Program

Australian Commission on Safety and Quality in Health Care
5.1.14 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
5.1.15 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]

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

5.1.16.1 Discomfort
Comfort has been addressed in Section 5.1.13.3. The Nurse ensures that each person has an individually tailored plan to manage discomfort.

5.1.16.2 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
5.1.16.3 Chronic Pain
Chronic pain may arise as a consequence of many problems, eg., 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


For further information see:
WHO’s pain ladder
Pain management – adults
Pain management - children
WHO: Pain Management Guidelines: Children
Pain Management for all Australians
NSW Health Pain Management Report 2010
Pain expression
Pain in Cerebral Palsy
[http://research.ncl.ac.uk/sparcl/publications/Published%20article%20Pain.pdf]

5.1.17 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
  - ears
  - nose
  - skin folds associated with scoliosis, contractures, obesity
  - perineum – penile hygiene, labial hygiene, peri-anal hygiene
  - feet
- menstrual management
- assisting with toileting
- changing continence pads
- changing soiled clothing
- cleaning up vomit, faeces, urine, blood, drool, mucus, 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)

For further information see:
Personal Care Tasks

5.1.18 Physical Fitness
The Nurse collaborates with the multidisciplinary team to prevent threats to health associated with poor physical fitness. See Sections 5.1.13.1.1: Exercise, and 5.1.5: Nutrition, Hydration and Weight Management

5.1.19 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)

For further information see:
Being a Healthy Woman
Preventative Women’s Healthcare for Women with Disabilities: Guidelines for GPs
Sexual health and Family Planning Australia
[http://www.shfpa.org.au/]
National Women’s Health Policy 2010

5.1.20 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
- erections
- inguinal hernia
- sexually transmitted infection
- referral to endocrinologist, urologist


For further information see:
Andrology Australia
[https://www.andrologyaustralia.org/]
Sexual health and Family Planning Australia[http://www.shfpa.org.au/]
5.1.21 Management of Mental Health Problems

People with intellectual disability have at least the same incidence of mental health problems as the general population. They have fallen between the service cracks since services for people with mental illness and people with intellectual disability were separated in the late sixties. There have been a number of attempts to rectify this with, for example, some psychiatrists specialising in the area, the development of the Intellectual Disability Mental Health First Aid Manual (Kitchener et al, 2010) (an excellent resource for Nurses and others), 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.

Nursing must take seriously its ‘single register’ role by ensuring Nurses have an understanding of both physical and mental health issues. Nurses 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.

5.1.21.1 Mental Health

The World Health Organization 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.

5.1.21.2 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, eg, 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.

5.1.21.2 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 disabilities, 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)
5.1.22 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 ADHC have access to MIMS on line and Mealtime Management Module 6.

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

For further information see:
Medication Guidelines
ADHC Medication Management Plan and Charts
Don’t Rush to Crush
Don’t Rush to Crush Option with MIMS Online
Medication via enteral feeding tube
Compounding Pharmacist

5.1.23 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; Therapeutic Guidelines, 2012)

For further information see:

Transition from Child to Adult Services
Hospitalised patients with ASD
[http://cpj.sagepub.com/content/52/7/652.short]
Hospital Experiences of Older People

5.1.24 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” (ADHC 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 ADHC (for ADHC and ADHC-funded services)


For further information see:
Future Care Planning
Trajectories at End of Life
Illness Trajectories and Palliative Care
NSW Ombudsman: Report of Reviewable Deaths 2010-2011
NSW Plans
NSW Government Plan Palliative Care 2012-2016
ACI: Framework for the Statewide Model for Palliative and End of Life Care Service Provision

Policies – ADHC and Health
ADHC: Palliative Care Policy
End of life care and people under guardianship
Client Death Policy (ADHC)
Advanced Care Planning
Decisions Related to No CPR: NSW Health
End-of-Life Care and Decision-Making – Guidelines: NSW Health

Intellectual Disability
Palliative Care in People With Congenital or Acquired Intellectual Disability and High Nursing Support Needs: A Literature Review
Cancer, Palliative Care and Intellectual Disabilities
Disability Residential Services Palliative Care guide (Vic)
NSW Council for Intellectual Disability-End of Life Care
Managing Grief Better: People With Intellectual Disabilities

Special Groups
Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander people
Challenges for Aboriginal Palliative Care Models
5.2 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 disabilities, 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.

Johanna Briggs Institute [http://joannabriggs.org/]
Clinical Nursing Skills Videos [http://www.youtube.com/watch?v=qrBNFTv-CVE]

5.3 Advocacy and Co-ordination
5.3.1 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 disabilities.

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, Vaartiaet 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, Brolanet 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 disabilities.

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 disabilities to the many disability advocacy groups and, with the emergence of the health advocate as an occupation in NSW, refer people to health advocates.

5.3.2 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

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

ICN Code of Ethics

Nursing and Midwifery Board of Australia: Codes and Guidelines

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

Guidelines on Whistleblowing and Nursing

Protection of Whistleblowers Australia

Disability Advocacy Groups NSW

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

5.4 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.
5.4.1 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 disabilities. 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 disabilities also have an education arm, usually for no cost to Nurses.

5.4.2 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 ADHC or NSW Health have access to free online databases and there are many free databases now on the internet, eg, 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.

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

5.4.3.1 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).

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

5.4.3.3 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/]
AADDMM [http://ausaddm.wordpress.com/home/]
ACN [http://www.acn.edu.au/]
ASID [http://www.asid.asn.au/]
CDDHV [http://www.cddh.monash.org/]
CDS [http://www.cds.med.usyd.edu.au/]
Cochrane Library

131
5.5 What does this mean for your nursing practice?

<table>
<thead>
<tr>
<th>Practice Points: WORKING WITH PEOPLE WITH CHRONIC and COMPLEX HEALTH CARE NEEDS</th>
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<tbody>
<tr>
<td>• The need for chronic and complex health care arises due to the <strong>impact</strong> and <strong>severity</strong> of diagnoses and/or conditions.</td>
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<tr>
<td>• Health threats associated with chronic and complex health care needs may be physiological or functional.</td>
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<tr>
<td>• Be familiar with threats to health associated with people with intellectual disability.</td>
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<tr>
<td>• Be familiar with threats to health for individuals.</td>
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<tr>
<td>• Anticipate threats to health and employ nursing interventions to prevent them.</td>
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<tr>
<td>• 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.</td>
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<tr>
<td>• Nursing interventions are evidence based.</td>
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<td>• Nursing interventions reflect the goals of the individual.</td>
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<td>• Nursing interventions enable meaningful participation in life activities.</td>
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<tr>
<td>• Collaborate with the multidisciplinary health team.</td>
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<tr>
<td>• Develop partnerships with people with chronic and complex health care needs and their significant others.</td>
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<tr>
<td>• Network with health, education and disability services.</td>
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<tr>
<td>• Teaching, coaching, access, coordination and ongoing evaluation are integral to health care and support.</td>
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<tr>
<td>• Anticipate guidance that others may need.</td>
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<tr>
<td>• The person with an intellectual disability is unlikely to have the capacity to consent to health interventions.</td>
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<tr>
<td>• The person responsible consents to health interventions.</td>
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<tr>
<td>• 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.</td>
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<tr>
<td>• If the person responsible withholds consent for a health intervention despite negotiation, the Nurse may seek a Guardianship hearing (through their employer).</td>
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<tr>
<td>• Identify and use specialist resources to promote the health and well-being of the person with chronic and complex health care needs.</td>
</tr>
<tr>
<td>• Utilise equipment resources such as Enable and AIDAS.</td>
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<tr>
<td>• Teach and coach people with chronic and complex health care needs, their families, and support workers in schools and day programs about health.</td>
</tr>
<tr>
<td>• Advocate for the individual, and for people with chronic and complex health care needs generally, to gain equitable access to health services.</td>
</tr>
<tr>
<td>• Stay current in nursing practice and health interventions for people with intellectual disability and chronic and complex health care needs.</td>
</tr>
<tr>
<td>• Utilise research to validate nursing practice.</td>
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5.6 Readings and Resources for Working with People with Chronic and Complex Health Care Needs


6. Mealtime Management

Mealtime Management is essential to health care practice in the field of intellectual disability because of:
(i) the prevalence of malnutrition that results in underweight and obesity, and lack of nutrients, and
(ii) the incidence of dysphagia that results in high rates of aspiration, pulmonary infection and death.

The Nursing and Health Care Standard, Mealtime Management, is addressed under the domains of:
- Nutrition for Health and Wellbeing
- Managing Dysphagia
- Enteral Nutrition

6.1 Nutrition for Health and Wellbeing

Good nutrition is essential for growth and development, for cell and tissue repair, for daily activities, and to keep people healthy, happy and well.

**Nutrition** refers to taking in and using fuel in the body. It is a complex, three-part process where:
1. food and drinks are consumed (eating and drinking)
2. the body breaks down food and drink into nutrients (digestion)
3. nutrients travel through the blood stream to body tissues and organs to be used as energy, and for growth and repair (absorption).

Nutrition then refers to more than just food and drink.

For effective nutrition to occur, people:
- must take in food and fluids that will provide enough energy and key nutrients for growth and repair
- must have a digestive system that works properly
- need healthy body systems to transport and absorb nutrients to be used by the body.

Good nutrition is also related to enjoyable sensual and social experiences, and is dependent on socioeconomic factors.

6.1.2 Nutritional Risks for People with Disabilities

Refer also to Section 5.1.5 Nutrition, Hydration and Weight Management for complementary information.

People with disabilities frequently have associated disorders that interfere with nutrition in terms of intake, digestion or absorption of nutrients. They often require assistance from others for nutritional planning, and some are dependent on others for eating and drinking. They also confront lifestyle risks, especially when mobile and having greater levels of functional independence.
The incidence of obesity is higher, particularly and when mental illness, intellectual disability, and limited mobility interact. People with Down syndrome and women are more likely to be obese. However, undernutrition is also a significant risk particularly for people with dysphagia and severe physical limitations such as spastic quadriplegia. Vitamin and mineral deficiencies (e.g., iron, vitamin D, folate) are common.

The relationships between intellectual disability, mental illness, complex medical conditions, nutrition, wellbeing, illness, and quality of life are multifaceted. However, greater understanding of the centrality of nutrition for health and wellbeing, along with improved technologies for nutritional support, have the potential to reduce the chance of people with disabilities being severely underweight or obese.

Following are some common nutritional problems and risks for people with disabilities.

**Appetite problems.** *Anorexia* (poor appetite) – may be associated with illness, medications, pain, constipation, disease, depression, grief, oral problems, stressful environment, and many other factors. *Polyphagia* (big appetite) – may be associated with medications, Prader-Willi syndrome, enjoyment of food, stress and anxiety, boredom, poorly controlled diabetes, and many other factors.

Problems with the regulation of appetite may lead to:
- malnutrition
- lack of energy, lethargy, etc.
- obesity
- type 2 diabetes
- binge eating
- bulimia nervosa (binge eating and purging)
- anorexia nervosa (obsessive fear of gaining weight)
- cachexia (a wasting of the body seen in cancer, chronic lung disease and other diseases).

**Undernutrition** occurs when the body does not get enough energy or nutrients for good health, or is unable to utilise energy or nutrients because of digestive problems or illness. Undernutrition (malnutrition) may result in starvation.

Causes of undernutrition include:
- increased energy requirements – e.g., hypertonia (spasticity); excessive drooling; following illness, etc.
- digestive problems – digestive chemicals (saliva, enzymes, etc.); delayed gastric emptying (GORD, nerve damage, smooth muscle disorders, medications, diabetes, inflammation, etc.); problems with peristalsis (too slow; too fast)
- absorption problems – malabsorption (of food or specific nutrients) occurs with coeliac disease, lactose intolerance, Crohn’s disease, liver disease, parasite infection (e.g., *Giardia*), some medications
- swallowing problems
- poor food variety and balance
- high kilojoule, low nutrient foods (junk foods) – people can be obese but malnourished at the same time.

**Medications** are a risk factor for poor nutritional status. They may influence food intake, as well as the digestion, absorption and metabolism of nutrients.

**Overnutrition and obesity.** Overnutrition may result in overweight and obesity, as well as other disorders related to specific nutrients, such as cardiovascular disease (linked to high dietary fats) and type 2 diabetes (linked to excess refined carbohydrates).

People with disabilities have a higher prevalence of overweight and obesity than the general community. This places them at even greater risk for further health problems such as cardiovascular disease, osteoarthritis, sleep apnoea, type 2 diabetes, reproductive problems, psychological problems.

**Neurological impairments** that affect eating and drinking will have an adverse impact on nutrition. Neurological impairments may affect:
- muscle tone and movement – posture, hand grip, intentional movement, drooling
- oral-facial hypersensitivity
- chewing and swallowing problems – dysphagia and aspiration

**Reflux and gastro oesophageal reflux disease (GORD)** are common and have a significant impact on nutrition. Oral and peptic ulcers are often associated. Pain and discomfort may cause loss of appetite or sometimes wanting to eat all the time.

**Adverse food reactions.** Food intolerance and food allergy, along with autoimmune disorders, have an impact on the digestion and absorption of nutrients. These include:
- GI problems
- pharmacological reactions, e.g., salicylates (tomatoes, strawberries), amines, preservatives
- metabolic disorders, e.g., PKU, lactose intolerance
- coeliac disease – an autoimmune disorder resulting in gluten intolerance.

People on restricted diets because of adverse food reactions need to be especially careful to eat a balanced diet to maintain good nutrition.

**Physiological digestive disorders** include:
- irritable bowel syndrome (IBS)
- inflammatory bowel disease (IBD) – includes Crohn’s disease and ulcerative colitis.

Weight loss and malnutrition can be dramatic.

**Communication problems and dependence on others** lead to problems with the communication of hunger and thirst, as well as information about food preferences. People with disabilities are dependent on others to a greater or lesser extent. Nutritional support may vary from guidance and assistance with healthy food choices and preparation to total dependence on others who need to ensure adequate nutrition and hydration.
Lack of education and knowledge about healthy nutrition on the part of support staff have been identified as significant factors contributing to obesity rates of people with disabilities living in supported accommodation.

The NSW Ombudsman’s Reviewable Disability Deaths Team has documented cases of preventable deaths associated with inadequate nutrition and hydration. These deaths of people with disabilities in accommodation services have been attributed to staff and systemic neglect.

6.1.3 Outcomes of Poor Nutrition
There are many adverse outcomes of poor eating and drinking practices and inadequate nutrition. Such outcomes apply to the general population, but are prevalent in people with disabilities who experience poorer health than the general population.

Outcomes of poor nutrition include:
- failure to thrive
- compromised growth and development
- malnutrition
- undernutrition
- obesity
- metabolic syndrome
- nutrient deficiencies
- impaired immunity and increased susceptibility to infection
- type 2 diabetes
- hyperlipidaemia
- hypertension
- cardiac disease
- stroke
- cancers
- diarrhoea
- constipation
- urinary tract infections
- oedema
- osteoporosis
- musculoskeletal disorders
- reduced respiratory muscle function
- sleep apnoea
- infertility
- oral problems
- eye problems
- decreased energy, reduction in participation
- psychological problems

Some of these health conditions are not necessarily always caused by nutritional problems – some people will develop the conditions even though they eat well and lead very healthy lives. However, the associations are strong. The development of many of the listed problems is the result of a complex interaction of genes and the environment. Many people have a genetic predisposition to a specific health condition (e.g., type 2 diabetes, hyperlipidaemia) which will become a problem in a particular environment such as poor nutrition.

6.1.4 Assessment of Nutrition
A multidisciplinary approach is often needed to assess nutritional problems in people with disabilities.

Body (anthropomorphic) measurements are the first steps in establishing underweight or overweight. These include:
- weight
- height
- BMI
- waist circumference
- skinfold thickness

When height cannot be measured accurately, BMI cannot be calculated. However, subcutaneous fat indicates significant underweight or obesity. Waist circumference and skinfold thickness provide information. **Serial measurements and recording** are an essential tool in assessing weight loss and gain, and for assessing the efficacy of interventions. In many circumstances, Nurses are responsible for ensuring this is done.

**GP assessment** includes identification of clinical disorders that may be associated with undernutrition or overnutrition, e.g., GORD, malabsorption, depression, constipation, anaemia, reduced immunity, insulin resistance, type 2 diabetes, pain.

**Blood biochemistry** assists in the assessment of nutritional disorders. For example, people at risk must be monitored for low calcium and vitamin D which is associated with osteoporosis, and low iron and haemoglobin (Hb) which are associated with anaemia.

**Medication assessment** may help in identifying sources of weight gain. Some drugs used by people with disabilities induce weight gain (e.g., some AEDs and antipsychotics).

**DEXA (dual energy X-ray absorptiometry) scans** measure bone mineral density. Low bone density indicates osteoporosis that may be related to nutritional problems.

**Endoscopy** visualises the gastrointestinal tract and may assist in the diagnosis of disorders such as GORD, ulcers, ulcerative colitis, etc.

**Dietary assessment** by a Dietitian for nutritional and energy (kilojoule intake).

**Swallowing assessment** by Speech Pathologist who will advise about additional investigations.

**Positioning, support and eating technique assessment** by Physiotherapist, Occupational Therapist, Speech Pathologist to ensure optimal positioning, support and equipment for effective and safe eating and drinking.

**Assessment of physical activity** by Physiotherapist to assist with estimates of energy requirements. Dietitian can then make any necessary adjustments.

**Dental assessment** to address oral concerns, e.g., gingivitis and sore gums often prevent eating and adequate nutrition.

### 6.1.5 Healthy Nutrition

Variety and balance are the keys to healthy nutrition and enjoyable eating. Nutrition must be based on the recommendations in the NHMRC’s [Australian Dietary Guidelines (2013)](https://www.nhmrc.gov.au/guidelines). The website has useful information and resources for healthy eating across the lifespan. The [Australian Guide to Healthy Eating Poster](https://www.nhmrc.gov.au/guidelines) is available from the website and is a useful reminder for staff and for people living in supported
accommodation. Community staff can direct families to the resources available there.

Comprehensive guidance regarding nutrition, eating and drinking, and food management, is available in the FACS:ADHC Nutrition in Practice Manual. This manual assists support staff to develop simple eating and drinking plans for people with minimal eating and drinking problems.

An excellent resource, Good Food, Good Living: Nutrition for People with Disabilities Living in Supported Accommodation, is available from Greystanes Disability Services. This resource shows how to put the ‘Australian Dietary Guidelines’ and the ‘Nutrition in Practice Manual’ into practice. It is an interactive guide and learning package for support staff and people with disabilities that covers the following areas:
- Nutrition for Health and Wellbeing
- Problems with Nutrition
- Who’s Who in Nutrition (Professional Roles)
- Strategies to Improve Nutrition and Wellbeing
- Food Management
- Food and Kitchen Safety.

Some people living in supported accommodation will have a nutrition plan and/or a mealtime management plan. In the absence of individual plans, healthy nutrition is achieved by providing meals in line with the Australian Dietary Guidelines. Food and Nutritional Health for Adults: Risk Screening and Monitoring Outline is a brief and easy to use tool that assists in risk identification and monitoring for people living in the community.

6.1.6 Nurses and Nutrition

It is essential that Nurses have an understanding of risk factors and adverse outcomes related to poor nutrition of people with disabilities. Nurses are responsible for the assessment of risk factors and nutritional screening. Referral to an Accredited Practising Dietitian is indicated for full nutritional assessment and planning. Dietitians develop individualised nutrition plans for people with specific needs. The Practice Package for Dietitians (available only on ADHC intranet) may be a useful resource for some Nurses. Referral to other members of the multidisciplinary team may also be necessary (see Section 6.1.4)

Nutritional problems for people with intellectual disabilities are often complex. Management may require a multidisciplinary approach, e.g., GP, Dietitian, Speech Pathologist, Gastroenterologist), and the close involvement of families, carers, and support staff.

Nurses are responsible for:
- ensuring that weight is monitored and documented
- monitoring of excessive weight gain or loss
- monitoring for dehydration
monitoring growth and development of young people
the assessment and documentation of nutritional risk factors
the assessment and documentation of adverse nutritional outcomes
elimination management
referral to other professionals as required, e.g., Dietitian, GP, Speech Pathologist, Dentist
being alert to the necessity for specialist investigations and consulting with GP referrals
development of strategies to minimise risk factors and adverse outcomes (in consultation with other professionals when necessary)
overseeing and monitoring healthy eating and drinking practices
overseeing the implementation of nutrition plans
education of families, carers and support staff.


6.2 Managing Dysphagia
Many people with disabilities have swallowing difficulties which make them vulnerable to risks from aspiration and choking, along with respiratory disease related to aspiration. Prevalence in adults with multiple disabilities is estimated to be as high as 76% (Therapeutic Guidelines, 2012). The NSW Ombudsman (2013) identified adverse events arising from dysphagia as a major area of preventable deaths of people with disabilities.

6.2.1 Dysphagia
Refer also to Section 5.1.1 Management of Dysphagia for complementary information for this section.

The severity of dysphagia ranges from mild to severe. Eating difficulties related to dysphagia may be affected by the following:
- environment
- alertness
- positioning and posture
- breathing
- neuromuscular control of mouth and throat
- ageing
- teeth
- dentures
- cough
- voice
- gag
- compensation

See the FACS:ADHC Nutrition in Practice Manual for further detail.
Consequences of dysphagia include:
- death from choking
- aspiration and its complications
- compromised nutrition (malnutrition and dehydration)
- changes to usual patterns of oral intake
- social isolation
- negative psychosocial effects, e.g., anxiety related to coughing and choking, depression.

6.2.1 Aspiration
Aspiration is the entry of material (food, liquid saliva) into the airway below the level of the true vocal cords. Aspiration is classified as:
- silent aspiration – no observable symptoms such as cough or clearing of the throat
- prandial aspiration – food is aspirated as it passes into airway on the way to the stomach
- salivary aspiration – aspiration of saliva
- gastric aspiration – gastric contents may be aspirated when reflux is severe.

Aspiration occurs in healthy people, but the airway is cleared by coughing.

Aspiration presents the greatest risks in people who:
- have a poor cough
- cannot swallow their saliva
- have problems sitting up and holding the head up
- have a weak or breathy voice
- are gurgly when they speak or breathe
- are drowsy
- have GORD.

Aspiration may lead to pulmonary inflammation, infection, pneumonia and chronic lung disease, wheezing and night time coughing. Some of these symptoms may be masked by, or mistaken for asthma. Aspiration pneumonia is one of the most common causes of death in people with intellectual disabilities (Therapeutic Guidelines, 2012).

6.2.2 Screening for Dysphagia
Screening tools assess for risk. If risks are identified, close monitoring is essential and further assessment is indicated. A number of dysphagia screening tools for use by Nurses have been developed for acute stroke care. Following are the dysphagia and risk screening tools developed for use with people with disabilities.

Nutrition and Swallowing Risk Checklist
This comprehensive and detailed tool includes valuable information. It has been developed specifically for adults with disabilities and is recommended for use in all ADHC funded services. All people using ADHC residential services must have the checklist completed at their initial assessment, and updated annually by Nurses, support workers, or case managers.
Functional skills deteriorate as people age. Swallowing function in some people with disabilities deteriorates after the age of 30 years. Therefore, regular review of swallowing ability and oral intake is essential.

Nurses need to be alert to the signs of dysphagia in people they are responsible for. Examples of dysphagia warning signs include:

- coughing
- wheezing
- wet respiratory quality
- excessive drooling
- pocketing of food in mouth
- sudden changes in colour around mouth and lips
- refusal of food and fluids
- watering eyes
- gagging
- grimacing
- fatigue during eating
- residual food left in mouth

6.2.2 Assessing Dysphagia

Referral to a Speech Pathologist may be necessary for further screening and assessment.

**The Dysphagia Disorders Survey (DDS) and The Dysphagia Management Staging Scale (DMSS)**

These are standardised screening tools for feeding and swallowing disorders in children and adults with disabilities. Speech Pathologists administer these tools following training and accreditation.

See [http://www.nutritionalmanagement.org/dds_dmss.htm](http://www.nutritionalmanagement.org/dds_dmss.htm) for further information.

The Speech Pathologist will advise the person’s GP and other professionals about what additional investigations are needed. These may include the following

**Modified barium swallow (MBS)** is an X-ray examination of swallowing function. It is conducted by a Radiologist and a Speech Pathologist following oral intake of barium-coated foods and liquids of different consistencies. Chewing and swallowing motions are X-rayed and videoed. Aspiration of food and fluids can be visualised.

**CT scans** allow visualisation of internal organs. They can be useful for assessing damage caused by swallowing problems and aspiration.

**Dysphagia Clinics.** Specialist dysphagia clinics are available at the Children’s Hospital at Westmead, Sydney Children’s Hospital, and at Westmead and St. George Hospitals. They provide comprehensive assessment of dysphagia and nutrition problems for children and adults with complex medical conditions and disabilities, as well as ongoing support and management.

See the [Dysphagia and Nutrition Clinic at CHW](http://www.nutritionalmanagement.org/dds_dmss.htm)

**Nursing judgment** is crucial in avoiding aspiration in people who are at risk. Nurses must always be sensitive to signs such as gurgling, wet cough, wheeziness, breathlessness during eating, choking, etc.
Following assessment and diagnosis of eating and drinking problems, the Speech Pathologist will develop an individual eating and drinking plan (sometimes called a Mealtime Management Plan). This plan may be developed with other members of the multidisciplinary team and will be implemented along with a person’s nutrition plan.

Sometimes, recommendation for eating and drinking via a gastrostomy will be made if it is considered that a person with a disability aspirates regularly and is at high risk of complications, or if nutrition is inadequate.

6.2.3 Eating and Drinking with Dysphagia

Safe eating and drinking for healthy and enjoyable oral intake are the goals for people with swallowing difficulties.

Eating and drinking plans specify strategies to reduce the risk of choking and aspirating, and increase the efficiency of oral intake. Strategies include:

- food and fluid consistencies
- mealtime equipment needed
- seating and positioning requirements
- supportive techniques
- environmental considerations

6.2.3.1 Food and Fluid Consistencies

Thickened fluids and texture-modified foods are provided for the therapeutic management of dysphagia. Inconsistent labeling and descriptions of modified foods and fluids threatens interprofessional and family and support staff communication, as well as the safety of people with dysphagia. Therefore, the Dietitians Association of Australia and The Speech Pathology Association of Australia (2007) have developed consensus standards for scales of modified foods and fluids that specify levels, labels and definitions to be used throughout Australia.

The Australian Standards for Texture Modified Food and Fluids specify the following:

**Fluid:**

- Mildly Thick (Level 150) – fluid runs freely off spoon but leaves a mild coating on spoon
- Moderately Thick (Level 400) – fluid slowly drips in dollops off the end of the spoon
- Extremely Thick (Level 900) – fluid sits on the spoon and does not flow off it.
Food:
- Texture A (Soft) – food may be naturally soft or may be cooked or cut to alter its texture
- Texture B (Minced and Moist) – food is soft, moist and easily mashed with a fork; lumps are smooth and rounded
- Texture C (Smooth Pureed) – food is smooth, moist and lump-free; may have a grainy quality.

The Australian Standards for Texture Modified Food and Fluids Poster should be readily available to all staff involved in food preparation and assisted nutrition for people with dysphagia (suggest: inside pantry or other kitchen cupboard).

6.2.3.2 Adaptive Equipment
Adaptive eating and feeding equipment suited to the needs of an individual with dysphagia is recommended and organised by Speech pathologists and Occupational Therapists.

Examples of adaptive equipment include:
- **Spoons, knives and forks.** These may be made of rubber or plastic to prevent biting down too hard. Weighted cutlery with or without thick handles and/or an angled head promote grip and make food transfer easier. Spoons should have a small bowl.
- **Straws** are used for people with dysphagia if they have problems with cup use because they allow drinking with the chin tucked down. **Warning:** Straws reinforce the sucking reflex, so are used only on the advice of a Speech Pathologist and with regular pauses.
- **Cups** with spouted lids and/or dual handles.
- **Plates** with raised edges assist some people with independent eating.

6.2.3.3 Positioning and Seating
Proper body positioning during eating and drinking is essential for safe swallowing. Incorrect posture increases the risk of choking and aspiration. Head position influences swallowing ability and airway safety.

The ideal position for eating and drinking is sitting upright in a chair with both feet on the floor, hips back in the chair, head facing the front and chin slightly forward.

If unable to sit in a chair, assistance is provided to promote an upright position in a wheelchair or bed (if ill). People who cannot sit in a chair need an individualised, supportive wheelchair with appropriate trunk and head supports as prescribed by a Physiotherapist or Occupational Therapist.

**When eating and drinking in a wheelchair:**
- the back of the chair should be upright
- knees should be at right angles to the hips
- feet should be on footplates
- head, trunk and limbs should be well supported – allows coordination of breathing and swallowing and promotes expulsion of particles from airway during coughing.
If these positioning principles cannot be implemented due to severe physical disability, proper positioning, seating and supports required for the individual are specified in a seating plan.

People need to remain upright for at least 30 minutes following eating and drinking. This reduces the risk of reflux and aspiration.

6.2.3.4 Supportive Techniques
An individualised eating and drinking plan will specify any techniques required to support safe swallowing. These may include:
- food to be taken in small mouthfuls
- allow ample time for chewing and swallowing before taking another mouthful
- do not rush
- if feeding, sit in front of the person
- give a dry spoon between every three-four mouthfuls of food to promote swallowing
- gently support jaw to ensure mouth closure
Support staff may need guidance and modeling from Nurses to effectively implement some techniques. Ensure that only person is fed at a time,

6.2.3.5 Environmental Considerations
A calm and relaxed eating and drinking is important for everyone. It is essential for people with dysphagia whose swallowing risks are increased in environments that cause hurrying or distraction. Noise levels, loud noise, distractions, unfamiliar people, unfamiliar environments, room temperature, comfort all have an impact on eating and drinking.

6.2.4 Hydration
People with dysphagia, particularly those on thickened fluids, often drink less. As people age, they drink less. People with communication impairments may have difficulty communicating thirst. Attaining adequate hydration can present problems in people with dysphagia, especially when they are dependent on others for drinks.

Nurses are responsible for monitoring the symptoms of dehydration which include:
- dry, sticky mouth
- thirst
- low urinary output
- concentrated urine
- dry skin
- headache
- constipation
- lightheadedness, dizziness

When indicated, nurses are responsible for organising the recording of daily fluid intake (and output if necessary). Fluid balance are tallied at the end of 24 hours and negative or positive balances are recorded in the person’s notes. Fluid requirements are usually calculated as 30ml per kg body weight or 6-8 cups of fluid a day

Strategies to increase hydration include:
- Communicate the importance of hydration to all team members and educate individuals, families, carers and support staff.
- Encourage and remind people to drink as per plan.
- Offer small drinks regularly and frequently.
- Replace disliked fluids with drinks that are acceptable.
Fluids are obtained from a wide range of sources (which may need thickening as per plan) – milkshakes, smoothies, tea, coffee, soups, jellies, custard, yoghurt. **Warning**: ice cream, sorbets, ice blocks, some jellies melt in the mouth and become thin fluids.

- Fruit and vegetables are a good source of fluid, especially those with a high water content like watermelon and tomatoes. Be cautious and re textures and add watermelon and other fruits to smoothies. Use tomatoes in cooking.
- Encourage fluids with medication when feasible
- Closely monitor and record on a fluid balance chart all episodes of diarrhoea and vomiting.

### 6.2.5 Medications and Dysphagia

Some medications may affect swallowing by interfering with oesophageal muscle control (e.g., Cogentin), or by causing a dry mouth (e.g., ACE inhibitors, diuretics).

Some medications are difficult to swallow and may be a problem for people with swallowing difficulties. However, a number medications cannot be crushed or dissolved to be given as a liquid, particularly when they are sustained-release or have an enteric coating.

Nurses should speak with a Pharmacist regarding information about crushing and dissolving medication. Always ensure that prescribing GPs, Specialists and Dentists are aware of a person’s swallowing difficulties when prescribing medication. Occasionally, in the absence of a suitable alternative, the Doctor will prescribe an essential medication that will have to be crushed or dissolved (even though this is not ideal).

Staff in ADHC organisations should refer to the Medication Policy and Procedures (available on ADHC intranet only).

### 6.2.6 Oral Health and Dysphagia

Poor oral health results in high levels of plaque and bacteria in the oral area. This has been implicated as a significant factor in the development of aspiration pneumonia. Oral health is essential in the prevention of complications of dysphagia. Refer to Section 5.1.4 *Oral Health* for information on the management of oral health.

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**For further information see:**


- **Medicines Optimisation in Patients with Dysphagia.** UK website that provides practical guidance on the administration of medications to people with dysphagia. [http://dysphagia-medicine.com/](http://dysphagia-medicine.com/)

- **Ensuring Safer Practice for Adults with Learning Disabilities who have Dysphagia.** UK NHS site with numerous resources. [http://www.nrls.npsa.nhs.uk/resources/?entryid45=59823](http://www.nrls.npsa.nhs.uk/resources/?entryid45=59823)
[http://www.cmaj.ca/content/172/7/871.full]
Understanding Dysphagia, Nestle Healthcare. YouTube Presentation
[http://www.youtube.com/watch?v=jK1o3LSQmB0]
‘Swallowsafe’ DVD – a guide to effective and safe swallowing for people with developmental disabilities. Available from the Gastroenterology Clinic, the Children’s Hospital at Westmead.

Following resources are available to ADHC staff only:
Contact your Manager or Nursing and Health Care Practice Leader regarding access.

ADHC Mealtime Management Modules are an excellent e-learning resources that cover the complex issues related to mealtimes and people with disabilities. They expand on material covered in this practice package. At the time of developing this Practice Package, the Modules are being rewritten. The web link will change.

ADHC Practice Packages:
Speech Pathology
Dietetics
Physiotherapy
Occupational Therapy

(Sources used for Sections 6.2 – 6.2.6: FACS:ADHC, 2012; Therapeutic Guidelines, 2012)

6.3 Enteral Nutrition
Refer also to Section 5.1.1 Management of Dysphagia for complementary information for this section.

When people are unable to take in food or fluids orally, non-oral feeding may be indicated.

Non-oral feeding falls into two main categories:
1. **Enteral nutrition** (sometimes called tube feeding):
   - via nasogastric (NG) tube – tube passes up through the nose, to throat and down to the stomach. Usually used as a short-term measure during illness, etc.
   - gastrostomy – tube goes through abdomen into the stomach. Usually this is a percutaneous endoscopic procedure (PEG tube)
   - jejunostomy – tube through abdomen into the small intestine. May be placed using percutaneous endoscopic jejunostomy (PEJ, sometimes called J tube)
2. **Parenteral nutrition** delivers nutrients directly into the bloodstream so as to bypass the gut. This is less common and managed by the medical team in hospital

The focus in this package is on enteral nutrition, especially via gastrostomy, because this is what is most commonly encountered in disability nursing practice.
**Enteral nutrition** support refers to the introduction of nutrition directly into the stomach or small intestine via a tube. Such nutrition is usually a complete nutritional formula. However, sometimes thickened fluids or a fortified drink might be given into the stomach to supplement inadequate oral nutrition.

### 6.3.1 Reasons for Enteral Nutrition

Enteral nutrition is considered when an individual is:
- not safe for oral intake
- or when oral intake is not enough to meet nutritional requirements.

These problems are often associated with:
- neuromuscular problems that affect chewing and swallowing coordination that may result in aspiration (e.g., dysphagia associated with cerebral palsy, motor neurone disease, brain injury, Huntington’s disease, stroke)
- medical problems and/or structural abnormalities of the gastrointestinal tract, e.g., inflammatory bowel disease, cancers, hepatic, renal or respiratory failure, anorexia, HIV/AIDS.
- cognitive impairments that affect capacity to coordinate chewing and swallowing safely
- fatigue associated with illness
- failure to thrive or severe reflux in infants
- reduced level of consciousness

If safety is a major concern, such as in the case of severe dysphagia and chronic aspiration, all nutrition and hydration will be administered via tube. Gastrostomy tube insertion has sometimes been combined with fundoplication to reduce reflux and aspiration. However, a person who has had both procedures may still aspirate saliva, so correct posture and positioning are still essential. Note that fundoplication is no longer recommended as best practice.

In some instances, tube feeding is a supplement to oral intake. This is more common in situations where intake is inadequate, but swallowing safety is a secondary consideration. It is preferable to maintain some oral intake where possible to maintain function and sensual enjoyment.

These decisions are made with persons and their families following assessment by a Speech Pathologist, along with other specialists, such as a Dietitian, Gastroenterologist, Paediatrician

### 6.3.2 Making Decisions about Enteral Nutrition

Making decisions about permanent gastrostomy placement is fraught for individuals and their families. Mothers in particular are faced with anxiety and guilt about not being able to adequately feed their children. Families and carers worry about causing unnecessary pain and distress and are also concerned about the loss of sensual and social pleasure derived from eating experiences. Families sometimes feel rushed and coerced by professionals to make decisions about tube feeding (Brotherton & Abbott, 2012; Sleigh, 2005).
It is essential that families are supported during the decision-making processes related to gastrostomy placement. Decisions must be person-centred to enable families feel they are making a true choice in the interest of the child or person for whom they are responsible.

An ethical decision-making framework is helpful when assessing and managing dysphagia in people with disabilities. *Therapeutic Guidelines, Developmental Disability* (2012, p.192) provides an example of a framework that considers swallowing function, along with potential harms and benefits to the person in the broader psychosocial context.

### 6.3.3 Delivering Enteral Nutrition

Decisions about methods of enteral feeding are made by the person, family and members of the multidisciplinary team in consultation with a Dietitian.

Enteral feeds may be delivered in the following manner:

- **Bolus Feeding.** Nutrition and fluids are delivered by gravity. This is the simplest method and requires minimal equipment. It allows for regular mealtime feeding regimes. However, it increases the risk of adverse gastrointestinal (GI) symptoms, e.g., ‘dumping’ leads to vomiting; diarrhoea.
- **Intermittent Feeding.** Involves smaller amounts by gravity or pump. Allows time free from feeding, but increases risk of GI problems.
- **Continuous Feeding.** Delivered by pump in small amounts. Decreases risk of GI symptoms but person is connected to system and mobility may be reduced.

The Dietitian calculates formula feed requirements and fluid intake. These calculations consider body weight, nutrition and energy requirements. Fluid intake includes water needed for flushes and medication administration. These requirements are documented on a nutrition care plan. Regular reviews (usually six monthly in the absence of change) by the Dietitian are necessary to ensure adequate intake of fluid, energy, protein and micronutrients.

Appropriate posture and positioning during feeding and for 30 minutes afterwards are essential to prevent reflux and aspiration.

### 6.3.4 Enteral Nutrition – Some Practical Considerations

**Diarrhoea** is a risk for people receiving enteral nutrition.

Causes of diarrhoea include:

- intolerance to the formula
- some medications, e.g., antibiotics
- feeding the formula when it is too cold, i.e., straight from the fridge
- feeding the formula too fast
- using formula at room temperature for more than four hours
- contamination by poor hygiene practices, e.g., poor hand washing, hanging feeds for too long, water flushes not cleaning tubing adequately.

Information about practical issues such as:

- feeding tubes – care and management
feeding tubes – trouble shooting
feeding and nutrition plans
HEN resources

is readily available. Many sources are listed in the box below. The Agency for Clinical Innovation (ACI): Nutrition is a good place to start. Go to Resources for Clinicians.

The sensual and social aspects of eating and drinking are important for people receiving enteral nutrition. Where possible the Speech Pathologist and Dietitian will incorporate some minimal oral intake if safe. This can be taken at regular meal times with other people. If not safe, consult with members of the multidisciplinary team regarding strategies to enhance nutritional enjoyment.

For further information see:
Agency for Clinical Innovation (ACI): Nutrition
Australasian Society for Parenteral and Enteral Nutrition (AuSPEN)
AuSPEN, Clinical Practice Guidelines: Home Enteral Nutrition in Australia
Gastrostomy Information and Support Services (GISS)
GISS (NSW) Membership Contact
Guidelines for Home Enteral Nutrition (HEN) Services. GMCT, now ACI.
Home Enteral Nutrition (HEN) Equipment Forms and Guidelines
HEN Feeding Plan
HEN Feeding Tubes – Troubleshooting
HEN Tubes – Care and Management
Medicines Optimisation in Patients with Dysphagia. UK website that provides practical guidance on the administration of medications to people with dysphagia.
http://dysphagia-medicine.com/
Ensuring Safer Practice for Adults with Learning Disabilities who have Dysphagia. UK NHS site with numerous resources.
http://www.nrls.npsa.nhs.uk/resources/?entryid45=59823
http://www.cmaj.ca/content/172/7/871.full
‘Swallowsafe’ DVD – a guide to effective and safe swallowing for people with developmental disabilities. Available from the Gastroenterology Clinic, the Children’s Hospital at Westmead.

**Following resources are available to ADHC staff only:**
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ADHC *Mealtime Management Modules* are an excellent e-learning resources that cover the complex issues related to mealtimes and people with disabilities. They expand on material covered in this package. At the time of developing this Practice Package, the Modules are being rewritten and will be available on ADHC’s Learning Management System. The web link will change.

ADHC Practice Packages:
- Speech Pathology
- Dietetics
- Physiotherapy
- Occupational Therapy

(Sources used for Sections 6.3 – 6.3.4: Burton, Cox & Sandham, 2009; DAA, 2011; FACS: ADHC, 2012; Pearce & Duncan, 2002; Somerville *et al*, 2008; Therapeutic Guidelines, 2012; Yates, 2013)
### Practice Points: MEALTIME MANAGEMENT

- Nurses must have a comprehensive understanding of risk factors and adverse outcomes related to poor nutrition.
- Nurses perform an essential role in the screening and monitoring of nutritional status, along with risk factors for poor nutrition.
- Good nutrition underpins health and wellbeing.
- Malnutrition, resulting in underweight, obesity and lack of essential nutrients, is prevalent in people with intellectual disabilities.
- Good nutrition is related to sensual and social experiences and socioeconomic factors.
- Nutritional problems may exist even when healthy food is available.
- Nutritional problems can be complex and are associated with pathology that interferes with intake, digestion and absorption of nutrients.
- Appetite problems are a signal for assessment of physical and psychological health issues.
- Undernutrition and overnutrition must be assessed for causes. Referral to members of multidisciplinary is necessary for full assessment.
- Impaired communication, along with dependence on others, are major contributors to inadequate nutrition and hydration for people with intellectual disabilities.
- Inadequate nutrition and hydration are identified as causing death in vulnerable people. Education of support staff and regular monitoring of people with disabilities are essential to address such preventable deaths.
- High rates of dysphagia in people with intellectual disabilities result in aspiration, pulmonary infection and death.
- Effective management of dysphagia enhances health and prevents death.
- Pulmonary aspiration of saliva, food, drink, or gastric contents may be apparent or ‘silent’.
- Regular screening for dysphagia is essential, along with referral to members of multidisciplinary team for specialised assessment when indicated.
- Appropriate positioning and posture are essential in dysphagia, and eating and drinking management.
- People with dysphagia are at high risk of dehydration.
- Nurses educate families and support staff about implementation of eating and drinking plans.
- Some medications affect swallowing.
- Poor oral health contributes to aspiration pneumonia.
- Enteral nutrition may be necessary for swallowing safety and adequate nutrition and hydration.
- Decisions regarding permanent enteral feeding are very difficult for individuals, families and carers. Nurses must be aware of this and ensure adequate information and support.
- Nurses are responsible for ensuring Dietitians’ plans for feed and fluid requirements are implemented correctly. Fluid calculations must include water flushes. Nurses may plan the fluids across a 24 hour period.
• Social and sensual aspect of eating must not be neglected for people with gastrostomies.
• Nurses are responsible for ensuring they are up to date with best practice in enteral feeding practice.
6.5 Readings and Resources for Mealtime Management


ThinkGP. Free online education and news for Australian health professionals. Create a free account to access many learning modules, some of which are accredited by the ACN for nursing CPD points. [http://thinkgp.com.au/](http://thinkgp.com.au/)

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