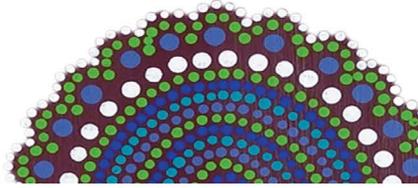
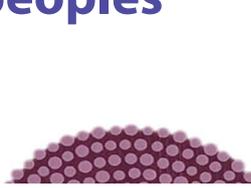
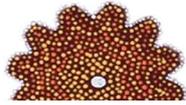


# 18

## Intellectual Disability in Aboriginal and Torres Strait Islander peoples



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### OVERVIEW

The aim of this chapter is to examine current and emerging themes in respect to intellectual disability to assist clinicians and their patients. Recent literature points to an increased rate of intellectual disability across the lifespan, from childhood, adulthood and old age, in Aboriginal and Torres Strait Islander peoples with a number of factors that appear to accelerate the prevalence from roughly two times the rate in childhood to five times the rate for people over 65 years of age. The chapter examines the various factors that impact on this issue including diagnosis, contributing factors, Aboriginal perspectives on intellectual disability, the impacts on family, the importance of an interdisciplinary approach in management and assessments that may be of use.

### INTRODUCTION

Current estimates state that approximately eight per cent of Aboriginal and Torres Strait Islander peoples aged between 12 and 24 years are considered to have ‘problems of psychological development’—this is approximately double the remaining population.<sup>1(p4-5)</sup> About 35 per cent of Aboriginal and Torres Strait Islander peoples who are affected by ‘severe or profound core activity disability’ have an intellectual impairment associated with this disability. Glasson et al.<sup>2</sup> (2005) in their study in Western Australia (WA) found that, although comprising 3.5 per cent of the population, Aboriginal and Torres Strait Islander peoples represented 7.4 per cent of all people registered with intellectual disability. The level of intellectual disability was assessed as borderline or mild in 40.7 per cent of cases, moderate in 19.9 per cent, severe or profound in 12.1 per cent, but had not been specified in 27.2 per cent of cases. Analyses of rates of childhood intellectual disability in WA by Leonard et al.<sup>3,4</sup> have indicated a significantly greater prevalence rate of 2.3 for mild to moderate intellectual disability in children of Aboriginal mothers. The analysis by Leonard et al.<sup>4</sup> further suggested that the occurrences of Autism Spectrum Disorders (ASDs) was less for the Aboriginal population. However, the issues raised by Roy and Balaratnasingam (2010)<sup>5</sup> in respect to the proper identification of Aboriginal and Torres Strait Islander peoples affected by ASDs suggests that the prevalence of intellectual disability may be greater than reported. In addition to this initial risk factor for intellectual disability in childhood and early adult life, Aboriginal and Torres Strait Islander peoples appear more at risk for other factors related to intellectual disability across the lifespan. A survey by Smith et al.<sup>6</sup> conducted in the Kimberley region of WA of Aboriginal people over 45 years of age found a prevalence rate of 8 per cent of cognitive impairment ‘not related to dementia’ and those over 65 appear to be suffering dementia at five times the rate of other Australians.<sup>7</sup>

## DEFINITION OF INTELLECTUAL DISABILITY

Leonard and Wen<sup>8</sup> describe a range of factors that can determine whether an individual is diagnosed as having an intellectual disability. This includes ‘medical’, ‘individual’ and ‘statistical’ (population and group) approaches to the definition, and the diversity in the key criteria for definition.

Brown and Percy<sup>9</sup> note that the evaluation of the term ‘intellectual disability’ relates to the ‘literal, definitional and social’ contexts in which it occurs. Depending on the definitions used, the prevalence can vary enormously and it is important to be consistent. For a detailed discussion see Leonard & Wen.<sup>8</sup>

- **Literal** definitions relate to the specific meanings of the words ‘intellect’ and ‘disability’ that compose the term. As an example of this, the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10)* defines intellectual disability as ‘arrested or incomplete development of the mind which is specifically characterised by impairment during the developing period of skills that contribute to the overall level of intelligence’.<sup>10</sup>
- **Definitional** meanings relate to what the terms mean for particular groups, organisations or purposes involved with individuals affected by the condition. As an example, intellectual disability is defined in a legal context as ‘a significantly below average intellectual functioning existing concurrently with two or more deficits in adaptive behaviour’<sup>11</sup> whilst in the context of a helping organisation as:

*... an impaired ability to learn. It sometimes causes difficulty in coping with the demands of daily life. It is a condition which is usually present from birth and it is not the same as mental or psychiatric illness*<sup>12(p2)</sup>

- **Social** definitions are dependent on how various societies evaluate ‘ability’ in respect to the skills that people should have and thus ‘what they should be able to perform’.<sup>13</sup> This has particular importance in the context of Aboriginal and Torres Strait Islander communities. Sotiri et al.<sup>14</sup> note that:

*Indigenous people often do not use, or recognise, the term ‘disability.’ Within communities, there is frequently recognition that someone is ‘different’, but this difference tends to be accommodated. Various impairments are viewed as simply one part of the person, but are often not considered central or core to one’s identity.*<sup>14(p9)</sup>

All these issues including disability are intertwined. The authors add:

*It was also noted by Indigenous stakeholders in our conversations, that in some communities, the presence of disability is viewed as simply one more disadvantage in a whole raft of disadvantages, and it is for this reason that it tends not to warrant any particular attention. When compared with suicide rates, imprisonment rates, levels of violence experienced in communities and institutions, drug and alcohol misuse, and other issues reflecting the challenges faced by severely fractured communities, disabilities were often considered to be fairly low on the scale of priorities. As with disability in the wider community, the support and management of cognitive and mental impairment is often left to the family to manage. And again, as is the case with the wider community, this only changes when the person with the impairment begins to impact on the wider community through their behaviours.*<sup>14(p9)</sup>

In addition, Stopher and D’Antoine<sup>15</sup> point out that Aboriginal families consider themselves to be accepting and supportive of family members with a disability and, while their specific impairment prevented them from doing certain tasks, they were still involved in the kinship system with roles and responsibilities.

Hollingsworth<sup>16</sup> also comments that:

*A long history of poverty, marginalisation and racism (for Australia's Aboriginal and Torres Strait Islander population following European colonisation) can mean that many Indigenous Australians do not see impairment as a disability but as an aspect of more general challenges and disadvantages.*<sup>16(p9)</sup>

## ASSESSMENT OF INTELLECTUAL DISABILITY

### Principles of Culturally Relevant Assessment

Brown and Percy outline five basic principles of assessment integral to the management of any person (including those of Aboriginal or Torres Strait Islander descent) believed to be affected by an intellectual disability and who is behaving in a way that brings them to the attention of others.<sup>9(p.1)</sup>

#### Principles for Assessing Intellectual Disability

1. Attend to a situation or problem that may have come to one's attention for a specific reason or simply because it is occurring in a person's life.
2. Gather as much information as possible about the situation or problem. In the Aboriginal and Torres Strait Islander context, significant information in respect to the family, cultural and spiritual context of the problem would also be of major importance.
3. Analyse which aspects of the situation are working well (strengths) and which are not working well (needs).
4. Understand the factors that help improve the situation as well as the factors that limit the improvement.
5. Decide on plans to maintain or enhance factors that help improve the situation and to decrease or eliminate factors that hinder improvement. Plans that are put into place in this regard are referred to as interventions.

A multidisciplinary team, in a context of cultural safety, best conducts such assessments. A broad based approach to the issue is also useful given the large number of potential genetic issues and other factors affecting Aboriginal and Torres Strait Islander peoples in Australia both prior to, and following, European colonisation. A good example of this is Machado-Joseph Disease, a severe neurodegenerative disorder (without intellectual disability) that profoundly affects some Aboriginal families living on Groote Eylandt. The disease was initially thought to be due to exposure to manganese which was mined on the island but it was then discovered that it had a genetic basis, probably related to contact between the Groote Eylandt population and Asian seafarers up to 7,000 years previously.<sup>17</sup>

A multidisciplinary/interdisciplinary team may involve medical experts (pediatricians, rehabilitation physicians, geriatricians, psychiatrists, general practitioners) appropriate to the age of the person being assessed along with other allied health professionals—see Chapter 13 (Shultz, Walker and colleagues). Psychologists, specialist nurses, speech pathologists, physiotherapists, occupational therapists, dieticians and social workers may also be members of the multidisciplinary team. Members of government and non-government organisations appropriate to the person's age and level of impairment may also be needed in such assessment.

The involvement of Aboriginal Health Workers (AHWs), Aboriginal Mental Health Workers (AMHWs), and appropriate family members and translators, are essential to address cultural safety issues within the multidisciplinary team process. Educational experts could be involved in the case of children being assessed in relation to their potential for school. Table 18.1 outlines the roles that different health professionals may play in the management of Aboriginal and Torres Strait Islander peoples affected by intellectual disability. For further discussion of interdisciplinary teams, see Chapter 13 (Schultz and Walker and colleagues).

**Table 18.1:** The Role of Health Professionals in Managing Intellectual Disability

<i>Health Professional</i>	<i>Roles</i>
Nursing	Monitoring of epilepsy, mental illness, medications, setting up of behavioural interventions, educating families on the impact of ID and comorbid conditions
Psychiatrists	Assessment and management of mental illness, epilepsy, developmental disorders e.g. autism, Attention Deficit Hyperactivity Disorder (ADHD)
Psychologists	Management of behavioural problems, provision of specialist interventions available to those without ID e.g. bereavement counselling, anger and anxiety management, social skills training
Occupational Therapists	Advice on activities, aids and adaptations, sensory integration for people with autism
Speech and Language Therapists	Communication, assessment of dysphagia
Physiotherapists	Management of contractures, mobility problems, aids and adaptations, seating assessments
Dieticians	Help with special diets for people with dysphagia, eating problems associated with autism, management of obesity
Social Workers	Accessing appropriate day activities, respite care, residential care, benefits

Source: Balaratnasingam and Roy (2013)

### The Physical Health Needs of People Affected by Intellectual Disability

The physical health of the person being assessed also needs to be considered. The median survival for Aboriginal people affected by intellectual disability was 55.1 years for men and 64.0 years for women, with a mean age at death (n = 102) of 19.6 years.<sup>2</sup> The leading causes of death were diseases of the respiratory and circulatory system, and accidents. Cheetham et al.<sup>18</sup> also review other medical conditions currently experienced by individuals affected by intellectual disability. For example, Aboriginal and Torres Strait Islander peoples have much greater impairments in hearing and vision than the general Australian population and this may influence the assessment process if not recognised<sup>1</sup>.

The contextual health problems of Aboriginal people affected by intellectual disability living in the community, and who have a high prevalence of physical health requirements, need to be understood in the context of the causes of intellectual disability, be they specific syndromes or what we might call ‘functional’—that is, mainly a cognitive deficit without other features. For instance, these physical needs may be just part of having intellectual disability, while others are associated with any underlying syndrome. Some may be associated with specific syndromes (e.g. cardiac abnormalities and thyroid dysfunction in Down syndrome); a side effect of drug therapy (e.g. obesity and metabolic syndrome due to antipsychotic medication); consequence of lack of opportunities (e.g. lack of exercise leading to obesity and inability to care for themselves and self-monitor leading to poor oral health); and poor hearing and vision. Other physical conditions include poor oral hygiene, exacerbated in rheumatic heart disease; gastrointestinal diseases; respiratory infections; musculoskeletal deficiency, including reduced bone and muscle strength from poor diet; genitourinary infections; central nervous system impairment; and neurological disorders such as epilepsy and skin infections.<sup>19</sup>

## Scenario 1 **Emily's story**

*Emily is a 37 year-old Aboriginal woman with profound intellectual disability who lives in a group home and is normally very settled in the context of a stable community of care staff who work at the home and a good relationship with the other residents of the home. She has a comprehensive behavioural plan that has been developed in co-operation with her care organization, her adult guardian and her family. She normally receives medical care from her General Practitioner. Emily is brought to the local hospital Emergency Department late one afternoon by her care staff because she has become acutely disturbed. She is unable to sit still or focus on her normal daily activities within her care and behaviour plans. In addition to her agitation, she has started repeatedly striking herself in the head. One of her care staff wants her placed on sedating psychotropic medication to “settle her down”. However, a careful physical examination of Emily by the Emergency Department physician reveals that she has a hard abdomen and an X-Ray of her abdomen confirms that she is severely constipated. Emily is treated for her bowel problems with the approval of her family and guardian and her agitation settles almost immediately once the constipation is resolved and she is subsequently able to return to her group home with recommendations for ongoing bowel care. At discharge from hospital, it is thought that Emily's intense agitation may have related to the discomfort that she experienced from the constipation and her inability to verbalise her distress.*

### Approach to Assessment and Management

Given the above factors, the ideal approach for the assessment and management of Aboriginal people with an intellectual disability should focus on:

- Gathering as much information as possible about the person's original function, the presumed disease process impacting on them, and what has changed for them and is impacting on their lives and the lives of their families, carers and community;
- Including allied health professionals to contribute to the identification of an individual's impairments and solutions for their rehabilitation;
- Identifying and implementing strategies (including medication, behavioural, environmental and social) developed in conjunction with the client, their families, communities and available services. This will lead to the best interim solution that will need to be evaluated and modified over time according to the needs of the client and their carer and support network. See the new guidelines relating the *Cultural Formulation Interview* in the DSM-5 in Chapter 16 (Adams, Drew and Walker).

## CHILDHOOD CONDITIONS ASSOCIATED WITH INTELLECTUAL DISABILITY

Percy makes the comment that intellectual disability is the end product of genetic and environmental factors.<sup>20</sup> There are usually a number of medical and psychiatric conditions alone or in combination that commonly underlie intellectual disability in children. These are briefly discussed in the context of this chapter. A more thorough discussion of each condition can be found in textbooks such as Brown and Percy<sup>9</sup> or other authoritative sources. Some of the genetic risk factors are referred to below and, given the ‘cultural mix’ in respect to the broader lineage of many Aboriginal and Torres Strait Islander peoples today, a range of genetic disorders may affect children and adults.

The environmental factors that Percy refers to include malnutrition,<sup>21</sup> toxic threats to a child's environment such as mercury and lead, prenatal maternal smoking and maternal alcohol misuse,<sup>22</sup> maternal effects such as diabetes and high blood pressure in pregnancy, low birth weight in infants,<sup>23</sup> intrauterine infections such as syphilis, rubella, cytomegalovirus and herpes simplex and post natal brain injury. Aboriginal and Torres Strait Islander peoples generally

appear to have a greater risk for most of these factors.<sup>24</sup> Glasson et al.<sup>2</sup> found in their prevalence study that non-genetic prenatal or perinatal factors were common, representing 36 per cent of cases.

These factors included maternal drug or alcohol use during pregnancy, physical trauma, multiple births, birth complications, infections and low birth weight. Women in rural and remote areas may also find it difficult to access optimal prenatal care and neonatal screening.

### ***Fetal Alcohol Spectrum Disorder***

Fetal Alcohol Spectrum Disorder (FASD) is technically one of a number of conditions contributing to intellectual disability in children. However, there is significant concern about the apparent increasing prevalence of the disorder in the Aboriginal and Torres Strait Islander population. For a detailed discussion of FASD, see Chapter 20 (Hayes and colleagues).

### ***Down Syndrome***

The condition is caused by an abnormality of Chromosome 21 that is associated with a number of physical abnormalities as well as intellectual disability.<sup>25</sup> Its prevalence in the developed world is 1 per 800 to 1,000 live births.<sup>25</sup> It is usually diagnosed initially by abnormalities in the foetal ultrasound and then by chromosome studies obtained through obstetric procedures such as amniocentesis.

### ***Fragile X Syndrome***

The condition is the most common form of inherited intellectual disability in the world and tends to affect men more severely than women. It has a range of characteristic physical features as well as intellectual disability.<sup>26</sup>

### ***Autism Spectrum Disorder (ASD)***

Autism is a behaviourally defined syndrome with a range of abnormal restrictions in the ability to form social relationships, language and symbolic or imaginative play in addition to stereotyped or repetitive behaviours.<sup>27</sup> The current prevalence of ASDs in the population is thought to be around 62.5 per 10,000.<sup>5</sup> Genetics, epilepsy and birth complications may have some relationship to autism although the appreciation of these issues is still at an early stage. A diagnosis of autism may be missed in the Aboriginal and Torres Strait Islander population owing to cultural and language barriers and the difficulty in obtaining an accurate developmental history, and individuals suffering from autism may be mistakenly diagnosed as suffering from schizophrenia as a consequence.<sup>5, 28</sup>

### ***Asperger Syndrome***

Asperger syndrome is another behaviourally defined syndrome characterised by impairments in emotional and social developments along with stereotyped or repetitive behaviours, inflexible adherence to routines, and abnormal preoccupations with objects or parts of objects.<sup>29</sup> The prevalence in the developed world is estimated to be 3.6 per 1,000 with a male to female ratio of 4 to 1. Genetic causes are thought to be a substantial contribution to the syndrome.<sup>29</sup>

### ***Cerebral Palsy***

Cerebral palsy is an umbrella term covering a group of disorders of movement and posture due to a non-progressive defect or injury to the developing brain occurring at any stage from conception to early childhood. These motor disorders can range in severity from barely noticeable to totally disabling and are often accompanied by other disabilities such as visual, hearing or cognitive impairments, epilepsy and/or disturbances of perception and behaviour.<sup>30</sup> The prevalence of cerebral palsy in developed countries is around 2–2.5 per 1,000 live births<sup>31, 32</sup> with a greater preponderance in more deprived socioeconomic groups.<sup>33, 34</sup>

## ***Epilepsy***

Epilepsy is defined as a group of neurological disorders characterised by spontaneous recurring seizures.<sup>35</sup> It is estimated that 4 per cent of the population may suffer from epilepsy during their lifetime.<sup>35</sup> Intractable epilepsy that starts in childhood may be associated with intellectual disability. Epilepsy can also occur in association with other conditions such as Down syndrome, cerebral palsy, Alzheimer's disease, stroke and acquired brain injury.<sup>31, 36</sup>

## ***Attention Deficit Hyperactivity Disorder (ADHD)***

Individuals affected by this condition have traditionally been regarded as possessing the ability to learn but having significant interruption to this ability through inattention and hyperactivity.<sup>37</sup> The prevalence of this condition in developed countries is thought to be 3 per cent to 7 per cent of school age children.<sup>37</sup> Neece et al. found that ADHD was three times more prevalent in children with an intellectual disability compared with those with a typical development and they experience a more prolonged course of the disorder.<sup>38</sup>

## ***Rare Conditions contributing to Intellectual and Developmental Disability***

Table 18.2 lists a number of other rare conditions that may result in intellectual and developmental disability.<sup>20</sup> Clinicians or families are advised to consult authoritative experts or information sources if they have concerns or are seeking further information in respect to these conditions.

**Table 18.2:** Rare Conditions of Childhood that may result in Intellectual and Developmental Disability<sup>20</sup>

Angelman Syndrome	Noonan Syndrome
Batten Disease	Paediatric Stroke
CATCH 22/22q11.2 Deletion Syndrome	Phenylketonuria
Congenital Hypothyroidism	Prader-Willi Syndrome
Congenital Rubella Syndrome	Progressive Myoclonic Epilepsy
Cornelia De Lange Syndrome	Rett Syndrome
Cri-du-Chat Syndrome	Sanfillipo Syndrome/ Mucopolysaccharidosis Type II
Developmental Coordination Disorder	Shaken Baby Syndrome
Hunter Syndrome/Mucopolysaccharidosis Type II	Smith-Lemli-Opitz Syndrome
Hypoxic-Ischemic Encephalopathy/Neonatal Encephalopathy	Smith Magenis Syndrome
Intraventricular Haemorrhage	Sturge-Weber Syndrome
Klinefelter Syndrome	Tourette Syndrome
Lafora Disease	Traumatic Brain Injury in infancy and childhood
Lesch-Nyhan Syndrome	Tuberous Sclerosis
Meningitis	Turner Syndrome
Neurofibromatosis	Williams Syndrome
Neuronal Migration Disorders	

## Scenario 2 Roger's story

Roger, a five year-old boy, is referred to a local child and adolescent mental health service by his paediatrician for further assessment. Roger is the third of four children for his mother and father. His mother is an Aboriginal person with an Irish grandfather and his father is Torres Strait islander with a French grandmother. Roger's mother reports that his pregnancy was complicated by poor weight gain and that he was very small when he was born at 34 weeks and required 6 more weeks of support in hospital before he was allowed to go home. Roger generally has had delayed developmental milestones, including language delay and delay in spontaneous play. His parents are now concerned about his lack of emotional response and temper tantrums. They are not aware of any history of mental illness on either side of their families.

The paediatrician says that Roger's hearing and vision appear to be normal and he does not appear to have any other serious medical problems. The paediatrician has also referred Roger to a speech pathologist to assess his communication development. Roger is assessed by a multidisciplinary team who work with Roger and his family to establish a context for his condition. This involved interventions that had been tried previously and assessing which of these had worked and which had not. Information about what is a typical day for Roger is also obtained. The process of family functioning is also explored in how they generally normally function and respond to crises and what supports they have. After gathering the data and an assessment of Roger that includes a mental state examination, the multidisciplinary team work together to develop a formulation about Roger's issues. The formulation includes a provisional identification of his problem and how the problem affects him, his family, their support systems. A 'philosophy of care' may focus on whether a chronological, developmental or age appropriate approach is best. The team also may decide that further investigations are needed such as psychological investigations.

The team then discuss their formulation and proposed interventions with Roger's family. In this case, it was decided to perform a further formal evaluation of Roger with an Autism scale. Behavioural programs to encourage emotional response and the temper tantrums were discussed with the family. The family were given information about support groups such as Autism Australia and educational resources available to Roger as he is approaching school age. Ongoing review by a mental health team clinician along with communication strategies for the team, Roger's family, paediatrician and general practitioner are discussed and implemented.

## ACQUIRED BRAIN INJURY

The risk of Aboriginal and Torres Strait Islander peoples suffering a brain injury appears to be substantially higher than among the wider population. Aboriginal and Torres Strait Islander peoples of both sexes and aged below 64 years are much more likely to die from 'injury and poisoning' causes and a significant number of these deaths relate to intentional self-harm, traffic accidents and assaults.<sup>1</sup> Outcomes of head injury and subsequent intellectual disability are closely aligned with this higher risk. Acquired Brain Injury (ABI) is any kind of damage to the brain that occurs after birth. Traumatic brain injury is the term that tends to be used for brain injuries that occur through accidents, falls, or assaults. Other kinds of acquired brain injury occur such as strokes, loss of oxygen to the brain, degenerative neurological diseases, and drug and alcohol misuse.<sup>14</sup>

### Acquired Brain Injury as a Result of Trauma

Males are about three times more likely to suffer severe brain trauma compared with females, and the most common causes of fatal head trauma are motor vehicle accidents, falls and assaults.<sup>39</sup> In Australia, death rates from external causes that closely align to traumatic head

injury, such as intentional self-injury, transport accidents and assaults in Aboriginal and Torres Strait Islander peoples, is over double that for the wider population.<sup>1</sup> Smith et al.<sup>40</sup> in their Kimberley survey found that the most common cause of head injuries in the survey population was fighting/violence (46.5 per cent) followed by horse riding accidents (14.6 per cent), motor vehicle accidents (10.3 per cent), falls (7 per cent), sorry time (hit head with hard object when family member died) (5.9 per cent), a sporting accident and lightning strike (both 0.5 per cent).

It is important to recognise that people do not have to experience loss of consciousness to suffer a potentially devastating brain injury. Impact to the head through activities such as sporting events, falls and fights may daze an individual without him or her being knocked out. The period of confusion and disorientation following impact to the head is called Post Traumatic Amnesia (PTA) and is another measure of the severity of brain trauma.<sup>41</sup>

PTA is measured from the moment a person suffers impact, to the time he or she is able to recall events and retain orientation consistently. If there is prolonged concussion, a person is deemed to have recovered from PTA on the first of three consecutive days, as assessed by a hospital clinician. It is a widely regarded indicator of the prognosis of recovery from brain injury, with longer duration of PTA correlating to poorer outcomes. PTA ranges from mild (1 minute to 1 hour) to moderate (1 hour to 1 day) to severe (1 day to 1 week) to very severe (1 week to 1 month) to extremely severe (more than 1 month) to chronic (more than six months).<sup>42</sup>

Invariably, after any length of PTA, a person will experience some level, even very subtle levels, of cognitive and/or behavioural change. Such changes range from difficulty organising multi-step or complex tasks and being stuck on one line of thinking, to problems remembering, lowered frustration tolerance and increased irritability. Fatigue is extremely common after brain injury, and the above changes tend to be accentuated when fatigued. There is often confusion and agitation when a person has not been admitted to hospital, but discharged after a few hours of neurological observation in the emergency department. It is common for the individual, family and friends to think 'he's fine'. However, people very often complain of the types of changes mentioned above, without realising that it relates to the impact of brain injury. Returning to pre-injury work or leisure activities is often inordinately difficult, with many even questioning whether it might be psychological in origin.

Moreover, the effects of brain injuries are cumulative, with a second brain injury having potentially much greater impact than the initial injury. That is, after initial injury, even a minor knock to the head can have potentially much more severe effect than that of the first injury. Further injuries after that tend to only compound problems in cognition and behaviour.<sup>43</sup>

Two of the most poignant reasons for this are reduced awareness of risk and thereby increased problematic behaviour, and behavioural disinhibition leading to assault by others who take offence. Whatever the factors underlying it, there is little doubt that people with a brain injury are some of the most vulnerable in our society.<sup>44</sup>

The initial severity of acute brain injury is evaluated with radiological means such as CT and MRI brain scans, along with clinical evaluation through instruments such as the Glasgow Coma Scale that measures alertness and response to stimuli.<sup>45</sup> Gottesman et al.<sup>45</sup> describe the classification of traumatic brain injury:

- Epidural haematoma (blood between the skull and outer layer of the brain meninges or *dura mater*)
- Sub-dural haematoma (blood deeper in the brain between the arachnoid and pia layers)
- Subarachnoid haematoma
- Intraparenchymal haematoma (blood in the brain matter)
- Intraventricular haemorrhage (blood in the brain ventricles)

- Duret haemorrhage (brainstem haemorrhage)
- Diffuse axonal injury (involving trauma and cell death of brain matter)
- Anoxic (Oxygen deprivation) brain injury with cell damage in certain brain areas such as the hippocampus, thalamus and cerebellum.

All the various types of injury have different prognoses depending on the area of the brain affected and the Glasgow Coma Score and are evaluated through the Glasgow Outcome Scale:

Glasgow Outcome Scale				
5	4	3	2	1
Independent	Moderate disability	Severe disability	Persistent vegetative state	Death

There are a number of complications that can occur after acute brain injury:<sup>45</sup>

- Elevated intracranial pressure
- Post traumatic epilepsy
- Stroke
- Hydrocephalus (build-up of cerebrospinal fluid within the brain)
- Dysautonomia (Sympathetic nervous storm within the brain matter that results in severe paroxysmal increases in temperature, heart rate and blood pressure, often with increased respiratory rate and diaphoresis (excessive sweating))
- Headache

### Acquired Brain Injury resulting from Harmful Substance Use

A number of substances currently misused by Aboriginal and Torres Strait Islander peoples may contribute to brain injury. This may occur from:

- the direct toxic effect of the substances on brain matter along with
- the increased vulnerability of people affected by substance intoxication and withdrawal to damage themselves and others by intent or accident and suffer traumatic brain damage as a consequence.

For further discussion of the impacts of harmful substance use, see Chapter 8 (Wilkes and colleagues).

#### *Alcohol*

High risk alcohol consumption for all age groups of Aboriginal and Torres Strait Islander peoples is much greater than for the wider population.<sup>1,46</sup> It is well recognised that harmful alcohol consumption has a direct effect on the brain. Oscar-Berman and Marinkovik<sup>47</sup> estimate that about one-half of people who had a problem with chronic alcohol dependence in the United States at the start of the new millennium may have been experiencing neuropsychological difficulties as a result of their alcohol misuse, and that these difficulties ranged from mild to severe. Harper<sup>48</sup> notes that long term excessive use of alcohol tended to damage brain areas in affected individuals such as the superior frontal association cortex, hypothalamus and cerebellum, and these areas are important for executive brain function. Alcohol-related damage to the diencephalic-hippocampal circuitry of the brain along with

thiamine deficiency due to poor diet may lead to severe and permanent memory loss in the context of Wernicke-Korsakoff Syndrome.<sup>48</sup> Oscar-Berman and Marinkovik<sup>47</sup> comment that the areas of the brain that are particularly vulnerable to alcohol are the limbic system (important for processing and feeling emotion), thalamus (important for communication within the brain), the hypothalamus (which releases hormones in response to stress and other stimuli and is involved in behavioural and physiological function) and the basal forebrain (the lower area of the front part of the brain involved in learning and memory). Deficits in these areas can contribute to, or exacerbate, pre-existing acquired brain injury.

### ***Volatile Substance Misuse***

Volatile Substance Misuse (VSM) has been termed ‘the hidden epidemic’ because it remains among the least researched and publicly recognised form of substance misuse. It is a significant but under-researched global health problem despite the significant criticism and consequences that often exceed those of other drug misuse.<sup>49</sup>

According to the 2001 National Inhalants Information Service,<sup>50</sup> young people aged 12–15 years appear to be the largest population of users. However, it is suggested that this group is expanding to include much younger and older users. In the 2008 National Aboriginal and Torres Strait Islander Social Survey (NATSISS), up to 4.2 per cent of respondents reported that they had inhaled volatile substances such as petrol and aerosols.<sup>51</sup>

Inhalant use is popular in some areas in Australia. This phenomenon is not restricted to any particular region as it occurs in urban, regional and remote settings. Some Aboriginal communities appear particularly at risk for this issue and it was estimated that the financial cost of volatile substance misuse (petrol sniffing) in Central Australia prior to the introduction of Opal fuel was \$78.9 million per year.<sup>50</sup>

Patterns of VSM differ across race, age, gender and time; albeit in the Northern Territory (NT) Aboriginal young people are overrepresented at approximately 80 per cent of all VSM admissions. In the NT, VSM use is effectively ‘self-medication’ to alleviate the meaninglessness and depression felt by many community members, and this is the key issue that must be addressed for an intervention to be effective and demand to be reduced.<sup>52</sup> Few options are available for long-term care of people who have become severely disabled as a result of VSM, and their care generally falls to family members.<sup>53</sup>

Marginalised young people, both Aboriginal and other Australians, indicate they use volatile substances as a way of relieving boredom, to block hunger pains, and to cope with emotional distress.<sup>54,55</sup> Victims of child abuse tend to be at greater risk for inhalant misuse, as are young persons whose friends or relatives misuse other substances.<sup>56</sup>

VSM is a difficult problem for any community to tackle, as it tends to occur cyclically, becoming highly visible and then dying down, often peaking at 14 years of age.<sup>51</sup> Many large national surveys have failed to identify significant gender difference in prevalence of VSM. This raises concerns about the specific risks that VSM may pose to adolescent and young women, and their children, and the consequences, such as spontaneous abortion and foetal solvent syndrome (FSS). FSS includes a range of physical/cognitive behavioural and/or learning disabilities with possible life-long consequences that are caused by perinatal exposure to inhalants. They include low birth weight, small head size, facial dysmorphism, and muscle tone abnormality similar to FASD presentations.<sup>57</sup>

Research shows that most inhalants are extremely toxic. Perhaps the most significant toxic effect of chronic exposure to inhalants is widespread and long-lasting damage to the brain and other parts of the nervous system. For example, chronic misuse of volatile solvents, such as toluene or naphthalene (the volatile ingredient in mothballs), damages the protective sheath around certain nerve fibres in the brain and peripheral nervous system. This extensive destruction of

nerve fibres is clinically similar to that seen with neurological diseases such as multiple sclerosis. Neurologic toxicity is the most recognised and reported chronic side effect of inhaled solvent misuse. Common findings on brain imaging include enlarged ventricles, widened cortical sulci and cerebral, cerebellar or brain stem atrophy.<sup>58</sup> Magnetic resonance imaging suggests that these white-matter changes in chronic abusers are irreversible.<sup>59</sup> Dementia, chronic encephalopathy, and peripheral neuropathy also occur. Peripheral neuropathy may present as proximal or distal muscle weakness, muscle wasting, absent or decreased tendon reflexes, or parenthesis.

Cognitive testing of Aboriginal and Torres Strait Islander peoples who misuse volatile substances on a regular basis has indicated that they experience poorer performance on complex tasks of psychomotor, visual attention, memory, learning, spatial awareness and executive function compared with Aboriginal people who did not misuse volatile substances. Follow-up studies by the same group indicated that, whilst there may be an improvement in some psychological testing after abstinence from harmful volatile substance misuse, other psychological deficits in respect to visual motor speed, learning, memory and executive function persisted.<sup>60</sup>

### ***Amphetamines and Cannabis***

High rates of cannabis and amphetamine misuse may also place Aboriginal and Torres Strait Islander peoples at risk for brain injury.<sup>1,61</sup> Research has demonstrated that chronic misuse of amphetamines may lead to substantive changes in brain chemistry, particularly dopamine and glutamate, that may make the abuser vulnerable to psychosis.<sup>62</sup> In addition, brain damage related to amphetamine misuse was demonstrated in a recent pilot study that appeared to show that one-in-five young people who presented to a hospital emergency department in the context of amphetamine use had an occult brain lesion, as a result of their amphetamine misuse, on MRI scans.<sup>63</sup>

Research also appears to indicate that cannabis misuse in adolescents can lead to changes in the brain (particularly in the hippocampus) and alterations of brain transmitters.<sup>62</sup> A recent brain imaging study in the United Kingdom shows an association between regular cannabis misuse and reduced brain grey matter in the cingulate and left insula regions of the brain, in a population of individuals who were at high risk for psychosis.<sup>64</sup>

## **Scenario 3**    **David's story**

*David, a 24 year-old Aboriginal male, is found unconscious in a laneway and brought to the local hospital emergency department. He appears to have been the victim of a serious assault. The medical team reviewing his condition become aware of the following information. David was born in rural community. His mother misused alcohol during pregnancy and he had a low birth weight when delivered. David had a number of admissions to hospital from the ages of two to five with malnutrition and diarrhoea. David left primary school at his community early because of poor learning performance and behavioural problems. He started sniffing petrol when he was about 11 years-old and had a number of apparent deliriums (where he appeared to be responding to auditory and visual hallucinations) related to volatile substance intoxication. David was noted to use cannabis from the age of 14 and had a couple of short admissions to the mental health unit with psychosis that was thought to be due to his cannabis intoxication. He moved to town at the age of 19 and had been consuming alcohol since then. David had a number of previous attendances to the Emergency Department following assaults whilst he was inebriated. He had a further presentation where he appeared to have an epileptic seizure whilst inebriated and another attendance at the Emergency Department after he was discovered hanging from a clothesline following an argument with his girlfriend when both were inebriated. David was reported to be unconscious and had a seizure but was resuscitated and appeared to recover.*

*Continued . . .*

### Scenario 3 David's story (continued)

*A mental health assessment at the time of this episode reported that David appeared to have low intelligence and poor impulse control, particularly in the context of alcohol intoxication. He did not appear to be depressed or psychotic. Alcohol counselling and assessment for entry into an alcohol rehabilitation program was offered but David declined.*

*In the current circumstances, David has a Glasgow Coma Score of 6, indicative of severe head trauma when he arrives in the emergency department. A CT Brain scan reveals an intraparenchymal haematoma with blood present in his brain frontal lobes. David initially requires artificial ventilation and is admitted to Intensive Care. After a week, he is discharged from Intensive Care to a rehabilitation ward. David appears to be suffering from Post Traumatic Amnesia and this is assessed daily through the Westmead Post Traumatic Amnesia Scale. David's family is consulted and an auntie travels to the hospital to assist the team with rehabilitation. The hospital Aboriginal Liaison Officer is also involved in working with the rehabilitation team and with David's family. David is noted to become obsessed with certain issues such as the location of an item of clothing and can easily become aggressive if this is not attended to. He is also noted to be tearful at times. At other times David appears to be responding to voices. The rehabilitation team and David's family work with the hospital Consultation Liaison Psychiatry team to assess these issues. It is decided that David does not appear to be depressed and that his obsessional behaviour is consistent with the severe frontal lobe brain injury he has suffered. It is also likely that he is suffering from a delirium related to his brain injury rather than a long standing psychotic condition.*

*The rehabilitation and psychiatry teams work together with David's family and the Aboriginal Liaison Officer to work on behavioural and other solutions that may involve appropriate psychotropic medication. After 6 weeks, David still has a score on the Westmead Post Traumatic Amnesia Scale that may be indicative of permanent brain damage. David is also unable to perform issues that he would normally be confident with, such as using his bank key card at the hospital ATM (an activity that he was reportedly familiar with prior to his current head injury).*

*The Kimberley Indigenous Cognitive Assessment is administered to David and he scores 28/39 with deficits in executive function, recall and verbal fluency. As a result of this, it is decided that David is likely to have a permanent brain impairment as a result of his brain injury. The rehabilitation team, in consultation with David's family, decide to apply for Adult Guardianship for David and such application involves further exploration of his psychological and other disabilities related to his brain injury by the multidisciplinary rehabilitation team. David is considered eligible for Adult Guardianship and is eventually placed in a group home in the community in coordination with his family, government and non-government agencies. His community are building an aged care facility and it is hoped that he will eventually be able to return to his community to be closer to his family.*

## DEMENTIA IN ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

Dementia is an umbrella term used to describe a syndrome that can have many different causes. The syndrome is characterised by a gradual decline in cognitive abilities and neuropsychiatric symptoms. The causes are most commonly brain disease including Alzheimer's disease, Lewy body disease, cerebrovascular disease and 'frontotemporal lobar degeneration.'<sup>65(p1)</sup>

Sheldon noted an emerging high incidence of cognitive decline in Aboriginal communities in Central Australia in the 1990's and commented that:

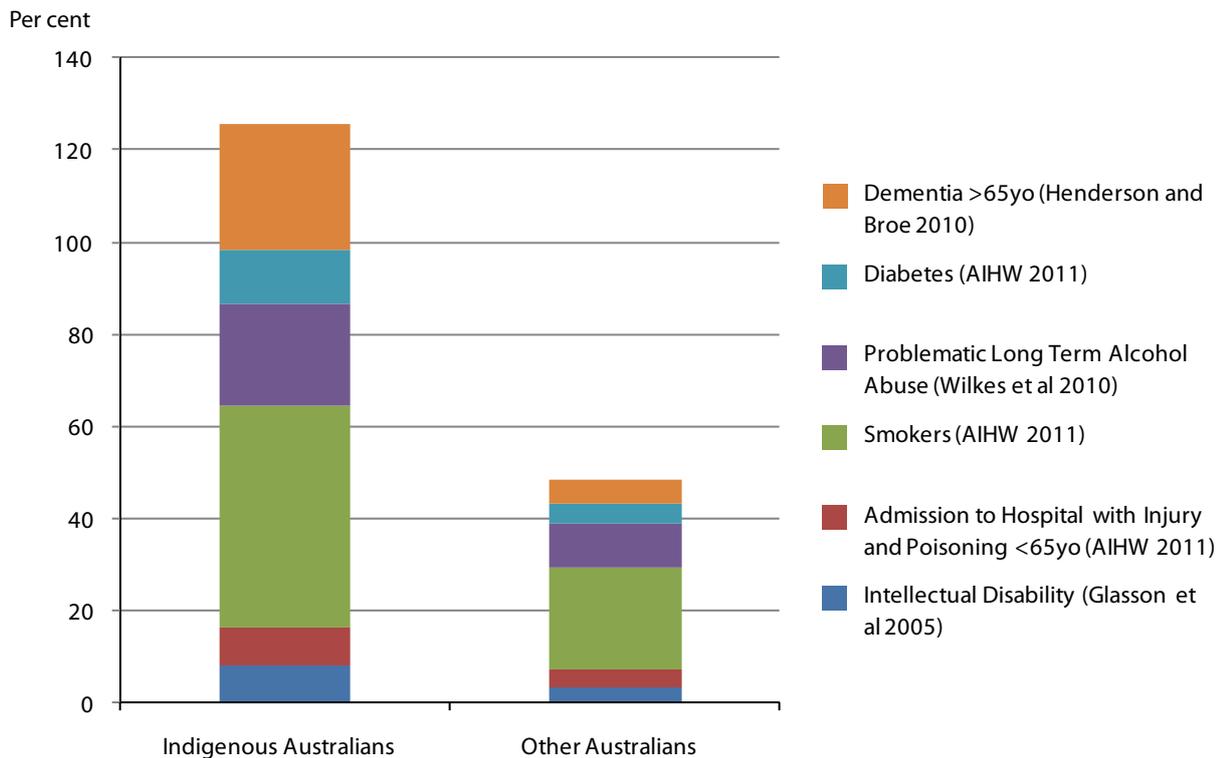
*Several cases of undiagnosed moderate to severe dementia were referred to me because of extreme disruptive behaviour while their declining abilities had been quietly managed by the family for the preceding several years.<sup>66(p35)</sup>*

The issue of dementia has become more widely recognised since that time with a much higher proportion of Aboriginal and Torres Strait Islander peoples having Aged Care Funding Instrument (ACFI) assessments compared with the wider population in 2008–09.<sup>1</sup> A much higher proportion of Aboriginal and Torres Strait Islander peoples with dementia (39 per cent) were aged less than 75 years compared with the remaining population (9 per cent).<sup>1</sup> A survey of Aboriginal people over 45 years of age in the Kimberley using the Kimberley Indigenous Cognitive Assessment (KICA) tool found a prevalence rate of 27 per cent.<sup>6, 67</sup> The study's finding of a prevalence of 27 per cent of participants over 65 years of age being affected by dementia was five times higher than the overall Australian population after standardisation.<sup>7</sup>

A further review of risk factors for their survey population found that older age, male gender, no formal education, currently smoking, previous stroke, epilepsy, head injury, poor mobility, incontinence and falls led to an increased risk of dementia.<sup>40</sup> This concurs with generally higher risk factors recognised for dementia that are present in the Aboriginal and Torres Strait Islander population, such as higher rates of tobacco smoking, physical inactivity and alcohol misuse, as well as poor diet and diseases such as coronary heart disease, stroke<sup>1, 68</sup> and Type II Diabetes.<sup>69</sup>

Diabetes as a cause for dementia is of particular concern, with the rate of diabetes within the Aboriginal community being three times the rate of the general Australian population.<sup>1</sup> These risks appear to have a particular cumulative quality (see Figure 18.1) that may in part explain the significant excess in dementia in Aboriginal populations.<sup>7</sup>

**Figure 18.1:** The Prevalence of Dementia and some Associated Risk Factors for Aboriginal and Torres Strait Islanders and Other Australians



For people with existing intellectual disability, there appears to be a higher risk of developing dementia. Alzheimer's disease is an established complication for people affected by Down syndrome who often develop the disease 20 to 30 years earlier than the general adult population.<sup>70</sup> There also appears to be emerging clinical and post mortem evidence for higher rates of Alzheimer's disease in individuals affected by other forms of intellectual disability.<sup>70</sup>

## Scenario 4 Gladys's story

*Gladys is 70 year-old Aboriginal woman who lives with her daughter in a remote community. She has suffered from high blood pressure and diabetes for many years and had a stroke three years previously that has left her with left sided weakness to the extent that she requires the use of a walking frame to get around. Her daughter brings her to the local health clinic because she is “not making much sense when she talks any more”. Gladys has also become increasingly forgetful and almost caused a fire at the house the other day when she forgot she was cooking some soup and left a saucepan on the stove top too long. Her daughter says that Gladys is more difficult to live with and argues more. She also used to enjoy caring for her grandchildren but her other children are less likely to ask her to do this currently because she does not appear to be able to care for them as well as she used to. Her daughter says that Gladys has become a bit “more smelly” and has not been showering or washing her clothes as frequently as she used to. Gladys used to enjoy playing cards with the other old women but does not go to the game now because she has trouble remembering the score and card patterns. She also has been accusing her daughter of taking her pension money but her daughter says that Gladys cannot remember buying things at the store.*

*Gladys is initially assessed by the medical staff at the health centre who determine that she has no organic cause for her condition such as syphilis, vitamin B deficiency or thyroid disease. She is then referred to the regional psychiatric team. The team's assessment, done in co-ordination with Gladys' daughter, results in a conclusion that they do not feel that she is suffering from depression or psychosis. Testing with the Kimberley Indigenous Cognitive Assessment reveals a score of 30/39 with deficits in recall, language fluency and executive function. Gladys is diagnosed as suffering from Alzheimer's Disease. She is referred to the regional geriatric service for further assessment and management. The team work with Gladys and her family to make her house safer for her and to enable her daughter and other family members to cope with her illness.*

## PSYCHIATRIC COMPLICATIONS OF INTELLECTUAL DISABILITY

There appears to be increasing evidence of mental health problems for people affected by intellectual disability<sup>71-73</sup> with the life time prevalence of severe psychiatric disorders in people affected by intellectual disability estimated to be five times that of the general population.<sup>74</sup> Organic factors such as genetic factors, brain injury, trauma, disease and infection can contribute to this issue.<sup>72</sup> Social factors such as poverty, unemployment and lack of social supports are also recognised as contributing factors.<sup>72</sup> Kerker et al.<sup>71</sup> comment on psycho-developmental stressors for people affected by intellectual disability that may result in mental illness:

*Individuals with intellectual disability are capable of experiencing the same disappointments and difficulties as those without intellectual disability. In addition, individuals with intellectual disability who are aware of their limitations may be at high risk for mental health problems, as such recognition may lead to self-concept problems, emotional disturbances, and depressive reactions. Parental and peer rejection, negative social relationships, limited supports, and exposure to degrading situations also may make functioning in the community difficult for those with intellectual disability. Children with mild intellectual disability, for example, have been found to be more rejected by peers and express more dissatisfaction and anxiety about peer relations than those without intellectual disability. Such feelings may affect an individual with intellectual disability more than someone in the general population because those with intellectual disability tend to have greater sensitivity and fewer interpersonal coping skills.* <sup>71(p410)</sup>

The reasons for the high rate of psychiatric illness in individuals affected by intellectual disability are complex, manifold and interacting. The brain damage or dysfunction can affect biological aspects of frustration, tolerance and impulse control leading to emotional and behavioural problems. Underlying genetic conditions may predispose to psychiatric disorder, for example, psychotic and mood disorders in people with velocardiofacial syndrome and alzheimer-type dementia in people with Down syndrome. Comorbid conditions such as ASDs and ADHD are themselves associated with a high rate of mood disorders. Higher prevalence of epilepsy may also predispose to epilepsy-related psychiatric disorders such as depression, psychosis related to epilepsy, etc. Endocrine disorders such as thyroid dysfunction in people with Down syndrome may also lead to psychiatric disorder. People with intellectual disability are also more susceptible to adverse life events and psychosocial stressors which may predispose or precipitate psychiatric events. Communication difficulties may compound other problems such as bereavement, making it more difficult to come to terms with grief.

### Diagnosis of Psychiatric Illness

Bradley et al.<sup>72</sup> note that diagnosis of psychiatric illness may be challenging in people affected by intellectual disability where symptoms may not be sufficiently recognised or attributed to the underlying intellectual disability. Other issues such as communication problems and sensory impairments, seizure disorders and contributing medical complications (such as cardiovascular disease, thyroid disease and pain from unrecognised bone fractures, infections and other causes), can further complicate effective diagnosis.<sup>72</sup> As a result, the authors recommend the following steps to achieve the best outcome in diagnosis:

1. Generate the best diagnostic hypothesis using information currently available;
2. Collect data to confirm or refute this hypothesis;
3. Review this data along with the results of assessments in other areas (e.g. psychological, communication, environmental, expectations).<sup>72</sup>

The diagnosis of psychiatric disorders for Aboriginal and Torres Strait Islander peoples affected by intellectual disability is complicated by the communication difficulties which people with more severe intellectual disability and those with autism display. It is important to obtain corroborative history from family members and carers. Changes in sleep pattern, appetite, mood, self-help skills and sociability can provide valuable clues in diagnosis. It may also be necessary to see the person on several occasions and in familiar settings to come to a diagnosis. The DSM-5 has removed the multi-axial system of diagnosis and replaced it with a non-axial documentation of diagnosis. It combines the former Axes I, II, and III, with separate notations for psychosocial and contextual factors (formerly Axis IV) and disability (formerly Axis V). This new method will be used to assess the level of intellectual disability, underlying physical disorders (including any underlying syndrome and epilepsy), psychiatric disorder (including any developmental disorder) and psychosocial issues (e.g. bereavement) and provide a comprehensive framework of the individual's needs to be addressed. These issues have been reconsidered in DSM-5 which now identifies Major and Minor neurocognitive disorders due to a range of causes.

Rates of intellectual disability and mental illness, often in the context of comorbid misuse of substances such as alcohol and cannabis, are significant in certain groups of Aboriginal and Torres Strait Islander peoples. Hunter et al.<sup>75</sup> report that approximately 40 per cent of Aboriginal people in Cape York who suffered from a psychotic disorder were also affected by intellectual disability. However, the question is whether it is actually intellectual disability or cognitive impairment associated with acquired brain injury or dementia. Similar comorbidity data may be emerging for Aboriginal people resident in the east Arnhem region of the NT (Krigovsky personal communication, 16 Sept 2012).

## Issues for Families

There are a range of issues affecting the families of children with intellectual disability that impact on their function and ability to care. These are the emotional and physical material wellbeing of family members, their parenting skills, and the disability-related supports they may or may not receive.<sup>76</sup> There are significant issues for the optimal functioning of Aboriginal and Torres Strait Islander communities in view of the history of generational trauma that can often disempower families and communities.<sup>77, 78</sup> Other issues relating to the impact on carers are also relevant in the context of caring for a person with intellectual disability (for a carer perspective, see Chapter 14, Wright).<sup>79</sup> Cultural safety is a particularly important element in the assessment of such caring abilities given the important contribution of Aboriginal and Torres Strait Islander traditions and attitudes to children, family and community (see Chapter 12, Walker, Schultz and Sonn). A further issue is the potential to overwhelm people who may not be able to perform a caring role because of their age and own health issues in addition to pre-existing family, community and tribal responsibilities.

O'Neill et al. describe a number of further complications in respect to the care of Aboriginal and Torres Strait Islander peoples with a disability such as dementia:

*Many Aboriginal and Torres Strait Islander peoples live in poverty and often cannot afford to care for more needy members of their group—the added expense entailed in caring for a person with a disability can disadvantage other members of the family. People with a disability can be very vulnerable to exploitation in environments where alcohol misuse and family breakdown have occurred. The burden of grief and stress carried in many communities can lead to inconsistencies in care. Family allegiances can make accessing services difficult and many people are disadvantaged by not knowing how to care and what services are available.<sup>80(p4-5)</sup>*

A recent study by Smith et al. evaluated the opinions of Aboriginal carers of people affected by dementia in the Kimberley.<sup>81</sup> The carers expressed views that they hoped that their relatives could stay in their communities as long as possible because they would remember familiar things and be close to country. The carers also felt that the availability of more Aboriginal dementia workers, cultural training for service providers and external community care staff, dementia training, and Elder abuse training would be advantageous. Aboriginal carers nominated overcrowded houses, the exaggerated expense of living in remote communities, and a lack of public and private transport to access health care as having a significant impact on the care of the elderly. Aboriginal carers also had a view on the quality of service provision. They felt that there needed to be improved communication and coordination amongst service providers. Intolerance and 'defeatist' attitudes by some service providers, in addition to a lack of flexibility and clinical pathways and protocols, were of concern to the carers consulted. They also felt that the lack of access to interpreters, community support services such as house cleaning; caregiver support organisations; as well as the lack of opportunities for the person affected by dementia to have meaningful activities and have respite care available, significantly impacted on the person's illness and their role as carers.<sup>81</sup>

A report by LoGiudice et al.<sup>82</sup> on a pilot model for dementia/disability care in a remote Kimberley community showed that a number of the above concerns can be successfully addressed given the right level of resources, coordination and community engagement. The project to improve services to people affected by dementia and other disabilities in the Looma community involved the coordination of a Steering Committee, Facilitator, Local Action Committee and Project Co-ordinator to develop a more effective use of, and access to, available resources. The project resulted in an increase in services in all domains (such as

home maintenance and social support, advocacy, provision of equipment, caregiver and wider community education) from 140 per month prior to the project to 2,356 per month during the project, leading to a much higher standard of care for the disabled members of the community.

## Forensic Issues

Sotiri et al. note that:

*Indigenous Australians with cognitive impairment are over-represented in criminal justice settings across Australia. This group (compared to the non-disabled population) is more likely to come to the attention of police, more likely to be charged, more likely to be remanded in custody, and more likely to be sentenced and imprisoned. They spend longer in custody than people without cognitive impairment, have far fewer opportunities in terms of program pathways when incarcerated and are less likely to be granted parole. They also have substantially fewer program and treatment options, including drug and alcohol support, both in prison, and in the community when released, than their non-disabled and non-Indigenous counterparts. In some Australian jurisdictions, Indigenous people with cognitive impairment are detained indefinitely.<sup>14(p19)</sup>*

The issues of Aboriginal and Torres Strait Islander peoples affected by intellectual disability and mental illness and their contact with the justice system are dealt with more fully in Chapter 10 (Heffernan and colleagues).

## Intelligence and Rating Scales

The definition of 'intelligence', particularly in cross-cultural situations, may be controversial but elements of intelligence such as information processing and adaptive function appear to be core features.<sup>83</sup> Such 'intelligence' would have been well satisfied through traditional Aboriginal and Torres Strait Islander economic, cultural and spiritual practices that existed for over 40,000 years and are described in Chapter 2 (Parker and Milroy).<sup>84, 85</sup>

Neuropsychological assessment is valuable as a non-invasive means of assessing strengths and changes (or weaknesses) after brain injury of any aetiology. Such tests can be particularly useful when imaging is unable to demonstrate the presence of structural damage. Neuropsychological assessment is a series of paper-and-pencil tests standardised on a normative population to gauge a person's performance relative to that general population. Responses to this series of tests allows the neuropsychologist to better understand the effects of injury and advise the individual, his or her family, and other treating clinicians as to adaptive strategies that might best suit the injured individual. It also allows for the gauging of improvement over time, as the assessment is repeated at intervals.

There are significant issues in terms of limitations of psychometric assessment of intellectual functioning when used with Aboriginal people. Many psychometric tests rely on a question and answer format, frequently using the English language. Written responses require formal education in western-based schooling systems. These are significant factors in some cultures which do not have a written language. The one-on-one encounter with a practitioner administering the test may affect performance in a culture which may consider it rude to be asked numerous questions by strangers from another culture.<sup>86</sup> Overall, most psychometric instruments developed for cognitive assessments in Aboriginal and Torres Strait Islander populations have been inadequately validated and require further evaluation (see Chapter 16, Adams, Drew and Walker).<sup>87</sup>

The identification of intelligence or its deficits as defined in the usual standard tests such as intelligence quotient (IQ), the Wechsler Adult Intelligence Scale (WAIS) and Wechsler Intelligence Scale for Children (WISC), and their applicability for Aboriginal and Torres Strait Islander peoples is somewhat more controversial. Practising Aboriginal psychologist, Yolonda Adams (personal communication, 12 April 2013) makes the point that practitioners need to draw on the strengths that enhance testing for Aboriginal and Torres Strait Islander peoples i.e. use tasks that rely on visual skills. Tests that rely heavily on terminology/verbal and time testing such as the WAIS and WISC may disadvantage Aboriginal people and affect performance on these types of tests. Administering tests and interpreting the results within context is reliant on the skills, abilities and cultural competency of the practitioner.

There is increasing recognition that testing needs to be culturally appropriate and within context. For instance, Sedighdeilami and Gindi<sup>88</sup> allow that standard unmodified tests may be of use amongst individuals from diverse cultural backgrounds affected by intellectual disability as long as the practitioner conducts the tests:

- in a culturally safe manner;
- to take account of the client's history, culture, language, customs, norms and life experiences and their impacts; and
- in the knowledge that such issues will impact on the accuracy of measurement within the test.

See Chapter 16 (Adams, Drew and Walker) for further discussion of culturally appropriate assessment, and for a discussion of the Cultural Formulation Interview in the recently released DSM-5. Speech Pathology Australia<sup>89</sup> lists a number of tests that have been developed, primarily in Western Australia, for working with Aboriginal children to assess language proficiency.

## TOOLS FOR ASSESSMENT OF INTELLECTUAL DISABILITY

In the context of the considerable limitations described above, there are some tests that, while usually used for the assessment of dementia, appear to be increasingly used for assessment of intellectual disability in Aboriginal and Torres Strait Islander peoples. When using such tests, it is important to consider the person being tested in the context of their prior education and abilities. As an example, it may be quite appropriate to consider the use of the standard Mini Mental State Examination<sup>90</sup> to assess residual cognitive impairment in an Aboriginal university academic who was severely concussed in a motor vehicle accident, whereas the KICA<sup>67</sup> may be more appropriate to assess cognitive impairment in an Aboriginal and Torres Strait Islander person with pre-existing limited education and language skills following a traumatic head injury.

### The Kimberley Indigenous Cognitive Assessment

This assessment tool was developed with Aboriginal and Torres Strait Islander health and aged care organisations in the Kimberley, and comprises cognitive, informant and functional sections. LoGiudice et al. note:

*The KICA-Cog assesses orientation, free and cued recall, language, verbal fluency, copying sequence pattern and ideational praxis. Many test questions rely on the use of culturally appropriate pictures requiring adequate vision, and commonly found objects (i.e. matches, comb and pannikin cup) were used.*<sup>67(p276)</sup>

The test is validated for Aboriginal and Torres Strait Islander peoples aged over 45 and a cut-off score of 33/39 may indicate that the person being tested could be suffering from dementia. However, the tests may also be useful for informally testing a specific cognitive deficit or a range of cognitive deficits to assist in diagnosis and management.<sup>67</sup>

### The Westmead Post Traumatic Amnesia Test

This test was developed as a prognostic screening tool for outcomes in people affected by mild traumatic brain injuries which constitute 70-90 per cent of all head injuries.<sup>91</sup> The test may be a good indicator of diagnostic accuracy for outcomes in people affected by mild traumatic brain injury and is also used to assess ongoing improvement and deterioration for Aboriginal and Torres Strait Islander and other patients suffering from PTA in Royal Darwin Hospital. Speech Pathology Australia<sup>89</sup> note that an adapted form of the Westmead PTA Test, *the Adapted Westmead PTA Scale for Indigenous Australians*, may also be useful for Aboriginal and Torres Strait Islander peoples affected by PTA.<sup>91</sup>

### Cognistat

Cognistat<sup>92</sup> is a further tool that may be useful<sup>93</sup> and is also used to review the progress of both Aboriginal and Torres Strait Islander and other patients suffering from PTA in Royal Darwin Hospital (Robert Parker, personal communication, 12 Dec 2012). However, there is also information that education and racial differences may have an impact on the outcome. This may need to be taken into account when using the instrument in Aboriginal and Torres Strait Islander peoples.<sup>94, 95</sup>

### Cogstate

The Cogstate battery<sup>96</sup> is a battery of neuropsychiatric tests that includes measures of visuomotor function, psychomotor/processing speed, visual attention/vigilance, attention/working memory, verbal learning and memory, executive function (spatial problem-solving, set-shifting), and social cognition.<sup>97</sup> The assessment is in the form of a computerised non-verbal assessment that can be downloaded from the Internet and administered on any computer. Dingwall and Cairney<sup>86</sup> note its potential popularity for Aboriginal and Torres Strait Islander peoples because of the role of playing cards in the tests and the popularity of card games in many Aboriginal and Torres Strait Islander communities. Research using a modified form of the test was able to demonstrate cognitive impairment in Aboriginal and Torres Strait Islander peoples resident in rural communities in the NT and affected by alcohol dependence.<sup>98</sup>

## PREVENTION OF INTELLECTUAL DISABILITY

Prevention of the high rates of intellectual disability currently experienced by Aboriginal and Torres Strait Islander peoples needs to be an important priority for health policy makers and health professionals. There are a range of primary, secondary and tertiary prevention strategies (see Table 18.3) that can be implemented to eliminate or significantly reduce intellectual disability in Aboriginal and Torres Strait Islander populations.

**Table 18.3:** Primary, Secondary and Tertiary Strategies for Prevention of Intellectual Disability

Primary Prevention	
Cause	Prevention
Genetic causes	Counselling, Screening, Amniocentesis
Infection in utero	Immunisation for Rubella, Measles, etc.
Toxins in utero	Culturally sensitive programmes to reduce alcohol, tobacco and drug use during pregnancy
Nutritional factors	High folate during pregnancy
Endocrine and metabolic factors	Screening for hypothyroidism, phenyl ketonuria
Perinatal factors	Improved access to antenatal care and improved obstetric care
Post natal infections	Early diagnosis and treatment of infections
Accidental Injury	Accident prevention
Non-accidental injury	Improved surveillance and early diagnosis
Societal factors	Empowerment of Aboriginal and Torres Strait Islander communities to improve their physical environments
Secondary Prevention	
<b>Secondary prevention</b> aims at treating or ameliorating the effects of the underlying cause to prevent or reduce disability. An example would be thyroxine replacement in a child with congenital hypothyroidism.	
Tertiary Prevention	
<b>Tertiary prevention</b> focuses on minimising the sequelae of an existing disability. Examples include regular hearing, visual and thyroid checks for people with Down syndrome. Intensive interventions for motor and communication delays can help to ameliorate the physical and psychological effects of under-stimulating home environments. Early diagnosis of epilepsy and comorbid psychiatric disorders will also reduce associated disabilities.	

## CONCLUSION

The discussion throughout this chapter confirms a disturbing incremental growth in risk factors for intellectual disability for Aboriginal and Torres Strait Islander peoples with childhood vulnerability (i.e. low birth weight, fetal alcohol syndrome, malnutrition and reduced participation in education) that translates into higher risk for acquired brain damage (e.g. high levels of smoking, excessive harmful use of substances and exposure to injury) that have an end point as high rates of dementia. The background social, historical and cultural factors are also very relevant in this regard<sup>14, 16</sup> and further detailed in Chapter 1 (Dudgeon and colleagues). Hunter<sup>99</sup> has recently pointed to similar additive factors around the significant social and health disadvantage of Aboriginal people in Cape York leading to very high rates of psychosis in the region, and a similar emerging epidemic of dementia in Aboriginal and Torres Strait Islander peoples nationally is of major concern. Any proposed solutions to the apparent very high rates of intellectual disability need to be approached by mental health practitioners and service providers in a broad context of cultural empowerment and social reform as much as targeted services for those affected. This will require genuine working partnerships with Aboriginal and Torres Strait Islander community controlled organisations as well as practitioner and system-wide commitment to cultural competence.

## REFLECTIVE QUESTIONS

1. Examine the various factors that may contribute to the development of dementia in elderly Aboriginal and Torres Strait Islander peoples. In this process, you may wish to construct your own graph (as per Figure 18.1) and develop an argument for the various factors that you feel are important.
2. Consider the factors that may impact on the validity of standard tests of intelligence for Aboriginal and Torres Strait Islander peoples.
3. Consider the ways that your role as a member of a multidisciplinary team may contribute to the assessment and management of an Aboriginal adult (such as David) with acquired brain injury.

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