

Assessment of acquired brain injury in Aboriginal and Torres Strait Islander Australians: Guidance for DisabilityCare Australia



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List of abbreviations

ABI	Acquired Brain Injury
FaHCSIA	Department of Families, House, Community Services and Aboriginal and Torres Strait Islander Affairs
ICF	International Classification of Functioning, Disability and Health
JCU	James Cook University
LAC	Local Area Coordinators
NDIS	National Disability Insurance Scheme
SP	Service Providers
WHO	World Health Organization

Glossary of terms

Acquired Brain Injury	Any damage to the brain that occurs after birth
Assessment	An evaluation or estimation of an individual's eligibility, function, impairments or needs
Carer	An individual who: (a) provides personal care, support and assistance to another individual who needs it because that other individual is a person with disability; and (b) does not provide the care, support and assistance: (i) under a contract of service or a contract for the provision of services; or (ii) in the course of doing voluntary work for a charitable, welfare or community organisation; or (iii) as part of the requirements of a course of education or training.
Cultural Acceptability	Something that has been deemed acceptable by Aboriginal and/or Torres Strait Islander Australians because it reflects the ideas, experiences and needs of their culture
Cultural Awareness	Acknowledging, accepting and appreciating the concepts, knowledge and experiences that are unique to Aboriginal and Torres Strait Islander Australian culture
Cultural Competence	The ability to interact effectively with Aboriginal and Torres Strait Islander Australians
Informant	An individual who provides information regarding a participant or prospective participant
Instrument	A pencil and paper or computer-based measure for determining a participant or prospective participant's eligibility, impairments or needs
Participant	A person who has been deemed eligible to participate in DisabilityCare Australia
Planners/Local Area Coordinators	Individuals employed by DisabilityCare Australia to conduct assessments
Practitioners	A broad range of health professionals, DisabilityCare staff, Local Area Coordinators and social workers
Prospective Participant	A person in relation to whom an access request has been made but not yet decided

Protocol	Guidelines for behavior to be observed when working with Aboriginal and Torres Strait Islander individuals, to ensure effective and respectful engagement and assessment.
Service Providers	A broad range of agencies, normally from the health, aged or disabilities sectors, situated in communities

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Executive Summary

In 2012, James Cook University, Synapse (Brain Injury Association of Queensland, Inc.) and Brain Injury Australia were funded by the Federal Government's Practical Design Fund (Department of Families, Housing, Community Services and Aboriginal and Torres Strait Islander Affairs) to prepare individuals, communities and services for the transition to DisabilityCare Australia. The project had three deliverables:

1. Develop best practice guidelines for engagement and assessment of Aboriginal and Torres Strait Islander persons with acquired brain injury and their communities.
2. Develop, pilot and evaluate a culturally appropriate instrument for assessing functioning, cognitive impairment, and the care and support needs of Aboriginal and Torres Strait Islander persons with acquired brain injury.
3. Develop a support framework for assessors including guidelines for training, peer mentoring, supervision, management and review.

Between February and May, 2013, a variety of stakeholders and communities with a vested interest in the assessment and support of Aboriginal and Torres Strait islander people with an acquired brain injury were consulted, across the Northern Territory, Queensland and New South Wales. The key findings of this research can be summarised as:

- Careful consideration of guidelines for the appropriate protocols for engaging Aboriginal and Torres Strait Islander Australians in the assessment process was undertaken. In consultation with stakeholders, a four-stage Planning and Assessment framework was developed that describes the appropriate actions that DisabilityCare Australia Planners and/or Local Area Coordinators need to take during the assessment process when determining eligibility to DisabilityCare Australia.
- A variety of existing instruments were identified and reviewed for their cultural acceptability and usefulness for use with Aboriginal and Torres Strait Islander Australians. A novel instrument toolkit was developed, containing cognitive and functional assessments that are culturally acceptable for assessment of acquired brain injury in Aboriginal and Torres Strait Islander Australians. This instrument toolkit must be scientifically validated before DisabilityCare Planners and Local Area Co-ordinators can use it.
- The necessary training components for the professional development of DisabilityCare staff were identified. Both cultural awareness and competency training and acquired brain injury training programmes and coursework are detailed in this report.

Recommendations pertaining to the delivery of culturally competent and acceptable assessment are as follows:

1. DisabilityCare should integrate the Planning and Assessment Framework into its Operational Guidelines.
2. When conducting assessments with Aboriginal and Torres Strait Islander prospective participants, assessors should work in accordance with the four stages specified in the Planning and Assessment Framework: Engagement, Pre-Assessment, Assessment and Follow-up.
3. Training for assessors should be developed to ensure the Planning and Assessment Framework is reflected in practice.
4. DisabilityCare should remain committed to using valid assessment instruments. The culturally acceptable instrument toolkit described should be validated to enable culturally acceptable and accurate assessment of Aboriginal and Torres Strait Islander Australians with acquired brain injury.
5. The alignment of the instruments with the DisabilityCare Assessment Toolkit must be reviewed when the DisabilityCare Assessment Toolkit becomes available.
6. Accredited training for assessors should be developed to ensure instruments are used appropriately.
7. DisabilityCare should ensure that all staff engage in training and ongoing formally accredited professional development in the area of cultural competence and awareness.
8. Accredited training must be developed to address the lack of training available. Training must cover causes and impacts of acquired brain injury, and assessment and engagement protocols.
9. DisabilityCare should remain committed to employing or contracting Aboriginal and Torres Strait Islander Australian staff to undertake assessment of Aboriginal and Torres Strait Islander clients with acquired brain injury.
10. An Aboriginal and Torres Strait Islander review committee should be established, to hear appeals from Aboriginal and Torres Strait Islander prospective participants whose assessment for eligibility was unsuccessful. This is extremely important during the interim period in which no validated assessment instruments or approaches exist.
11. Awareness of acquired brain injury must be raised in DisabilityCare staff and Aboriginal and Torres Strait Island communities, to ensure that Aboriginal and Torres Strait Islander individuals with this disability are recognised and have access to DisabilityCare support.



Chapter 1: Introduction & Background & Method

DisabilityCare Australia aims to provide long-term, person-centred care and support to all Australians with a significant and ongoing disability, including individuals with an acquired brain injury (ABI) (Brain Injury Australia, 2012). The scheme has significant potential, and it is critical that all Australians with a disability benefit equitably from this opportunity (First Peoples Disability Network, 2013). However, the needs of people living with an ABI are often overlooked and misunderstood by disability services, health professionals and governments (Brain Injury Australia, 2012). Furthermore, for some population groups, including Aboriginal and Torres Strait Islander Australians with a disability, equitable benefit can only be achieved if additional and specialised measures are devised and implemented to overcome the pre-existing disadvantage to which Aboriginal and Torres Strait Islanders with disability are subject relative to other Australians with disability (First Peoples Disability Network, 2013). Therefore, in 2012, James Cook University (JCU), Synapse (Brain Injury Association of Queensland, Inc.) and Brain Injury Australia made a submission to the Federal Government's Practical Design Fund (Department of Families, Housing, Community Services and Indigenous Affairs) to prepare individuals, communities and services for the transition to DisabilityCare Australia (also known as the National Disability Insurance Scheme). The project was funded in December 2012, with Brain Injury Australia co-managing the project with Synapse, and contracting JCU to conduct the research.

The project had three deliverables:

1. Develop best practice guidelines for engagement and assessment of Aboriginal and Torres Strait Islander persons with ABI and their communities.
2. Develop, pilot and evaluate a culturally appropriate instrument for assessing functioning, cognitive impairment, and the care and support needs of Aboriginal and Torres Strait Islander persons with ABI.
3. Develop a support framework for assessors including guidelines for training, peer mentoring, supervision, management and review.

This chapter provides a description of ABI, including causes, outcomes and incidence statistics in the general Australian population. It then discusses a number of policy frameworks that are particularly relevant to Aboriginal and Torres Strait Islander Australians with a disability. Further, this chapter

details the unique experiences of Aboriginal and Torres Strait Islander Australians with an ABI, including a number of factors that can prevent or delay service access. Finally, the methodological framework used to conduct this study and achieve the three deliverables defined above, is described.

The outcomes are presented in Chapters 2 to 4. Chapter 2 describes a Planning and Assessment framework developed to illustrate the best-practice guidelines found to engage Aboriginal and Torres Strait Islander persons with ABI in assessment. Chapter 3 reviews instruments currently used for assessing functioning and the care and support needs of Aboriginal and Torres Strait Islander Australians with ABI, evaluates their cultural acceptability, and describes the development of a culturally acceptable ABI Assessment Toolkit. Chapter 4 provides a framework for the ongoing training and professional development of DisabilityCare Planners and LACs. The framework encompasses current training opportunities and centralises the role of Aboriginal and Torres Strait Islander people in the mentoring of non-Indigenous Australians to develop cultural competency of practice.

This submission concludes with a brief summary and key recommendations for the implementation of the deliverables. Overall, this document aims to provide clear and justified recommendations concerning the assessment of Aboriginal and Torres Strait Islander Australians with an ABI by DisabilityCare Australia.

Acquired Brain Injury

Globally, brain injury is a leading cause of disability, with around 1 in 45 Australians (432,700 people) reported as having an ABI with activity or participation limitations due to disability in 2003 (Australian Institute of Health and Welfare, 2007). ABI refers to any damage to the brain that occurs after birth (National Community Services Data Committee, 2006), with the exception of Foetal Alcohol Spectrum Disorder (FASD) (Brain Injury Australia, 2012). Brain injury can be traumatic (caused by a head injury from an external force) or non-traumatic. Non-traumatic causes include stroke, alcohol or drug misuse, tumours, haemorrhages, poisoning, infections, hypoxia (decrease of oxygen supply to the brain) and anoxia (absence of oxygen supply to the brain) (National Community Services Data Committee, 2006).

The consequences of ABI are complex and difficult to predict, as each individual's brain injury varies in the extent and location of damage (Fortune & Wen, 1999). Damage can be widespread or focal (Fortune & Wen, 1999), and even a mild injury can result in a serious disability (Brain Injury Australia,

2012). Brain injury often leads to a range of impairments in cognitive, physical and psychosocial functioning (Jamieson, Harrison, & Berry, 2008) (see Figure 2.1). The wide-range of impairments and disabilities that can result from a brain injury means that people with an ABI have very diverse support needs (Fortune & Wen, 1999). Further, impairments frequently fail to resolve over time, and the on-going cost of disability due to brain injury is often substantial: services may need to be provided for life, with the family often shouldering a large share of the burden of care (Jamieson et al., 2008). Implications also extend to the communities within which people with an ABI live (Gauld, Smith, & Kendall, 2011; Geurtsen, Van Heugten, Meijer, Martina, & Geurts, 2011; Keightley et al., 2011), their workplaces (Andelic, Stevens, Sigurdardottir, Arango-Lasprilla, & Roe, 2012; Lundqvist & Samuelsson, 2012), their experience of education (Linden, Braiden, & Miller, 2013) and their ability to participate in everyday activities (Fleming et al., 2011). For Aboriginal and Torres Strait Islander Australians, despite a raft of policy statements, the experience of ABI is further compounded by a number of issues relating to lack of knowledge and culturally appropriate services, and barriers to service access.

Figure 1.1: Key Functions Impaired by an Acquired Brain Injury

Body Functions
Higher-level cognitive functions
Emotional functions
Energy and drive functions
Control of voluntary movement functions
Memory functions
Sensation of pain
Attention functions
Consciousness functions
Body Structures
Structure of brain
Activities & Participation
Carrying out daily routine
Conversation
Walking
Complex interpersonal interactions
Acquiring, keeping and terminating a job
Self care
Recreation and leisure
Family relationships

Based on the World Health Organisation International Classification of Functioning, Disability and Health (ICF) Core Sets for traumatic brain injury (Laxe et al., 2013).

Note: There is no ICF Core Set available for non-traumatic ABI, however

Policy settings

Remote Indigenous communities and communities in remote areas with significant populations are entitled to standards of services and infrastructure broadly comparable with that in non-Indigenous communities of similar size, location and need elsewhere in Australia (Council of Australian Governments, 2012)

A number of disability and Aboriginal and Torres Strait Islander policy frameworks recognise that Aboriginal and Torres Strait Islander People have unique needs. These include the National Disability Strategy (Council of Australian Governments, 2011), the Carer Recognition Act 2010 ("Carer Recognition Act"), and anti-discrimination legislation to address Equal Employment ("Equal Employment Opportunity,"). Australia is a signatory of The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)(United Nations: Web Services Section - Department of Public Information, 2006) and United Nations Declaration on the Rights of the Indigenous Peoples (United Nations, 2008).

The *Close the Gap: National Indigenous Reform Agreement* (Council of Australian Governments, 2012) sets out key principles for programs and service delivery. In regards to DisabilityCare Australia the following service delivery principles carry significant relevance:

- **Priority principle:** Programs and services should contribute to Closing the Gap by meeting the targets endorsed by COAG while being appropriate to local needs.
- **Indigenous engagement principle:** Engagement with Indigenous men, women and children and communities should be central to the design and delivery of programs and services.
- **Sustainability principle:** Programs and services should be directed and resourced over an adequate period of time to meet the COAG targets.
- **Access principle:** Programs and services should be physically and culturally accessible to Indigenous people recognising the diversity of urban, regional and remote needs.

Access to quality, effective health services by strengthening the service infrastructure, has been seen as essential to improving access by Aboriginal and Torres Strait Islander peoples to health services. The Indigenous Urban and Regional Strategy (Council of Australian Governments, 2009) commits governments to coordinate funding for infrastructure to address Indigenous disadvantage in urban and regional locations. Governments are to improve access to better-coordinated and targeted

services, and strengthen individual, family and community wellbeing and capacity to improve take-up of services. The National Disability Agreement between the Federal Government and each State and Territory recognised that disability need to be addressed through appropriate service delivery arrangements (Mines & Mines, 2011).

The *National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013* (Commonwealth of Australia, 2007) Implementation Plan emphasised the need for health care services to be culturally sensitive, through increased coordination between Aboriginal community controlled health services and general (mainstream) services, with a focus on the priorities identified in the Framework, including increased participation in planning and managing health services by Aboriginal and Torres Strait Islander peoples (Commonwealth of Australia, 2007, p. 12). Specific to disability, the Framework states that governments will consult with Aboriginal and Torres Strait Islander communities in planning and development of disability services to meet local and regional needs, increase take-up of services, support carers and assist those with disabilities to gain and maintain employment (Commonwealth of Australia, 2007, p. 36).

The National Disability Strategy (Council of Australian Governments, 2011) acknowledges:

Aboriginal and Torres Strait Islander Australians experience higher rates of disability than do other Australians. After taking into account age differences between the Indigenous and non-Indigenous populations, the rate of disability among Aboriginal and Torres Strait Islander Australians is almost twice as high as that among non-Indigenous people... [Strategies] need to tackle specific barriers faced by Aboriginal and Torres Strait Islander Australians with disability.

As a result, it is critical that the needs of Aboriginal and Torres Strait Islander Australians with disabilities be explicitly addressed by DisabilityCare Australia. This must include delivery of culturally competent services, developing appropriate models of service delivery (particularly in remote areas), and provide leadership for a community-wide shift in attitudes to disabilities.

Aboriginal and Torres Strait Islander Australians and Acquired Brain Injury

Whilst there is little data or research on brain injury in Aboriginal and Torres Strait Islander Australians, statistics suggest that risk factors for brain injury, including head injury, substance use and stroke are more common in this group than in the mainstream population. For instance, head trauma accounts for 30% of injuries requiring hospitalisation in Aboriginal and Torres Strait Islander Australians (Helps & Harrison, 2006) compared to 18% in the general population (Tovell, McKenna,

Bradley, & Pointer, 2012). Between 2005-2008, Aboriginal and Torres Strait Islander Australians were 21 times more likely to suffer a head injury due to assault than their mainstream counterparts (Jamieson et al., 2008). Aboriginal and Torres Strait Islander Australians are also 1.5 times more likely to drink alcohol at risky levels (Australian Institute of Health and Welfare, 2011), and rates of risky-drinking and alcohol-related head trauma appear to be much higher than this in some regions, such as the Northern Territory (Jayaraj et al., 2012). In addition, the hospital admission rate for stroke among Aboriginal and Torres Strait Islander Australians is approximately 1.5 times greater than for the general population (Thrift & Hayman, 2007).

Furthermore, people with brain injury are over-represented in the criminal justice system (Sotiri, McGee, & Baldry, 2012), and Aboriginal and Torres Strait Islander Australians constitute one-quarter (26 per cent) of Australia's prison population compared to 2% of the general population (National Indigenous Drug and Alcohol Committee, 2013). For example, the 2010 National Prisoner Health census found that 41 per cent of female and 38 per cent of male prison entrants reported having sustained at least one head injury that led to loss of consciousness. Furthermore, Aboriginal and Torres Strait Islander Australians with cognitive impairment (including an ABI) are over-represented in criminal justice settings across Australia (Sotiri et al., 2012). Aboriginal and Torres Strait Islander people with a cognitive impairment (compared to the non-disabled population) are more likely to come to the attention of police, more likely to be charged, and are more likely to be imprisoned (Sotiri et al., 2012).

Despite the high rates of risk factors for brain injury, the use of relevant health, rehabilitation and advocacy services is extremely low among Aboriginal and Torres Strait Islander Australians (First Peoples Disability Network, 2010; Gauld et al., 2011). There are a number of barriers Aboriginal and Torres Strait Islander Australians with an ABI face that may prevent them from accessing services. These include a variety of systemic non-supports, different notions of health and disability, the lack of culturally acceptable and validated assessment instruments, discrimination and stigmatisation, and the lack of services in rural and remote locations.

Systemic non-supports

A range of systematic failures pose a barrier to support for Aboriginal and Torres Strait Islander Australians with an ABI. According to Drew, Adams, and Walker (2010), the lack of cultural competence in past practice has contributed to the overall failure of systems of care for Aboriginal and Torres Strait Islander people. The existing disability support system in Australia has been described as a 'market failure' for Aboriginal and Torres Strait Islanders with a disability and their

families, resulting in severe personal and systemic disempowerment (First Peoples Disability Network, 2013). Consequently, Aboriginal and Torres Strait Islander people are far less likely to engage with non-Indigenous services if they perceive or experience the service as lacking cultural competency. Further, it is thought that an unwillingness to self-identify with another potentially discriminatory or stigmatising aspect of one's life has also led to the under reporting of disability in Aboriginal communities (Aboriginal Disability Network New South Wales, 2007). Therefore, the absence of a diagnosis of an ABI may result through individuals and/or their carers and families avoiding or declining services or medical interventions. In addition, Aboriginal and Torres Strait Islander Australians who want to engage with the disability system may be unaware of their rights or entitlements to receive supports, or of the necessary requirements (such as paper work and personal information)(Australian Government Productivity Commission, 2011).

Another systemic non-support is the lack of appropriate services for Aboriginal and Torres Strait Islanders with an ABI. There are very few Aboriginal and Torres Strait Islander specific disability services, and no such services exist in many communities (First Peoples Disability Network, 2013). Furthermore, many service systems have specific criteria for participation, which presents a problem when a person requires support for multiple issues, for example cognitive impairment, mental illness *and* drug and alcohol misuse (Sotiri et al., 2012). Ultimately, services that are able to address a combination of issues in a way that is Aboriginal and Torres Strait Islander specific are incredibly uncommon (Sotiri et al., 2012), which presents a significant deficit in service provision for Aboriginal and Torres Strait Islander Australians with an ABI, given the complex needs of a person with an ABI, and the possibility of co-morbidities.

Further, a lack of ABI specific services and trained service providers may contribute to ABI going undetected or misdiagnosed. ABI is distinct from intellectual disability and mental illness (Brain Injury Australia, 2012; Sotiri et al., 2012), however poor training of staff may contribute to low identification of ABI, as symptoms may be misinterpreted or obscured by competing co-morbidities (NSW Agency for Clinical Innovation, 2011). This issue is compounded by policy and legislative frameworks, where mental illness and cognitive impairment are often conflated (Sotiri et al., 2012). This is problematic for people with an ABI, as cognitive impairment is not 'treatable' in the same way that much mental illness is (Sotiri et al., 2012), nor can it be considered an intellectual disability, as intellectual abilities are usually retained after an ABI (Brain Injury Australia, 2012). Therefore, ABI needs to be recognised as a distinct health condition, and those providing assessments and support services need to receive the appropriate levels of education and training in ABI.

Concepts of health and disability

Resonating through most, if not all issues concerning the health of Aboriginal and Torres Strait Islander Australians, are concepts of health and ill-health. Aboriginal and Torres Strait Islander concepts of 'health' differ from a Western view, and the concept of disability is also a Western idea (Sotiri et al., 2012). Aboriginal and Torres Strait Islander people often view health in a broad sense, that includes consideration of the physical, cultural and spiritual components of wellbeing (Drew et al., 2010). Culture and identity are central to Aboriginal perceptions of health, ill health and disability. In fact in many cultural linguistic groups, there may not be a word that translates directly into English that means 'disabled' or describes a particular type of disability. Despite the need and desire for Aboriginal and Torres Strait Islander carers to have a working understand the nature of the disability they are dealing with, being labelled with an English speaking word or term is often undesirable.

In regards to service provision, these perceptions of health are highly significant and influential. They influence an individual's attitude to their own health status, and when and why people access services (Australian Health Ministers' Advisory Council, 2004). Further, they affect an individual's acceptance or rejection of treatment and the likelihood of continuing to follow treatment recommendations, as well as the likely success of prevention and health promotion strategies (Australian Health Ministers' Advisory Council, 2004). Disability is often medicalised to treat the individual's health condition and fail to consider the broader impact of their condition on the person's whole quality of life (Aboriginal Disability Network New South Wales, 2007). The Aboriginal Disability Network Report states:

The impact of living with disability as an Aboriginal person relates to the whole of life of the individual. It is not enough to assume that an Aboriginal person with disability simply requires support for one facet of their life. [Their] needs ... are often of a complex nature where longer-term support is required to ensure that there is appropriate and equitable participation both in the wider community and also within their own communities. [They are] less likely to be able to access employment and education... [which are] fundamental ...to escap[ing] a life of poverty. (Aboriginal Disability Network New South Wales, 2007, pp. 10 - 12)

Lack of Instruments

Currently, there are limited validated and culturally acceptable psychometric instruments designed to assess the impairments and outcomes (including cognitive function) associated with ABI for either Aboriginal Australians or Torres Strait Islanders. This is a significant concern, as cultural competence is essential to good assessment practice (Drew et al., 2010), and the inability to assess with reliable and valid measures can result in further disadvantage, as impairments may go undetected, undiagnosed and untreated (Dingwall & Cairney, 2009). Accordingly, national consultations by Brain Injury Australia reported widespread concerns about the assessment, management and outcomes of brain injury in Aboriginal and Torres Strait Islander communities and individuals (Brain Injury Australia, 2012).

Racism and Discrimination

Racism and discrimination may also be a barrier to Aboriginal and Torres Strait Islanders accessing services. The Aboriginal Disability Network New South Wales (2007) reports that Aboriginal people with a disability and their carers frequently experience discrimination in the area of service provision. Furthermore, in addition to overt racism and stereotyping, a key issue relating to lack of cultural competence in mainstream disability support services is “structural racism”, where lack of cultural knowledge and sensitivity result in processes that are incompatible with Aboriginal and Torres Strait Islander cultural approaches and values (First Peoples Disability Network, 2013).

Remote communities

In 2006, 24% of Aboriginal and Torres Strait Islander Australians lived in remote or very remote areas, compared to around one per cent of the general population (Australian Government Productivity Commission, 2011). Remoteness can be a significant barrier for service access for Aboriginal and Torres Strait Islander Australians with an ABI, there are often no or very limited disability support services and workers in remote communities (First Peoples Disability Network, 2013). This leads to a reliance on the much resented ‘fly in/fly out’ ‘outsider’ service delivery (First Peoples Disability Network, 2013), where the development of trust and engagement is difficult (NSW Agency for Clinical Innovation, 2011). Furthermore, many Aboriginal and Torres Strait Islanders with a disability are currently denied their right to live independently and access the physical environment, transportation, information and communications due to a lack of accessibility in their communities (Mines & Mines, 2011).

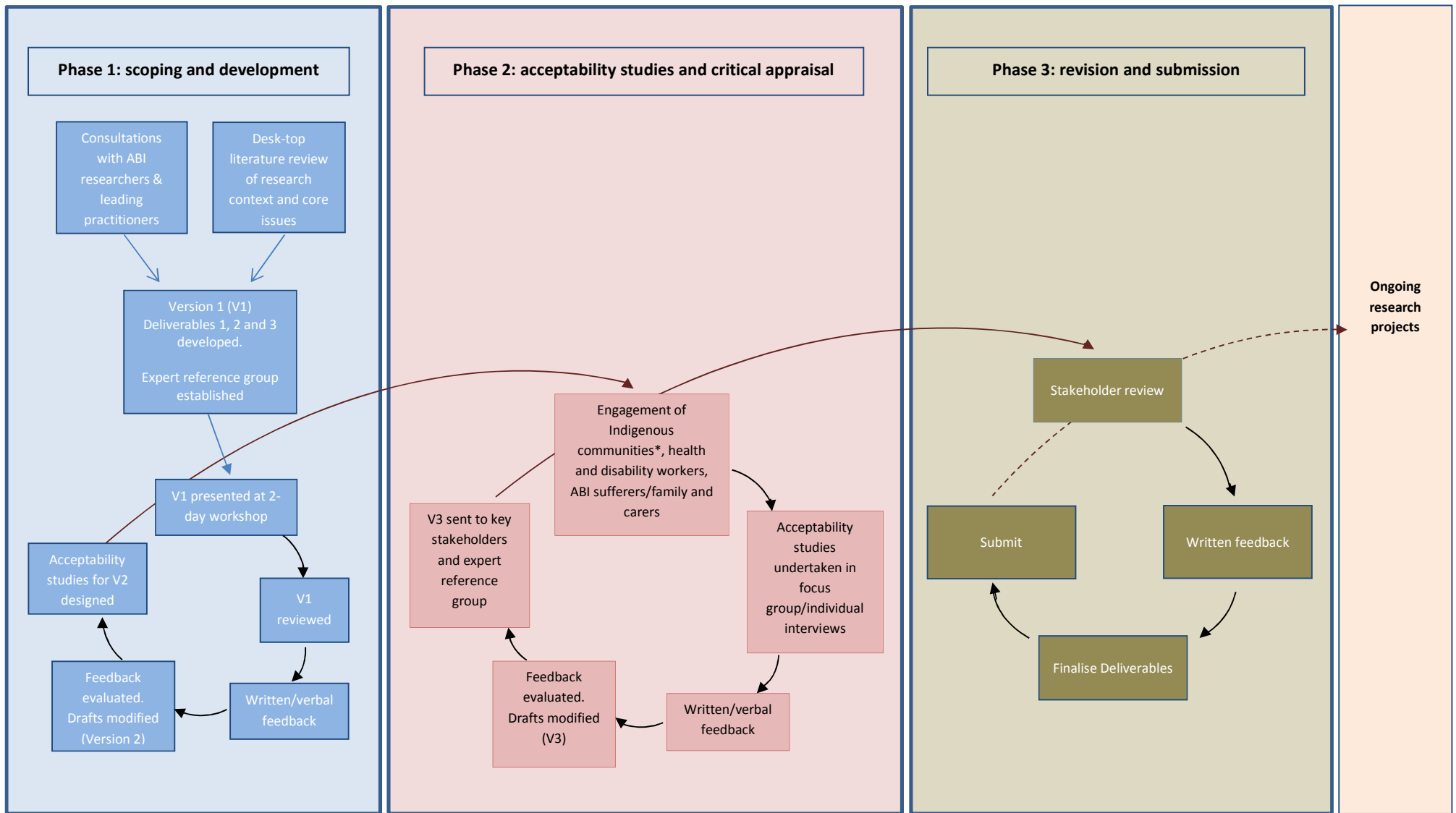
In addition, living remotely limits an individuals' access to specialised ABI rehabilitation programmes and experienced specialised staff and services. There are limited allied health services available to people with an ABI in remote communities, and a lack of adequate transport and support for travel create additional barriers (NSW Agency for Clinical Innovation, 2011). Rehabilitation within outer regional hospitals is restricted due to limited numbers of skilled practitioners, in addition to a lack of expertise in working with people with ABI (NSW Agency for Clinical Innovation, 2011).

Methodology

The project was conducted within Participatory Action Research, Continuous Quality Improvement and expert consensus frameworks. These approaches are closely related in practice, and all are endorsed for research with Aboriginal and Torres Strait Islander peoples as they emphasise collaboration, capacity building, tackling the underlying causes of ill health, and improving outcomes within a culture of evaluation and not blame. Participatory Action Research maintains that community concerns are reflected in research and requires that the community be actively engaged and involved in the study. Participatory Action Research is endorsed for research with Aboriginal and Torres Strait Islander people because it engages end-users, experts and stakeholders, all of whom contribute to the development of key outcomes as well as to the research process. The Continuous Quality Improvement framework is underpinned by a cyclical collection of data (qualitative and quantitative), which is analysed reflectively to determine necessary improvements to the system. This cycle is regularly continued and fosters a culture of on-going learning, evaluation, quality improvement, outcome-driven practice, and acceptance of change. The expert consensus approach (Minas & Jorm, 2010) is endorsed for cultural minorities, for which there is often little published evidence regarding what constitutes best practice (e.g. in the assessment of ABI in Aboriginal and Torres Strait Islander persons). Specifically, expert consensus methods provide a way to systematically tap the expertise of people working in the area of interest.

Procedure

The project was conducted across three phases depicted in Figure 1.2 below.



* Communities visited: Mt Isa, Redfern, Wujal Wujal, Thursday Island

Figure 1.2: Phases of the study and the cycle of Continuous Quality Improvement

1. Scoping and Development:

An extensive review of the literature was undertaken concurrently to the first phase of consultations. Consultations were undertaken across Queensland, New South Wales, the Northern Territory and the Torres Strait Islands (Figure 1.3).

Interviews and focus groups were semi-structured and conducted using a 'research yarning' approach, endorsed for research with Aboriginal and Torres Strait Islander Australians. Interviews were conducted in person or via telephone, and focus groups were conducted in person. When possible, interviews and focus groups were recorded and transcribed. If participants were uncomfortable with being recorded, extensive notes were taken. Topics addressed in the interview or focus group were tailored to suit the participants' experience, but included one or more of the following: the utility, accuracy and cultural acceptability of instruments currently used to assess ABI with Aboriginal or Torres Strait Islander clients, ideal characteristics of an instrument, culturally acceptable and unacceptable assessment and engagement practices and processes. A systematic synthesis of the transcripts and notes was conducted using Nvivo 10 to extract the key themes across the relevant domains.

Seventy-five participants were interviewed or attended a focus group. Interviewees included allied health professionals (including psychologists, social workers, speech therapists, occupational therapists and indigenous liaison officers), individuals working with advocacy organisations for indigenous disability or ABI, disability services staff, community-based health service providers, rehabilitation clinicians, individuals with ABI or caring for someone with ABI, representatives from the Department of Aboriginal, Torres Strait Islander and Multicultural Affairs, and individuals in the education sector (including primary/secondary and tertiary education sectors).

Sixty participants were drawn from Queensland (including 10 from the Torres Strait Islands), seven were from NSW, six were from the Northern Territory, and one participant was drawn from each of Victoria and South Australia. Twenty-seven participants were Aboriginal, three were Torres Strait Islander, and 45 were non-Indigenous.

Table 1.1: Participants interviewed for this study

	Total	Allied health	Advocacy	Disability Services	Community-based Health Service Provider	Education	Individual with ABI and family members
Total	75	25	12	8	16	5	9
Non-Indigenous	45	23	4	7	8	3	0
Aboriginal	27	1	8	1	6	2	9
Torres Strait Islander	3	1	0	0	2	0	0

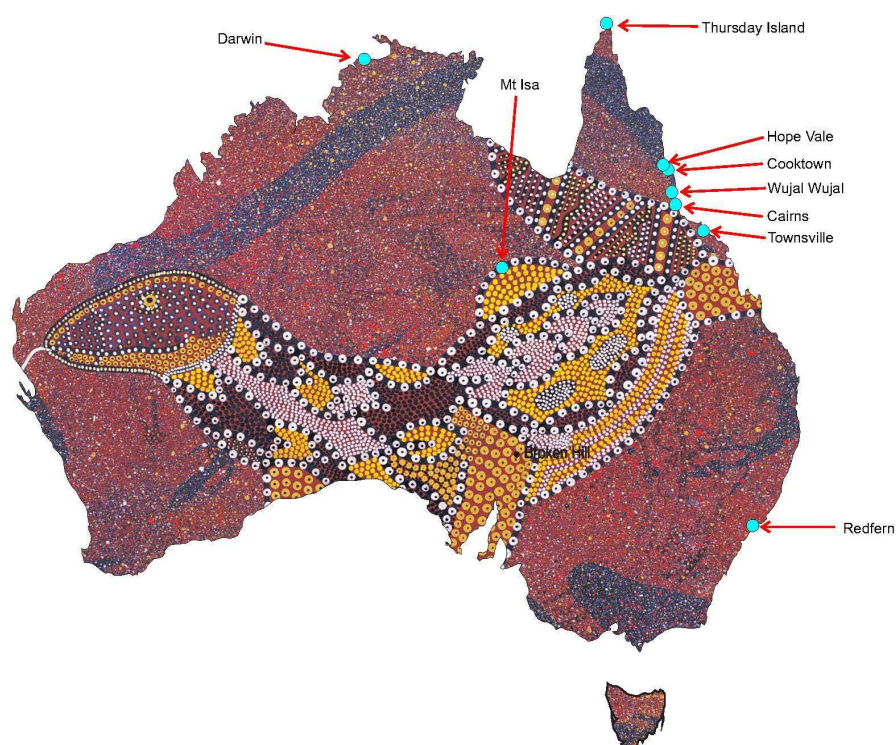


Figure 1.3: Map of communities consulted

In line with the expert consensus approach, a multi-disciplinary expert reference group was established, drawing participants from the consultations. This group formed part of the ongoing evaluation process to ensure continuous quality improvement. A workshop was held with this reference group, which involved preliminary evaluations of the draft deliverables. The draft deliverables were presented, and feedback was sought to gauge the level of agreement and convergence of opinions regarding both the relevance and

cultural appropriateness of key elements of the draft deliverables. Expert consensus drove further modifications to the development of the three deliverables.

2. Pilot Studies, Review and Modification

Phase 2 of the project involved engagement with stakeholders and community members to undertake pilot studies. The draft deliverables were presented in individual interviews or focus groups and verbal or written feedback was sought. Consistent with the Continuous Quality Improvement approach, feedback was then evaluated and the deliverables were further modified, with endorsement sought from key stakeholders prior to finalization.



Chapter 2: Engagement, Planning and Assessment Framework for Aboriginal and Torres Strait Islander People

DisabilityCare Australia starts with the presumption that all people with disability have the ability and the right to make their own decisions and exercise choice and control over their supports. The realisation of the many potential benefits of DisabilityCare for Aboriginal and Torres Strait Islander people calls for culturally appropriate engagement strategies to undertake planning and assessment. Such a strategy will encompass good practice principles for engagement, consultation, planning and participatory collaboration, within a culturally competent framework, that empowers individuals, families and communities.

Figure 2.1 below is a diagram of a four-stage Planning and Assessment framework. The four stages are:

Stage 1: Engagement with the community and prospective participant/family

In the framework, strategies and guidelines for culturally appropriate engagement are provided. It is also a requirement that practitioners receive and maintain formal training in culturally appropriate assessment prior to visiting communities to undertake assessment (See Chapter 5).

Stage 2: Pre-assessment

This stage requires assessors to undertake a comprehensive interview and investigation of the disability with their prospective participant and immediate family/carers. The objective of this stage is to explore the participant's cultural history, living environment and case history. This may include using an interpreter LAC and or community person and/or having material translated. A crucial element of this stage is to explain fully and document the limitations of any testing protocol that may be used.

Stage 3: The assessment process

Assessors undertake the ABI assessment in a face-to-face interview to assess the eligibility of the prospective participant. This stage is likely to involve immediate family/carers and community members.

Stage 4: Post-assessment follow-up: The interpretation and reporting of results

Assessors report back to the participant and their family the outcomes of the assessment within a reasonable period. They need to incorporate cultural explanations and avoid labelling in the final stage when interpreting the results.

Figure 2.1: Planning and Assessment Framework

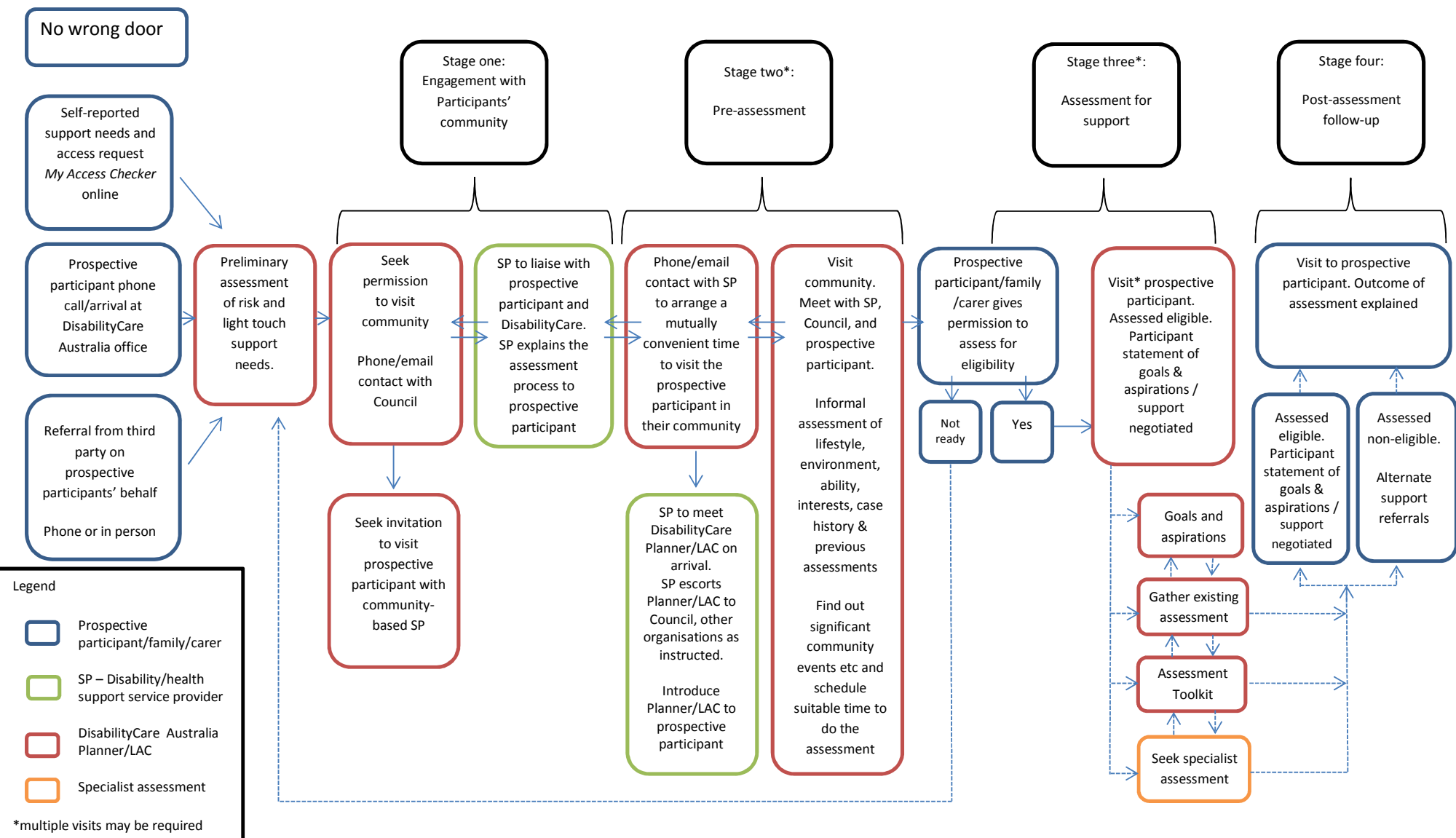


Figure 2.1 pictorially describes a framework for planning and assessment of ABI to engage Aboriginal and Torres Strait Islander people in the assessment process. In practice, a necessary precondition for DisabilityCare staff engaging with the Planning and Assessment framework is training in cultural competency and ABI (see Chapter 4). Having a well-developed cultural knowledge is essential. It is strongly recommended that pre-assessment and assessment be conducted in a face-to-face mode, by locally trained DisabilityCare Planners and LACs, recruited from the community itself when possible (NDIS 2013). Aboriginal and Torres Strait Islander people recruited to work for DisabilityCare Australia may also need to undergo the appropriate cultural awareness training when working in communities other than their own heritage. The potential of providing an inaccurate assessment and misdiagnosis is increased if each stage of the Planning and Assessment framework is not adhered to.

This chapter presents general principles of working with Aboriginal and Torres Strait Islander people followed by best-practice guidelines for each of the four stages of the Planning and Assessment framework. These guidelines are informed by several crucial resources; the Service Delivery Principles for Programs and Services for Indigenous Australians (Council of Australian Governments, 2012), National Urban and Regional Service Delivery Strategy for Indigenous Australians (Council of Australian Governments, 2009); Engagement and Partnership with Indigenous People FAHCSIA guidelines (Australian Government, 2012); and principles abiding by the United Nations Declaration on the Rights of Indigenous Peoples (United Nations, 2008). Protocols and principles are derived from several sources including the Protocols for consultation and negotiation with Aboriginal People (Queensland Department of Aboriginal and Torres Strait Islander Policy and Development, 1999); Protocols for the delivery of social and emotional wellbeing and mental health for Aboriginal and Torres Strait Islander people in North Queensland: Guidelines for health workers, clinicians, consumers and carers (Haswell et al., 2009), Mina Mir Lo Ailan Mun, Proper Communication with Torres Strait Island People (Queensland Department of Aboriginal and Torres Strait Islander Policy and Development, 2001), Working as a Culturally Competent Mental Health Practitioner in Working Together: Aboriginal and Torres Strait Islander Mental Health and Wellbeing Principles and Practice (Walker & Sonn, 2010) and FAHCSIA's guidelines for Engagement and partnership with Indigenous people (Australian Government, 2012). Comments drawn from recent consultation interviews with Aboriginal and Torres Strait Islanders and health professionals, described in Chapter 1, are included in the many of the discussions.

General principles of working with Aboriginal and Torres Strait Islander people affected by ABI

... I mean that was just false or mis-information. They were simply wrong. So you couldn't really rely on a lot of the information you were given. The only reliable information really, was people who worked within that community, who knew them well and were possibly Elders from the same mob.

The Elders were the most reliable ones in my work with them... (Disability assessment officer, Queensland).

There are many different views as to the correct protocol when working with Aboriginal and Torres Strait Islander people and communities. A protocol is a means by which to build relationships and communicate in a way that takes into account (or is based upon) the customs and lores of the people and community (Queensland Department of Aboriginal and Torres Strait Islander Policy and Development, 1999, p. 21). General principles are presented in Figure 2.2 below. These principles should underpin all ongoing engagement activities.

Be respectful

- Accept that you are in another social and cultural setting
- Respect and trust the knowledge and views of Aboriginal and/or Torres Strait Islander Australians
- Engage through the community's preferred and/or nominated channels
- Be factual

Be informed and inform others

- Know as much as possible before proceeding with engagement. Acquire knowledge of the broad physical, social, historical, cultural and political context in which engagement is to occur
- Undertake cultural awareness training
- Disseminate information or ideas broadly across all key stakeholders and the relevant community members in a fair and equitable manner - ensure no one is disadvantaged
- Clearly communicate the assessment process to ensure prospective participants understand their involvement and the potential outcomes

Establish sustainable relationships

- Adopt a participatory rather than controlling role. Involve the prospective participant, their families and relevant community members as partners and participants in all processes of engagement, consultation of the planning and assessment process
- Anticipate barriers in cross-cultural communication because of the differing conceptual systems and provide whatever support is necessary to help people participate and contribute to the pre-assessment and assessment stages
- Be clear about why participation in the pre-assessment and assessment stages is being

sought and how people's participation will affect the process

- Build enduring relationships with service providers
- Seek to develop healthy working relationships with Councils, communities and Individuals.
Promote goodwill and understanding between all parties
- Be a reflective practitioner, seek feedback on your conduct and learn from all experiences to improve one's personal practice in future

Behave ethically

- Be transparent and honest
- Be clear about why DisabilityCare is engaging and what it hopes to achieve to ensure that expectations are aligned with what outcomes can be reasonably expected

Be meaningful

- Allow adequate time for genuine engagement, particularly with the prospective participant and their family, carers and relevant community members
- Allow time for people to think about ideas and proposals and to discuss them informally amongst themselves in their own language
- Accept prospective participants' decision to withdraw at any stage from the planning and assessment process, without consequence or harming future applications for eligibility support
- Provide opportunities for input early and often

Be outcomes focused

- Ensure engagement activity is outcomes focused, not just a box to be ticked
- Analyse situations or problems carefully and in detail to offer or provide an appropriate solution or outcome
- Successful outcomes need to demonstrate how the relationship has been improved through the engagement
- Work for 'win-win' outcomes

Follow up

- Acknowledge the participation of Aboriginal or Torres Strait Islander Australians in the engagement activity
- Ensure that there is clear feedback of the assessment outcomes and how their input has

been utilised

- Feedback should be provided through the appropriate channels
- Communicate to the family how the ascertained level of support is to be managed and administered

Figure 2.2: Principles for culturally appropriate engagement

Be respectful

It needs to be emphasised that every community is unique. DisabilityCare Planners will find that they may need to develop their own repertoire of strategies to use the Planning and Assessment framework in different settings. The diversity of Aboriginal society means that there is no single recipe. There are remote communities such as Doomadgee or Mornington Island, rural communities such as Innisfail or Boulia, provincial towns or cities such as Townsville or Alice Springs and major cities such as Brisbane, Sydney and Melbourne and so on. Planners may need to deal with one community in a certain style, but in another community 100kms away they may need a totally different style (Queensland Department of Aboriginal and Torres Strait Islander Policy and Development, 1999, p. 20).

Be informed and inform others

Both Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander DisabilityCare workers need to investigate and research the culture and history of the communities in which they are about to work. This knowledge is to be used when making professional judgements about, and dealing directly with, Aboriginal and Torres Strait Islander prospective participants. As two health practitioners stated:

The biggest mistake that everyone makes, I think, is to lump people together... Things have to be tailored to the patient more than they do probably for [other] Australians. I mean ... a lot of the other cultures we deal with, whether it's Greek or Italian or Vietnamese or what these days... a lot of it is based on European sort of concepts. You don't have that with Aboriginal and Torres Strait Islander people. So you're starting from scratch.

You try and take a history but trying to take that is clearly quite different with Aboriginal and Torres Strait Islander people, compared with non- Aboriginal and Torres Strait Islander people. Because of all the cultural differences, you can't just sit down and chat to them and ask them the usual range of questions. A lot of them really don't know what you're talking about.

DisabilityCare workers need to take responsibility to become aware of the value systems and authority structures operating in the Aboriginal and Torres Strait Islander communities for whom they provide services (The Australian Psychological Society, 1995).

Awareness also extends to socio-political issues that are likely to adversely affect the wellbeing of Aboriginal and Torres Strait Islander participants and the effectiveness of the disability and health services provided. The effect of post-colonisation and trauma is still experienced by Aboriginal and Torres Strait Islander people, for example. The following statement was provided by a professional working with Aboriginal and Torres Strait Islander communities of Cape York:

I mean there's been a lot of people over the years, like the Stolen Generation, well it happened in Cape York, particularly, and the Torres Straits, where people who had kids with disabilities were taken away, at a very early age. They were told that they couldn't look after them, whether they could have or not. They weren't given much choice... I think we've all probably worked with a number of people over the years, to try and get them back out of institutions, back into their communities.

DisabilityCare staff will need to find out what the local protocols are concerning women's and men's business. For example, it may not be appropriate for male DisabilityCare staff to discuss health and care matters with women. Some communities have protocols around age and there may be taboos on discussing past community members, which may affect the ability to gather information related to assessment with some clients.

It would be appropriate for DisabilityCare staff to clearly inform Aboriginal and Torres Strait Islander clients of their rights as participants (or prospective participants), and the means by which those rights will be safeguarded. For example, it is vital that the views of the prospective participants, their family, carers, guardians and/or other relevant members of communities, be afforded opportunities to engage in their own care and support eligibility assessment and ongoing care plan, as Aboriginal and Torres Strait Islander people's health is a whole-of-community concern.

Establish sustainable relationships

It is not uncommon for people with special needs in Aboriginal and Torres Strait Islander urban, rural or remote communities to have a number of carers, due to the extended family, mob, skin and community networks. All aspects of assessment, treatment and management should be discussed with family and relevant (and invited) community members, regardless of the time commitment this may require.

An ABI will further confound smooth communication between DisabilityCare staff and the prospective participant. Assessors may find that despite being informed that a prospective participant has the capacity to give consent to be assessed, on arrival they find, "... the particular client would not know the day or the time." . Therefore, it is very important for staff to establish clear communication with family members who can speak for the prospective participant or interpret for them, where necessary. This is especially important where the DisabilityCare worker does not speak the same language as the prospective participant, or where they have speech impediments, hearing loss or any other loss of function that might affect their capacity to communicate. As one experienced assessor noted:

I might say, "Look, your son has indicated to me that he can possibly manage all his own finances and he does his shopping. Is that correct?" ...And then the family will come back, "No he doesn't. We have to go and buy his food and he runs out of money and he's phoning us all the time." So often it's the other networks that will give you the more appropriate information, so it's not just always the client that you're always going to do the assessment with.

To discuss ABI with a group of people DisabilityCare workers should allow a lead family member or community leader to pace and manage the meeting. Community members need time to discuss matters in their own language. DisabilityCare workers need to be relaxed about this and adopt a participatory role, not a controlling role and not expect to have questions resolved in one meeting. DisabilityCare workers should not push individuals, families or communities for an instant decision as, "If you push hard you might be able to get a decision but it will be one that may not be regarded as binding" (Queensland Department of Aboriginal and Torres Strait Islander Policy and Development, 2001). It is also important to provide time for answers to be thought about and discussed. Practitioners advise that this can take weeks in some assessment contexts:

My first contact [with a community to do an ABI assessment] is normally by phone to get some information. Then I organise either a meeting with the family members, with advocates, with maybe the service provider... Sometimes it might take two or three times to get that initial contact with the client going.

In many instances, Aboriginal and Torres Strait Islander people with disabilities do not access mainstream health services. Services that have had some success have demonstrated flexibility and adaptability in work patterns and service development. Ultimately, it has required a genuine shift in the ways non-Aboriginal and Torres Strait Islander health providers approach psychosocial assessments. A female non-Aboriginal and Torres Strait Islander health worker described the following strategy:

Interviewer: *So how would you determine who's the best person to speak with?*

Interviewee: *Well usually within the community. Usually a lot of the women. If I'd meet the women, they would go, 'Oh, that is the client's sister or next of kin.' So then the next of kin would sign the document to say that they were... their next of kin or their Aunty to this particular person or you know, third sister.*

Behave ethically

Genuine respect for beliefs, opinions and lifestyle is essential. DisabilityCare staff need to demonstrate sincerity to gain the trust of prospective participants. Staff must be truthful at all times. Many Aboriginal and Torres Strait Islander people in communities place a good deal of emphasis on courtesy and kindness. In the Torres Straits this is known as 'Good Pasin', meaning good fashion or behaving with a degree of sophistication and charm (Queensland Department of Aboriginal and Torres Strait Islander Policy and Development, 2001).

The main reason why, you know, we're valued ... is about establishing a relationship with people. Not a 'gammon' [pretend, shallow or weak] relationship, but a really genuine relationship... If you can do that and people learn to trust you, then we end up often being a conduit between the person with the disability and other Health Professionals.

Be meaningful

Responses to time differ in Aboriginal and Torres Strait Island communities to those of Western societies. In most cases more value is placed on other priorities. An 'in by 9 out by 5' process is rarely possible (Queensland Department of Aboriginal and Torres Strait Islander Policy and Development, 1999, p. 24). DisabilityCare must allow for flexibility as community events and local matters e.g. "Sorry business" a death; a funeral; a mourning period, can cause cancellations of meetings, appointments etc., with little or no notice.

Be outcomes focused

It is particularly important to interact with Aboriginal and Torres Strait Islander peoples in an environment where they feel protected and comfortable. DisabilityCare Planners and LACs, not based in a community, will be required to travel to remote communities to see clients and their families, most likely in the home setting. Family members are a rich source of information. Seeing the family in the home setting can aid in the process of determining the client's level of self-care when it comes time to complete stage four of the Planning and Assessment framework.

Critical reflective practice

The transformative potential of self-critical reflexivity is a powerful tool for practitioners. Critical reflective practices bring cultural competency behaviours into the foreground of one's professional and interpersonal practice. It involves both interrogating and integrating Aboriginal and Torres Strait Islander and Western knowledge systems (Walker, McPhee, & Osborne, 2000) to help non-Aboriginal and Torres Strait Islander people know 'how to act' when working within unfamiliar contexts. Walker et al. (2000, p. 322) state:

All practitioners, both Aboriginal and Torres Strait Islander and non-Aboriginal and Torres Strait Islander, tend to operate according to a complex interaction of their own values, beliefs and experience and the values, assumptions and paradigms of their professional discipline or field. The way individual practitioners carry out their roles, and the way they act with clients and other professionals, depends largely on their interpretation of that discipline which is largely influenced by their own beliefs and values, knowledge and experience.

Critically reflective practice involves examining social and cultural identities, power and privilege. Walker and Sonn (2010, p. 168) state that "in doing so we become more conscious of the power that inheres in our own practice in order to democratise relationships, interactions and processes and to promote a culturally secure process and environment that will improve their health and wellbeing outcomes". Tools to guide reflective practice are provided in Figure 2.3 below.

Tools and techniques for critical reflection

The following are tools and techniques developed to facilitate the process of critical reflection that will enable practitioners to make more conscious decisions in their work to support the interests of the groups with whom they are working.

Questioning—helps to generate new knowledge about ourselves, others, the context and their interconnecting influences. Questions should uncover reasons, factors, links, possibilities, intentions consequences, feelings (*how* others feel and *why*).

Analysing—requires looking behind what's happening for underlying issues, causes and effects, identifying own/others' assumptions, and deconstructing complex situations into specific issues. Analysis helps make meaning of situations, events, issues and practices, both at a personal and professional level, privately and publicly.

Defining the issue—identifying issues that cause concern or require further exploration and/or evaluation. The issues may be related to one’s practice, someone else’s response, or feelings of uneasiness or uncertainty with respect to an interaction or intervention.

Seeking other perspectives—involves reading widely, talking with relevant people, and ‘stepping into the shoes’ of clients/others to see how situations and ideas appear for them.

Mapping—helps to draw links between different perspectives and ideas to reveal how taken-for-granted things fit together. It can help to clarify the problem and situate it within the bigger picture.

Critical reflection through dialogue—takes place formally or informally between the practitioner’s personal experience and the shared understandings, discipline knowledge and professional rules and practices that inform their experience. These different perspectives are underpinned by values and assumptions that may differ substantially from, and challenge, those of the practitioner. Approaching critical reflection as a kind of dialogue helps us to work through our own mental processes and to see other perspectives we might not come up with on our own. As such, critical dialogue can assist practitioners to use tools and discourses to challenge the accepted boundaries of traditional or dominant theories and practices. It helps practitioners to identify, critically assess and articulate how one’s informal theories about working at the Aboriginal and Torres Strait Islander/non-Aboriginal and Torres Strait Islander interface contributes to and has the potential to transform understandings about personal practice.

Recording activities/observations—keeping a diary or journal or using tape-recordings can be a useful way to record activities or observations or pose questions relating to specific differences between cultural values, beliefs and those of discipline and self. These observations can form a basis for self-reflections, further discussions or assessment, although issues of confidentiality need to be acknowledged.

Figure 2.3: Guidelines for reflective practice. Adapted from (Walker et al., 2000, p. 319) and (Walker & Sonn, 2010, pp. 168 - 170)

The context of assessment in Aboriginal and Torres Strait Islander communities

The utility and political bias of psychological testing regimes is a contested issue. Aboriginal and Torres Strait Islander Australians have been subjected to a history of inadequate and inappropriate testing typically based on a Western framework and therefore, have had a significant impact when working with Aboriginal people, particularly in the field of mental health assessment. Drew et al. (2010, p. 192) state that:

Much of the suspicion that Aboriginal and Torres Strait Islander people have regarding assessment derives from the political misuse of assessment as a process of social and cultural control. Historically, assessment ... was deeply rooted in the power differential ... [and an] absence of ethical reflection.

Strengths versus deficit-based approach

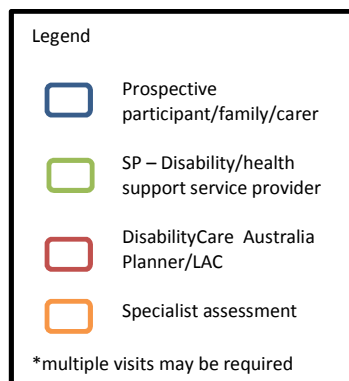
Typically, assessment instruments developed by Western psychologists use a deficits-based approach (i.e. they seek to identify what is 'wrong' or 'not working well' with the individual). On the other hand, a strengths-based approach (i.e. identifying what is 'right' or 'working well' with the individual) is typically endorsed for use with Aboriginal and Torres Strait Islander Australians. Strengths-based approaches typically identify what an individual can do well, or is satisfied with, and aim to support this while at the same time identifying what an individual might need help with. This is an important consideration in the assessment process. Deficits-based assessment approaches may cause distress in Aboriginal and Torres Strait Islander Australians, which will certainly be compounded if assessments tap only into Western notions of health and wellbeing.

The principles of DisabilityCare provide an opportunity to introduce a strengths-based assessment approach to ascertaining the functional and care and support needs of participants with ABI from an Aboriginal or Torres Strait Islander heritage. This approach focuses on what the participant can achieve, rather than what they cannot do. The strengths-based approach should never be used to preclude a participant's ongoing eligibility for care and support but provide a benchmark for beneficial early intervention and therapeutic care to build a participant's quality of life. In the context of working with Aboriginal and Torres Strait Islander participants, the strengths-based approach involves understanding and working from a community's collective strengths to assist DisabilityCare prospective participants to address their challenges. Communities can provide local solutions to local issues. The DisabilityCare workers are advised to bring together different people with specific skills; from family, relevant community members and support agency personnel, to collectively address a range of issues. This approach incorporates the practice of using culturally appropriate and consultative strategies (see Figure 2.4 below) and maximises the collective and individual strengths of contributors.

Key stakeholders

DisabilityCare will be required to engage with key stakeholders in Aboriginal and Torres Strait Islander urban and remote communities. In the Planning and Assessment framework stakeholders are identified throughout. On the Planning and Assessment diagram (see Figure 2.1) stakeholders are represented by

different coloured boxes and these are explained on the legend provided. Each stakeholder group is discussed below as they appear on the legend.



The Prospective Participant/Family/Carer

Figure 2.4: Key Stakeholders

A DisabilityCare ‘participant’ is defined in the NDIS Act as someone who has met the access criteria for eligibility . Throughout this discussion individuals with an ABI will therefore be referred to as ‘prospective participants’ (*"National Disability Insurance Scheme Act 2013,"* p. 32).

DisabilityCare acknowledges that where “... people with disability are unable to make decisions... in all circumstances the Agency will seek to put people with disability at the centre of decision making, and to involve family members and carers where that is appropriate” (National Disability Insurance Scheme, 2013, p. 24). Aboriginal and Torres Strait Islander people with a known, suspected or, as yet undiagnosed ABI, residing within urban and remote communities commonly receive “personal care, support and assistance”(“*National Disability Insurance Scheme Act 2013,*” p. 12) from members of their immediate or extended family. In many communities, extended family are the most appropriate carers of disabled people to make decisions on the behalf of the person that are “... as far as possible, those decisions that the decision-maker believes the person would make if they had the capacity” (National Disability Insurance Scheme, 2013, p. 25). In some circumstances, authority is vested with the state (e.g. the Adult Guardian).

The term ‘family’ in Aboriginal and Torres Strait Islander cultures needs to be understood in an extended sense. Community structures centralise the role of family. Children, for example, are raised by multiple adult figures – grandmothers, aunts, uncles, sisters, cousins and grow up acknowledging more than one mother and father.

Families and carers are looking after people with complex needs. For Aboriginal and Torres Strait Islander participants, maintaining their cultural links with their land, family, ancestors and community is of utmost importance. Families and carers can often provide emotional, social and therapeutic supports to a person with ABI to maintain continued participation in community life and existing supportive relationships, where it is safe to do so for the client and the family.



SP – Disability/health support service provider

DisabilityCare staff will be expected to play a coordination role with referral services to help participants realise their potential for physical, social, emotional and intellectual development and participate in the social and economic life of their community. DisabilityCare may liaise with government and Non-government service providers (SPs) for coordination, strategic and referral service or activity, including a locally provided coordination of services ("*National Disability Insurance Scheme Act 2013*," p. 21). The Planning and Assessment framework assumes a position of partnership between SPs and DisabilityCare from the outset of the process.

SPs include a broad range of agencies, normally from the health, aged or disabilities sectors, situated in communities. SPs can include advocacy groups, state-wide disability services, state or federally funded SPs such as Home and Community Care and aged care residential facilities, school staff, men's and women's groups, well-being centres, primary health agencies and so on. In remote and outer regional communities, SPs often have a working knowledge of the people living in the community with disabilities, such as mental health disorders and/or ABI, the needs of individuals, and, importantly, how the individual's disability affects others members of the community.

According to practitioners interviewed, SPs may have the confidence and trust of communities if they meet the following characteristics:

- Employ local men and women, deriving from the communities they serve;
- Have trusted accountability and governance mechanisms that are designed to ensure that they are not self-serving, exploitative or serving the interest of a privileged minority within a community (i.e. one clan group over another);
- Work within the service setting for a long period of time and be seen to be committed to the genuine well-being of the people in the community (that is, in contrast to the highly transitive nature of local workforces in remote and outer regional areas);
- Conduct business with sensitivity to the local cultures of the community; acknowledging the nuances in social structure, traditional lore, language dialects and family relationships within and between communities in a region;

- Do no harm.

In remote communities, local health and disability care workers and their SP agencies will be an asset to DisabilityCare.

DisabilityCare Planner and Local Area Coordinators

Key personnel described by DisabilityCare Australia are:

- Planners;
- Local area coordinators (LAC)s; and
- Regional Support Officers.

Staff will be employed through DisabilityCare offices, which will be active and locally represented in communities across Australia.

The Agency will actively foster community based supports for people with disability, and help them access and engage with mainstream and local services. It will do this through local area coordination, which could include providing some funding to community-based organisations that provide support that people with disability can access as they need it. (National Disability Insurance Scheme, 2013, p. 5).

Specialised assessment

Under Section 171 of the Act, DisabilityCare may engage consultants to assist in the performance of its functions. External consultants may be procured to undertake specialised neurological assessments of a person's cognitive and functional capacity. External consultants are indicated on the diagram with an orange outline.

Referral into DisabilityCare

"There will be no wrong door"

Personal communication with Senator Jan McLucas (2013), former Parliamentary Secretary for Disabilities and Carers

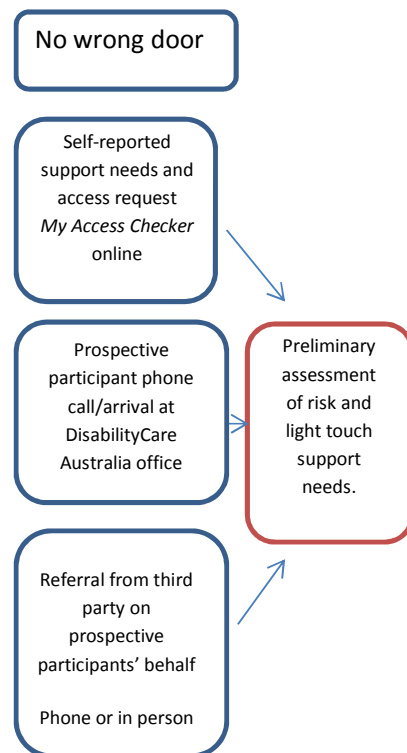


Figure 2.5: No wrong door

A person, or someone acting on their behalf, may make a request to become a DisabilityCare participant (an access request). This can be done online, by phone or in person. Aboriginal and Torres Strait Islander people who were consulted explained that they were concerned about a 'self-referral' requirement given the reluctance of people to come forward and present themselves for non-acute care.

Participants suggested that men and women of mature age, who are not presently receiving supports for ABI, may be unlikely to self-refer for the following reasons:

- Potential participants will avoid singling themselves out and acquiring a health label that might stigmatise them in the future;
- Aboriginal and Torres Strait Islander people, historically, lack trust in health and disability service provision and are likely to exercise scepticism that the DisabilityCare scheme is available to them until it is demonstrated otherwise;
- Many communities expressed pride in their self-reliance and ability to manage their own concerns. Bringing issues of disability to the attention of government agencies was counter-intuitive and would bring unwanted intrusion into private community and family affairs.

For people with an ABI in general undertaking the online screener, *My Access Checker* (DisabilityCare Australia, 2013) may be incommensurate with their functional abilities as a direct consequence of their disability. Accessing *My Access Checker* is more problematic for Aboriginal and Torres Strait Islander people due to English as a second language, lack of computer literacy skills, limited availability of Internet services, and reluctance to engage in non-face-to-face communication modes. These issues will render this point of access to the service less effective for many Aboriginal and Torres Strait Islander Australians. In addition to this, an audit of the cultural security of the tool found it is deficient in terms of appropriate language and conceptual qualities. Overall *My Access Checker* is not suitable for use with Aboriginal and Torres Strait Islander people in its present form. We therefore recommend the use of a modified tool (see Chapter 3).

Referral from a third-party, a trusted SP, family member, carer or guardian, is more likely to be an effective point-of-entry and contact for Aboriginal and Torres Strait Islander people. Third parties will need to be recognised as legitimate people to speak on behalf of a prospective participant at the initial point of contact with DisabilityCare.

SPs and/or family members will need to provide the Planner with the appropriate level of information to undertake the 'light touch' assessment of support needs and agree to continue to Step 1 of the Planning and Assessment framework. We caution, however, that DisabilityCare Planners do not base a 'light touch' assessment on completing the *My Access Checker* screener on the prospective participant's behalf.

DisabilityCare Planners and LACs should be required to demonstrate appropriate skills in culturally competent engagement with Aboriginal and/or Torres Strait Islander prospective participants. The following sections provide general principles and protocols for working with people, families and communities affected by ABI.

Stages of Assessment

Stage one: Engagement with Participants' community

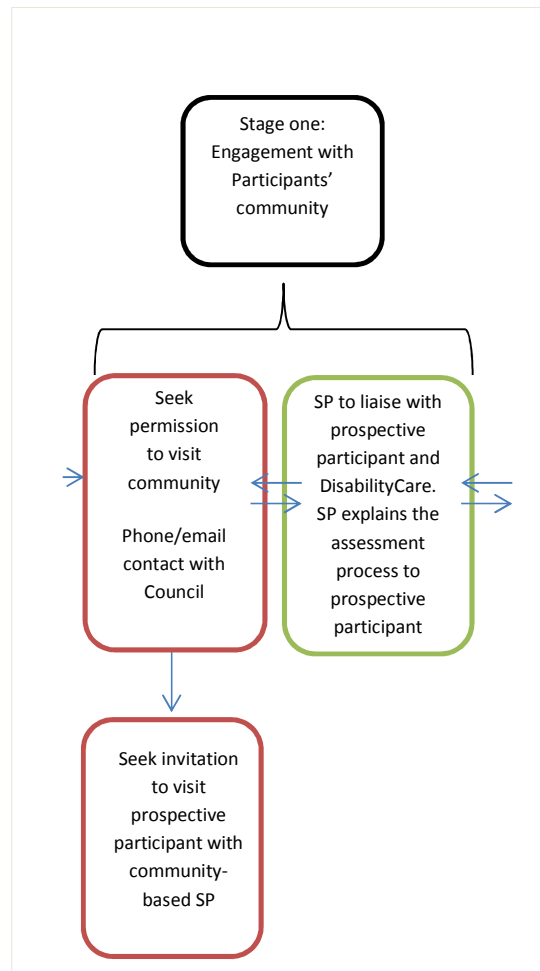


Figure 2.6: Engagement with Participants community

Effective engagement with the prospective participant being referred, and their family/carer or guardian, requires a spirit of partnership between the referring SP and/or community members, and DisabilityCare. Stage one of the Planning and Assessment Framework (See Figure 2.1) is about pre-visitation engagement. DisabilityCare staff are advised not to approach families directly to undertake an assessment without using appropriate pre-assessment engagement strategies. This condition applies generally to Aboriginal and Torres Strait Islander communities in remote, urban and outer regional settings.

DisabilityCare staff need to:

- i. *Seek and obtain permission to visit a community. Be mindful that discreet Aboriginal and Torres Strait Islander communities of people can co-exist as a subset of a larger urban community. Protocols for the appropriate engagement of people living within these communities may still need to be observed.*
- ii. *Seek and obtain permission to visit the family and/or individual with the suspected ABI.*

i. Seek and obtain permission to visit a community

Discreet remote communities across Australia appreciate cultural respects to be afforded by those coming in from 'out of town'. Prior to scheduling a visit to a community, it is appropriate that certain measures be taken into account. This is the case even if invited to visit from an SP, family or prospective participant themselves.

There are several organisations in Aboriginal and/or Torres Strait Islander communities that should be contacted as a courtesy. Importantly, community councils should be the first contact or point of call. It may also be appropriate to connect with other agencies. These may include Commonwealth agencies such as the Indigenous Coordination Centre, Regional Operations Centre and/or the Government Business Manager of that community. State-based departments of Aboriginal and/or Torres Strait Islander affairs are often present in communities and play an active role in community development matters and social service provision. The local councils or regional authorities may request that DisabilityCare staff meet with the traditional owners of the country. An opportunity to meet with the Traditional Owners is a culturally appropriate gesture that demonstrates interest in local culture, politics and community.

The various organisations should be informed of the intended visit by phone and/or email. Be clear about the aims and objectives of the visit; stipulate who DisabilityCare plan to meet and work with; the agency/people who requested the visit, and the intended outcomes of the visit. Request support such as a cultural liaison officer and/or translator if required. A health worker interviewed described their process as;

My first contact's normally by phone, to get some information. Then organise either a meeting with the family members, with advocates, with maybe the service provider, initially, and then go in from the ground from there. So sometimes it might take two or three times to get that initial contact with the client... If I present with folders and paperwork and dog-tags around my neck, that's normally not appropriate. It's getting in and getting that trust built and then I can get the relevant information... We were very flexible in the time frame when we actually would do the assessment. And that was so that

we could then build that rapport ... we don't do the nine to five. Sometimes I'd have to meet two or three different family members. I'd have to meet one in the morning and then one in the afternoon, so I had to work quite a bit around timeframes that would suit the Aboriginal/Torres Strait Islander's families and build rapport and trust.

Who is available to support you in community?

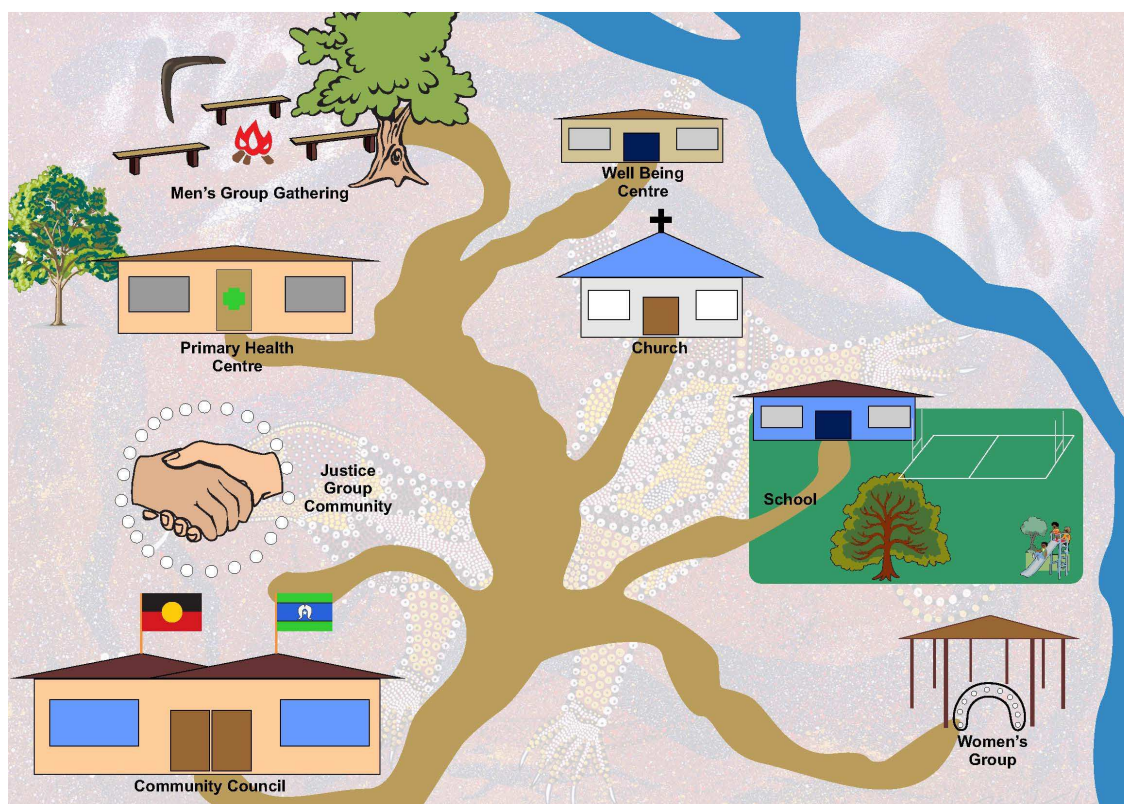


Figure 2.7: Typical services, organisations and facilities available in remote

ii. Seek and obtain permission to visit the family and/or individual with the suspected ABI.

In the event that a SP has referred an individual, DisabilityCare Planners and LACs need to be certain that the family and individual living with a suspected brain injury are willing to meet with DisabilityCare workers. In some cases, despite the intentions of well-meaning SP workers, an individual and/or their family may not wish to be contacted and do not welcome intervention. Efforts to ascertain that a person living with a disability is receiving appropriate care must be made. The SP/DisabilityCare planner/LAC may refer the matter to another community agency if there is concern that neglect, assault or harm is being inflicted upon an individual.

The SP can be a liaison officer, if this is more acceptable to the individual and family. DisabilityCare must ensure that the SP clearly represents the purposes of the visit, expected outcomes and duration of stay.

DisabilityCare staff may be asked upfront how much the support package will be worth. It is not advisable to give an indicative estimate of levels of support but clearly explain the process of assessment and how support is determined.

DisabilityCare will need to find out what significant community events are to take place and schedule pre-assessment and assessment visits in lieu of these events.

Stage 1: Key Do's and Don'ts for DisabilityCare Planners and LACs

Do:

- Seek to obtain permission to visit
- Contact the local council and be clear about the purpose of your visit
- Rely on community supports offered, such as interpreters, cultural liaison officers etc
- Provide accurate information to individuals/families
- Be flexible and accept sudden changes at short notice.

Don't:

- Exaggerate anticipated outcomes of the visit
- Hurry or urge individuals, family, carers or others to make decisions

Figure 2.8: Do's and Don'ts for DisabilityCare Planners and LACs

Stage two: Pre-assessment

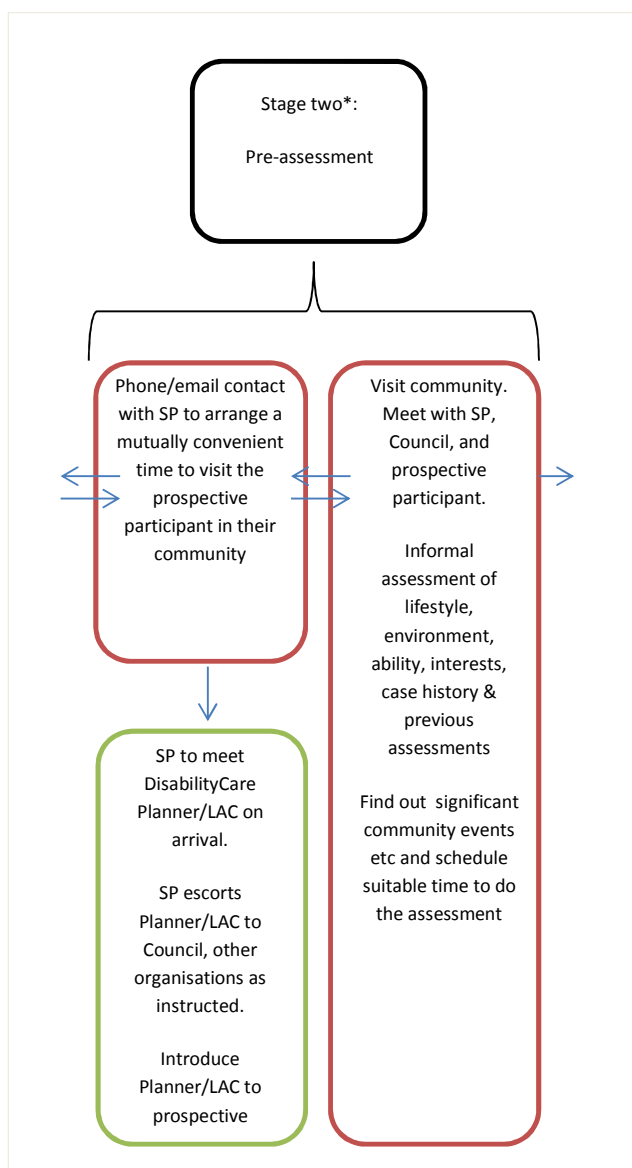


Figure 2.9: Pre-assessment

Making the visit

DisabilityCare staff need to ensure that time is allocated to meet the various individuals and organisations spoken to prior to the visit. This is time for rapport building that will save time and resources in the longer-term. Community people are more likely to be honest with DisabilityCare Planners and LACs, provide resources and information, and teach staff their cultural ways of working with ABI (Westerman, 2010).

Experienced practitioners advise that new visitors be relaxed and do not express anxiousness about wanting to get started with assessment processes.

It is advised that DisabilityCare staff undertake cultural awareness and cultural competency training prior to making visits particularly if they are a non-Aboriginal and/or Torres Strait Islander person. Effective assessment requires a culturally competent approach. DisabilityCare workers must be encouraged to listen carefully, ask questions, gain an understanding of the communities' needs and expectations, and build connections with people in the community. Aboriginal and Torres Strait Islander communities have multiple and nuanced layers of interconnectedness. The SP/DisabilityCare partnerships can be used to gain multiple perspectives on a prospective participant's situation, as there may be community politics, cultural issues or community lore at work that non-Aboriginal and Torres Strait Islander and non-residents of a community are not permitted to know.

The pre-assessment stage provides the opportunity to undertake informal assessment. The DisabilityCare Planners and LACs can learn about the prospective participant's lifestyle, environment, living conditions and interaction with their broader community. A person's interests, case history with schooling, primary health care services and other relevant agencies, i.e. forensic experiences, and if any previous assessment for ABI may have been undertaken, can be ascertained. Aboriginal and Torres Strait Islander people may manifest mental disorders (caused by an ABI) that take on forms that are unique to their culture and experience (Drew et al., 2010, pp. 192 - 194). Family and respected community members must be consulted to determine whether the symptoms an individual is experiencing are within their cultural context. Spiritual beliefs should not automatically be dismissed as hallucinations, delusions, pathological thinking or a sign of emotional imbalance (Haswell et al., 2009, p. 32). DisabilityCare staff must talk to others about their abilities and take a strengths-based approach. It was stated by Aboriginal and Torres Strait Islander people consulted that they are tired of hearing negative comments about their communities from non-residents. Furthermore, some Aboriginal and/or Torres Strait Islander cultures do not have a cultural framework or language to describe 'disability'. They may struggle with, or be offended by, suggestions of what people cannot do.

You try and take a history but trying to take that is clearly quite different with Aboriginal and Torres Strait Islander people compared with non- Aboriginal and Torres Strait Islander people. Because of all the cultural differences, you can't just sit down and chat to them and ask them the usual range of questions... So I asked them their story, you know, which mob they come from, what languages they speak and how they relate to other people, how they relate to the land.

Again, DisabilityCare's partnership with a well-known and trusted SP will be helpful in managing delicate conversations. As the experience of the following interviewees testified:

Where possible, I'd try and incorporate the families to get some collateral information or anyone else from the community. At times if possible, I'd utilise Aboriginal Health Workers because I found them extremely useful... But it was certainly helpful in terms of some cultural issues. To help me try and understand cultural issues, particularly with the individual I was talking to.

The first thing I would've done probably would be to get an appropriately trained Aboriginal Health Workers to assist. The so-called experts, like myself or physicians... They would be trained to help you deal with the cultural aspects in particular. They would be able to tell you what type of questions are inappropriate... I want to ask this person some questions about their memory and about how their behaviour's changed. How would I go about doing that? Within this culture? And they would probably give me some reasonable ideas on how to phrase some of that.

Note taking during a visit needs to be discreet. Some practitioners may choose to write up their notes in private at the completion of the visit. As a courtesy, staff should ask permission to take notes and be transparent concerning the purpose and intention of the note taking.

In some communities it may not be regarded as appropriate for men to talk to women about personal, health, hygiene or other matters. Similarly, some communities have taboos about certain topics and communication styles, for example, making eye contact. Shyness or shame should not be confused with sadness, or a reserved response as evidence of flat affect. Delayed answers or minimal speech should not automatically be considered as a sign of slow or impaired functioning (Haswell et al., 2009). As Aboriginal women interviewed explained;

So you get questions that, you know, 'if you wet the bed at night?' or something of that nature, which is very inappropriate when asking a fifty year old person or an older person these sorts of questions. And yet [assessors] feel the need to just go down these same series of questions for everyone, regardless. That's very inappropriate. And the people, you can see people cringe.

... they'll send in an eighteen year [woman] to support a twenty-three year old young gentleman with ABI and wonder why there's problems? Or they might send in a male when they've run out of staff, to support a female Aboriginal/Torres Strait Islander, which is totally inappropriate.

It is imperative for families and carers to receive available information about ABI health services, treatments, and support services. This will include relevant information about complex comorbidity, allied health, respite and the rights and responsibilities of all parties.

Assessment, like most work with Aboriginal and Torres Strait Islander communities, is a socially and culturally mediated practice, it is therefore important to recognise Aboriginal and Torres Strait Islander notions of health, noting that nuanced and subtle differences in language and thinking exist between communities themselves (Drew et al., 2010, pp. 192 - 194).

I always would ask [the service], 'Is the particular client an Aboriginal or a Torres Strait Islander person or a South Sea Islander person?' because they don't relate to one another. So I went into Townsville, I said to the particular client, 'Good morning. My name's ... I believe you're an Aboriginal lady.' And she was livid. She lashed out and carried on. She was angry. She didn't relate to Aboriginal. She's a Torres Strait Islander. So it's very important you know the heritage of the client... Assessors [need to] have a really good understanding or even some sort of training surrounding cultural awareness and protocols.

Stage 2: Key Do's and Don'ts for DisabilityCare Planners and LACs

Do:

- Allow adequate time to spend getting to know people and letting them get to know you
- Be an active and engaged listener
- Undertake informal, observational assessment
- Actively encourage the prospective participant and their family to see themselves as partners in the process with other relevant community members or SPs

Don't:

- Focus on deficits in ability
- Arrive without some cultural awareness and knowledge of the community you are visiting

Figure 2.10: Stage 2 Key Do's and Don'ts for DisabilityCare Planners and LACs

Stage three: Assessment for support

Choice and control for people with disability is central to DisabilityCare. This means that in DisabilityCare, people with disability have the right to make their own decisions about things like:

- *the type of supports and services they use;*
- *who provides them;*

- *how they are designed and provided;*
- *how supports are able to be managed; and*
- *how their funding is managed.*

(National Disability Insurance Scheme, 2013, pp. 3 - 4)

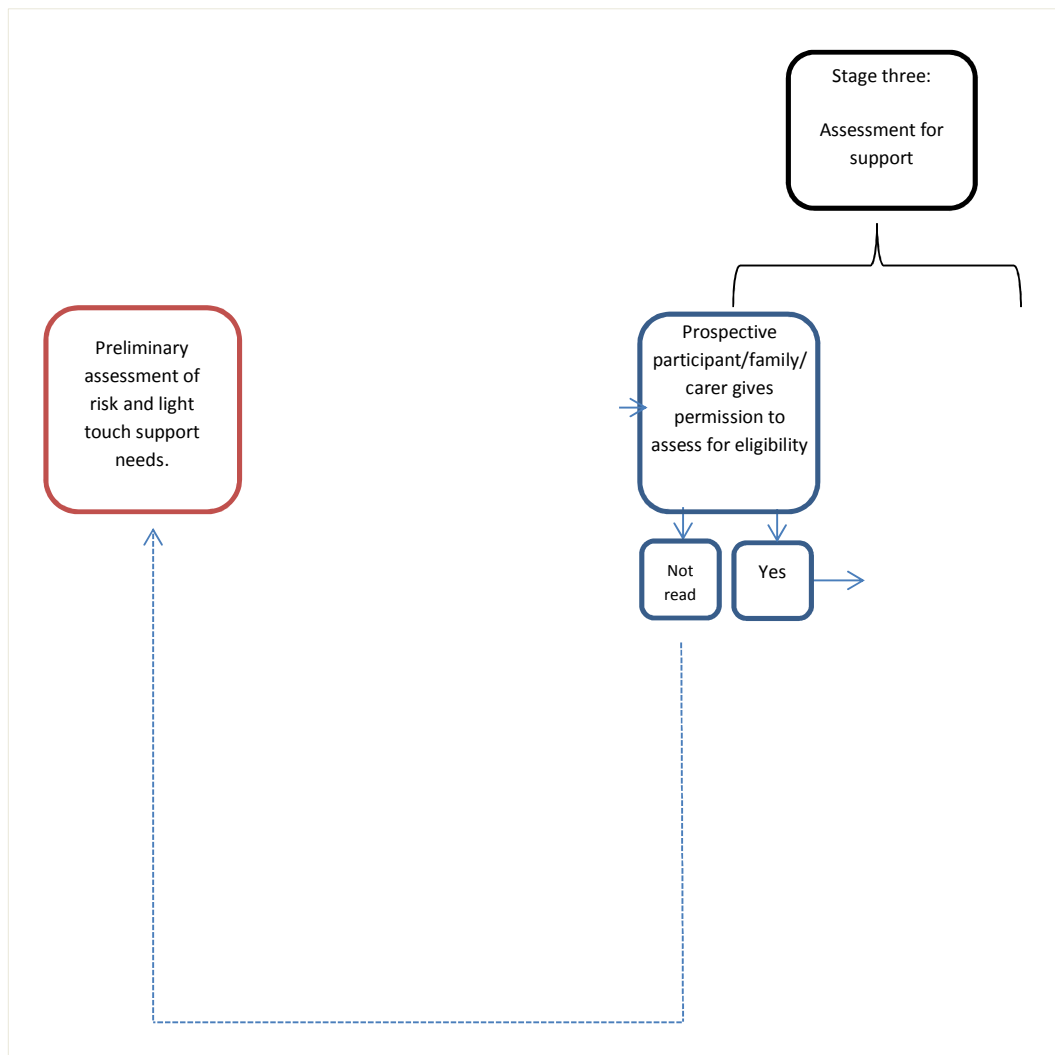


Figure 2.11: Stage 3: Assessment for support

The process of making decisions about how a person's supports are managed is to be as inclusive and flexible as the person with a disability desires. It should be directed by the person, and include others that the person wishes to be involved (e.g. family members, carers, guardian, advocates, and support providers). It will be able to be reviewed as a person's needs change over time.

Participant/family give permission to assess for eligibility support

DisabilityCare will assess a person's support needs after permission to undertake assessment has been obtained from the prospective participant, family/carer or guardian or other relevant community member on the person's behalf.

Assessments of ABI will use a consistent set of tools for identifying a person's needs and any potential risk or need for safeguards, and make consistent decisions about what support people will get under the DisabilityCare.

People needing more time to consider undertaking formal assessments are to be respected for making that decision. Historically, assessment for services may be seen as an intrusion into private affairs that is unjustified considering the limited support services available in remote and outer regional areas. Aboriginal and Torres Strait Islander people may require time to assess the impact and benefits of DisabilityCare for themselves.

For some people this stage is an opportunity for DisabilityCare to perform other important functions including referring individuals to community based and mainstream organisations that can best support their needs or connecting them to other systems, such as the health, palliative care, aged care, employment, public housing or education systems, that might appropriately support their needs.

Stage 3: Key Do's and Don'ts for DisabilityCare Planners and LACs

Do:

- Obtain permission to conduct an assessment
- Ensure the assessment process is clearly explained
- Refer prospective participants to relevant support agencies
- Allow prospective participants time to make a decision and respect their right to defer assessment

Don't:

- Pressure people to consent to doing an assessment
- Discriminate if they take time to make a decision or if they choose to defer

Figure 2.12: Stage 3 Key Do's and Don'ts for DisabilityCare Planners and LAC's

Assessment for eligibility for support

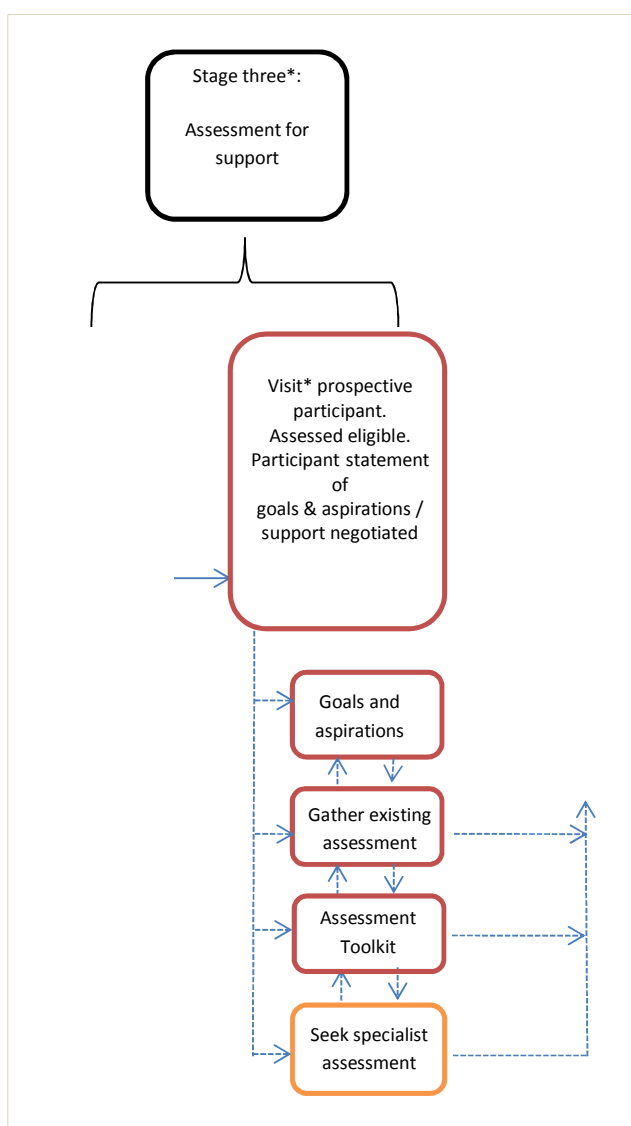


Figure 2.13: Assessment for eligibility for support

The decision as to whether or not a person is eligible for DisabilityCare-funded support may be decisive and simple particularly for people who have a long-standing relationship with state-based disability support services. DisabilityCare may negotiate the participant's goals and supports without requiring further formal assessment.

For prospective participants who have had limited formalised assessment DisabilityCare will need to develop a statement of goals and aspirations at the same time as establishing the ABI disability and prospective participant's support needs. Completing the assessment may take several visits over several days.

The perforated blue line indicates the additional assessment procedure described below.

Always conduct face-to-face assessment

Given the range of assessment mediums available (e.g. telephone, video conference, online), the appropriateness of these strategies was investigated. Practitioners and community members interviewed were overwhelmingly of the opinion that assessment must be undertaken on a face-to-face basis. Practices involving telephone assessment were not endorsed, particularly as they may be undertaken as a singular approach to assessment rather than within a four-stage approach as outlined in the Planning and Assessment framework being described. Similarly, videoconferencing approaches were not regarded as equal substitutes for face-to-face assessments, which were more likely to give accurate data because of the interpersonal and trusting relationship that has been established in the engagement and pre-assessment stages. Interviewees in the Northern Territory and Queensland relayed the following experiences:

I recently had someone with an ABI who I'd referred to [a service] for an assessment. They rang him up and asked him a series of questions and he goes, 'Yeah I'm good yep, everything's going really well'. They talked to his sister (who also happens to have an ABI) to verify some of his stuff. They concluded that he is really good, he copes really, really well, and he doesn't need support. He had a significant cognitive impairment but he's bright enough to be able to say 'yeah' in the right places. So basically he was wiped off because he sounded really good.

I had a situation where I had to do some sort of a report for the [name omitted] for a male... They gave me the background the information that'd been written by professionals, but when I actually talked to this guy, I really felt the reports were very inaccurate because, obviously they'd done a video link and hadn't got the message that the guy was actually very reluctant to talk. They made him sound like he had this major disability that he really didn't have. I felt they got it totally wrong and that's what worries me with that way of assessing people or doing reports, because that assessment could make a real difference in his life.

When undertaking the assessment flexibility regarding the setting is also required. Negotiate the location and setting so that the prospective participant is comfortable. As one participant said:

I know in Alice Springs I didn't actually use an office. I sat out in the back yard under a tree with them.

Statement of goals and aspirations

Central to DisabilityCare is the participant's statement of goals and aspirations;

Which will be developed by each participant to set out their goals and objectives and personal circumstances (National Disability Insurance Scheme, 2013, p. 13).

Not unlike the paradigmatic differences between Western and Aboriginal and Torres Strait Islander notions of health, the concept of goal setting also aroused concern amongst the people interviewed. In remote and outer regional communities, goal setting for employment outcomes is often regarded as an unrealistic or pointless exercise, given that employment opportunities are low. Similarly, it is often difficult to distinguish between recreational and economic activities where the activity of non-commercial fishing, for example, is an activity imbued in traditional cultural mores, generates food for the table and is regarded widely as an occupational activity. One interviewee stated;

If you talk to a lot of young Aboriginal men, in their twenties and thirties, a big part of their culture is still hunting and gathering. Believe it or not, it still is. And a lot of them want to get back to being one of the men and going out, either doing the actual hunting with them, or at least being taken along so they feel like part of the male group. You would try and incorporate that... and make it meaningful for them, otherwise they just won't do it if it's not meaningful ... [Setting goals] that's quite reasonable as a concept, but it has to be done in a culturally appropriate way.

DisabilityCare workers need to be mindful that a statement of goals and aspirations might reflect notions of quality of life, relationship with family and community and value one has in living on country. Many Aboriginal and/or Torres Strait Islander people are unlikely to express a set of individualistic achievement goals. Again, the role of the family/carer will be important in negotiating this statement in terms of the capabilities of the prospective participant and social supports available.

Assessment of the ABI

Chapter 3 contains details of the Assessment Toolkit developed for culturally appropriate assessment. It is important to note in this discussion the key tasks concerning assessment.

1. Gather existing assessments.

This involves establishing as full and complete history of the prospective participant from all known available sources. This process may have commenced in the pre-assessment phase. A clear history of ABI should be determined.

2. Assessment Toolkit

Planners and LACs should consider the cultural acceptability and validity of the instruments when assessing the cognitive, functional and care and support needs of Aboriginal and Torres Strait Islander people with ABI (discussed in Chapter 3). It is strongly recommended that DisabilityCare staff follow the best practice guidance presented here.

3. Seek specialist assessment

Neuropsychological and other specialist assessments may be required and should be obtained to ascertain a complete understanding of the prospective participant's cognitive, functional and care and support needs, particularly for multiple disabilities.

Stage 3: Key Do's and Don'ts for DisabilityCare Planners and LACs

Do:

- Conduct assessment face-to-face
- Formal assessment may take several visits to be completed
- Be mindful of the difference in Aboriginal and Torres Strait worldview in regards to personal goals and aspirations
- Undertake the appropriate training in ABI assessment, including forthcoming ABI Assessment Toolkit developed for DisabilityCare Australia
- Seek specialist assessment to ascertain as comprehensive assessment of cognitive, functional and care and support needs, possible

Don't:

- Conduct assessment by phone or video link-up
- Do not hurry the process and accept that multiple visitations may be required

Figure 2.14: Stage 3: Key Do's and Don'ts for DisabilityCare Planners and LACs

Stage four: Post-assessment follow-up

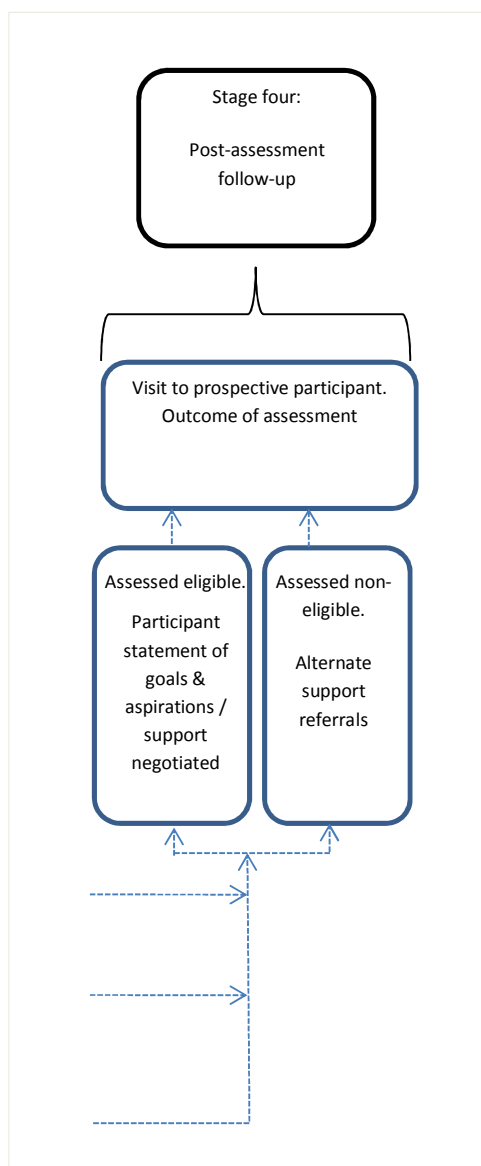


Figure 2.15: Stage 4 Post assessment follow-up

A widespread concern of SPs and Aboriginal and Torres Strait Islander people across settings was expressed about the lengthy delays between undertaking an assessment and learning the outcomes of that process. It was reported that in some instances, families have waited over 9 months before the outcome of an assessment is known. This compounds Aboriginal and Torres Strait Islander people's hesitation to embrace mainstream services.

The DisabilityCare personnel, who undertook the assessment, are in the best position to discuss the outcomes of the assessment with the prospective participant, and their family/carer or guardian.

Ineligible prospective participants may need the assistance of DisabilityCare to refer them to alternative community based and mainstream organisations that can best support their needs. Systems such as the health, palliative care, aged care, employment, public housing or education systems may be appropriate.

For eligible prospective participants, the nature of the support needs to be collaboratively determined. The NDIS Rules state that:

Once a person has met the age, residence, and disability or early intervention requirements, they become a participant in the NDIS. At the centre of the NDIS is an individual plan for each participant. This plan sets out a participant's support needs, as worked out through a planning process with the Agency. The plan will have two parts:

- *The statement of goals and aspirations, which will be developed by each participant to set out their goals and objectives and personal circumstances*
- *The statement of supports, setting out any supports provided or funded by the Scheme, as well as any relevant informal or mainstream supports (National Disability Insurance Scheme, 2013, p. 13).*

This involves tailoring treatment to suit the personal, cultural and religious beliefs of participants. Participants must be able to maintain their cultural beliefs and practices. This includes the use of traditional Aboriginal and Torres Strait Islander healers and the use of traditional bush medicines (Haswell et al., 2009; Keightley et al., 2011). If Aboriginal and Torres Strait Islander consumers seek the help of traditional healers, DisabilityCare Planners and LACs should respect their decision, while continuing to provide other agreed forms of care.

Similarly, DisabilityCare staff must be mindful of the wishes of the client regarding their choice of where they wish to reside. Communities regarded as lacking in health or rehabilitation services should not be restricted from the participants' available choices.

In locations where there are limited disability services, creative solutions should be negotiated between the person with ABI and DisabilityCare and any solutions should reflect the principle that Aboriginal and Torres Strait Islander people with a disability should not be disadvantaged because they happen to live in an under-resourced community.

Stage 4: Key Do's and Don'ts for DisabilityCare Planners and LACs

Do:

- Provide timely feedback to the prospective participant concerning the outcomes of the assessment
- Report outcomes in a transparent, honest and clear manner
- Collaboratively negotiate ongoing supports

Don't:

- Insist that the participant relocate from the community where they choose to live to receive disability supports

Figure 2.16: Stage 4: Key Dos and Don'ts for DisabilityCare Planners and LAC's



Chapter 3: Development of a culturally acceptable instrument toolkit for assessing functioning cognitive impairment and the care and support needs of Aboriginal persons with ABI.

This chapter describes the development of a culturally acceptable instrument toolkit for assessing cognitive and functional impairments in Aboriginal Australians with ABI, as per Deliverable 1 in the original Practical Design Fund application¹⁻²:

Develop, pilot and evaluate a culturally appropriate instrument for assessing functioning, cognitive impairment, and the care and support needs of Aboriginal and Torres Strait Islander persons with ABI

This component of the project was conducted within Participatory Action Research, Continuous Quality Improvement, and Expert Consensus frameworks (more detail provided in Chapter 1). The participatory approach of Continuous Quality Improvement adheres to the research principles and values of Aboriginal and Torres Strait islander peoples and similarly, Participatory Action Research is endorsed for research with Aboriginal and Torres Strait Islander peoples given that this approach engages end-users, experts and stakeholders, all of whom contribute to the development of key outcomes as well as to the research process.

It is anticipated that the instrument toolkit described here, with further research, monitoring, evaluation and validation, will provide a set of culturally acceptable and valid instruments for use by DisabilityCare Planners and LACs. The project team are concerned about the potential (mis)use of the instruments that have been developed in this project, given that they have not yet been validated. Hence, as a precautionary measure, this report — which, we understand, will be made publically available — does not include the instruments in their entirety. The project team will, however, be able to present the instruments to the team currently developing the DisabilityCare assessment toolkit and/or any individuals responsible for evaluating/reviewing this report — that is, on the assumption that the instruments will not be made public or used in any assessment process prior to validation (unless in the context of a validation study).

¹ The instruments described in this chapter have been developed based on consultation with Aboriginal people and communities only. Further research is needed to determine the instruments needed to assess ABI in Torres Strait Islander Australians.

² The activities described in this chapter, and the instrument toolkit, refer to adults aged 18-55 only. Whilst assessment of younger and older age groups is recognised as important, examination of assessments for these age groups was beyond the scope of the current project.

Assessment and DisabilityCare

To be eligible for support under DisabilityCare Australia, a participant must meet the Disability requirements (below). Requirements a), c) and d) highlight the need to ensure that accurate assessment of impairments is obtained.

Disability requirements:

The person has a disability that is attributable to one or more intellectual, cognitive, neurological, sensory or physical impairments or to one or more impairments attributable to a psychiatric condition; and

- a) The impairment or impairments are, or are likely to be, permanent; and*
- b) The impairment or impairments result in substantially reduced functional capacity to undertake, or psychosocial functioning in undertaking, one or more of the following activities: (i) communication; (ii) social interaction; (iii) learning; (iv) mobility; (v) self-care; (vi) self-management; and*
- c) The impairment or impairments affect the person's capacity for social and economic participation; and*
- d) The person is likely to require support under the National Disability Insurance Scheme for the person's lifetime.*

("National Disability Insurance Scheme Act 2013," p. 28)

Cross-cultural assessment

Assessment instruments are developed to assess, through a series of questions or tasks, human behaviours, needs, thinking processes, emotions and personality characteristics (Groth-Marnat, 2009, p. 5). Before any instrument is used, the assessor must investigate and understand the theoretical basis of the instrument, examine its practical utility, determine the appropriateness of the normative sample on which the test was validated, and be satisfied with its reliability and validity (Groth-Marnat, 2009, p. 9).

The paucity of assessment instruments available for assessing psychosocial and cognitive functioning in Aboriginal and Torres Strait Islander Australians has previously been highlighted, and represents a challenge to undertaking evidence-based assessment in this population (Dingwall & Cairney, 2010; Dingwall, Pinkerton, & Lindeman, 2013; Sheldon, 2010, p. 15). Most assessments are designed for use with Western English-speaking populations. If tasks are used with cultural groups for which they aren't designed

they may yield inaccurate results, which can lead to discrimination and misdiagnosis (Dingwall & Cairney, 2010).

Issues of bias must be at the forefront of any assessor's mind when undertaking cross-cultural assessment (van de Vijver & Leung, 2011, p. 17). Bias in testing refers to systematic errors in measurement among certain groups or individuals, and this bias can have adverse effects if testing screens out a proportionally larger number of individuals from minority groups (Groth-Marnat, 2009, p. 53). Construct bias occurs when there is incomplete overlap in the behaviours associated with a certain construct between cultures (van de Vijver & Leung, 2011, p. 17). For example, in our consultations, the construct of 'disability' in Aboriginal and Torres Strait Islander Australian populations is poorly defined and even absent in some communities; thus attempts to measure 'disability' become challenging. Our consultations also suggest that the impacts of ABI in Aboriginal people are significantly different to the impacts in non-Indigenous Australians, with a broader focus on family, social, cultural and community impacts. Aboriginal and Torres Strait Islander Australians often have non-Western concepts of numbers, space, time, health and wellbeing, which brings into question the theoretical orientation of many available assessment instruments (Dingwall & Cairney, 2010). Similarly, Aboriginal and Torres Strait Islander Australians often speak English as a second language, may have reduced formal education, and may distrust assessment, thus the practical considerations may render many assessment as inappropriate. Additionally, in the case of cognitive assessments, there is a severe absence of normative data for Aboriginal and Torres Strait Islander Australians, thus yielding most assessment instruments as unreliable and invalid.

For reasons such as this, most assessment instruments remain to be demonstrated as being appropriate for use with Aboriginal and Torres Strait Islander populations. This is a severe hindrance to undertaking accurate assessment in this culturally unique group (Dingwall & Cairney, 2010). This is a critical limitation in the context of assessment of Aboriginal and Torres Strait Islander Australians by DisabilityCare Planners and LACs. Without culturally acceptable, valid and reliable instruments, it is likely that assessment of Aboriginal and Torres Strait Islander Australians will be susceptible to bias. Given the higher rates of disability (including but not limited to ABI), it is critical that culturally acceptable instruments be developed and integrated into the DisabilityCare Australia assessment process.

The instrument toolkit

This chapter describes the development of a culturally acceptable instrument toolkit for assessing cognitive impairment, functioning and the care and support needs of Aboriginal Australians with ABI. We have used recommended approaches to dealing with bias, including consultation with informants with expertise in local language and culture, independent within-culture development of instruments, conduct of local pilot

studies, consideration of non-standard instrument administration, and examination of connotation of key phrases (e.g. examining similarity between the meanings of key terms such as ‘somewhat agree’) (van de Vijver & Leung, 2011, p. 23).

The instrument toolkit has been developed and refined through Continuous Quality Improvement and represents the views and opinions of those consulted regarding what should be measured to assess the impairments and impacts of ABI in Aboriginal Australians, and how it should be measured. This toolkit represents a significant step toward ensuring culturally acceptable and valid assessment is provided for Aboriginal Australians with an ABI. The subject of ongoing pilot studies and Continuous Quality Improvement, it is anticipated that this instrument toolkit provides a clear focus for future validation studies.

To develop the instrument toolkit, we conducted the activities shown in Table 1. Firstly, the literature was reviewed and interview transcripts were reviewed to identify instruments currently being used to assess functioning, cognitive impairment, and the care and support needs of people with ABI (both Aboriginal and Torres Strait Islander and non-Indigenous) (Aim 1). Subsequently, an evaluation framework was developed based on analysis of interview transcripts and the literature review, to determine the optimal characteristics of an instrument for assessing ABI in Aboriginal and Torres Strait Islander Australians (Aim 2). This evaluation framework was used to rate existing instruments (Aim 3). An instrument toolkit was then developed, containing a combination of existing instruments and an instrument developed by the investigators (Aim 4). This toolkit has undergone preliminary pilot testing and evaluation (Aim 5).

Table 3.1: Stages of instrument toolkit development

Aim	Activities undertaken	Outcome
Aim 1. Collate instruments currently used for assessing function and participation in ABI	<ul style="list-style-type: none"> Literature review and expert consultations 	<ul style="list-style-type: none"> Cognitive assessment instruments (Appendix 1) Functional assessment instruments (Appendix 1)
Aim 2. Develop an evaluation framework identifying characteristics of instruments that enable culturally acceptable and effective assessment	<ul style="list-style-type: none"> Analysis of expert consultations Analysis of consultations with informants with expertise in local language and culture 	<ul style="list-style-type: none"> Development of an evaluation framework to determine utility of instruments for assessing ABI in Aboriginal clients
Aim 3. Evaluate the cultural acceptability of instruments currently used for assessing function and participation in ABI (identified in stage 1)	<ul style="list-style-type: none"> Rating of instruments against evaluation framework (using framework developed in stage 2.) 	<ul style="list-style-type: none"> Relative ratings of existing instruments (Appendix 2) Identification of gaps in content
Aim 4. Development of a culturally acceptable instrument toolkit for assessment of	<ul style="list-style-type: none"> Development of a draft instrument toolkit based on the framework for 	<ul style="list-style-type: none"> Draft instrument toolkit developed

function and participation in Aboriginal Australians with an ABI	culturally acceptable instruments (using framework developed in stage 2.) <ul style="list-style-type: none"> Review of toolkit at stakeholder workshop 	
Aim 5. Instrument pilot studies	<ul style="list-style-type: none"> Community-based pilot studies in Wujal Wujal, Darwin, Mt Isa, Redfern (additional sites: Townsville and Palm Island) 	<ul style="list-style-type: none"> Evaluated and modified instrument toolkit

Aim 1. Collate instruments currently used for assessing function and participation in ABI

Existing instruments for the assessment of ABI were collated and reviewed for their potential suitability for use by DisabilityCare to assess cognitive and functional impairment in Aboriginal and Torres Strait Islander Australians with acquired brain injury. Instruments were identified through the following key data sources:

- Interviews with professionals (psychologists, allied health practitioners, disability services staff etc) from across New South Wales, Queensland, the Northern Territory and the Torres Strait Islands who are regularly involved in undertaking or assisting with assessments of Aboriginal and/or Torres Strait Islander clients.
- Centre for Outcome Measurement in Brain Injury (COMBI):
<http://www.tbims.org/combi/index.html>

The COMBI is a collaborative project co-ordinated by the Rehabilitation Research Centre at Santa Clara Valley Medical Centre. It provides commonly used outcome measures for brain injury rehabilitation and assessment, together with detailed information and support. Each measure on COMBI contains a syllabus and training information, rating forms, background information on validity and reliability, a reference list of published studies, and testing materials.

- Psychological Database for Brain Injury Impairment Treatment Efficacy (PsycBite):
<http://www.psycbite.com/>

PsycBITE is a database of studies on cognitive, behavioural and other treatments for psychological problems associated with ABI. Each study is rated for their methodological quality and scientific rigour. Free access is available to individuals to assist in clinical practice or research.

Summary of findings of Aim 1

A variety of instruments were identified from the literature and consultations (Appendix 1). In terms of assessing cognitive impairments due to ABI, one instrument was found that had been developed

specifically to screen for, or assess cognitive impairments due to ABI (Behavioural Assessment of Dysexecutive Syndrome). Psychologists interviewed were using a variety of instruments and informal approaches to assess cognitive impairment in ABI in Aboriginal and Torres Strait Islander Australians, consistent with previous findings by Dingwall et al. (2013). One of these instruments, the Kimberley Indigenous Cognitive Assessment, was designed specifically for Aboriginal Australians, however the Kimberley Indigenous Cognitive Assessment is only validated for the assessment of use with older people (> 45 years) and is designed to screen for dementia. Another, the Q Test, was designed for assessing general cognitive function in Aboriginal Australians, however no published data on validity was found. As shown in Appendix 1, neuropsychologists reported using variety of well-established cognitive tasks, which they found to be effective when assessing cognitive function in Aboriginal Australians (Verbal List Learning, Trail making [verbal and pictorial versions], Story re-telling, Go/No-Go), however none of these have been formally validated for use with Aboriginal or Torres Strait Islander Australians. One test battery, CogState, was identified that was designed specifically for assessing cognitive function in Aboriginal Australian communities in the Northern Territory. The CogState battery has been used in several research studies but has never been validated.

In terms of instruments assessing functioning and care and support needs, a variety of instruments are currently being used (Appendix 2). Several instruments have been developed specifically for the assessment of functional impairments in ABI, particularly traumatic brain injury. These instruments typically assess the key domains from the WHO ICF Core Sets for traumatic brain injury. No instruments were found that had been developed specifically to assess functional impairments in non-traumatic ABI, and none have been designed for, or validated for use with Aboriginal or Torres Strait Islander Australians.

Aim 2. Develop an evaluation framework identifying characteristics of instruments that enable culturally acceptable and effective assessment

Following collation of the instruments currently being used, we aimed to identify characteristics that a culturally acceptable and effective instrument should possess. This was undertaken to determine which instruments should be included in the toolkit. These characteristics were drawn from analysis of expert consultations, with a focus on trying to integrate perspectives from allied health professionals with those of community members, community-based disability service providers, Aboriginal and Torres Strait Islander advocates and cultural advisors. Integration of these perspectives was intended to give equal weight to clinical, cultural and community perspectives. By doing this we anticipated that any instrument developed would be acceptable to assessors and Aboriginal end-users. Additionally, we sought to represent urban, regional and remote perspectives, to ensure that any instrument developed would be acceptable in these settings.

As per Chapter 1 (methodology), neuropsychologists, clinicians, allied health practitioners, disability services staff and community members were interviewed from across New South Wales, Queensland, the Northern Territory and the Torres Strait Islands. These individuals are regularly involved in undertaking or assisting with assessments of Aboriginal and Torres Strait Islander clients. In addition, Aboriginal individuals with ABI were consulted.

Summary of findings of Aim 2

An evaluation framework was developed, which contains the key features of culturally appropriate assessment instruments:

✓ Validity for use with Aboriginal and/or Torres Strait Islander Australian adults (aged 18-65)

All interviewees expressed frustration at the lack of scientifically valid and culturally acceptable assessment tools available for use with Aboriginal clients. Clinicians reported that this significantly impaired their ability to reliably assess impairments and function. With regard to assessing cognition, consultations revealed that neuropsychologists use a variety of adaptations of assessment tools, informal and non-validated strategies. Though inadequate, these methods currently represent the best available in Aboriginal and Torres Strait Islander ABI assessment. For Aboriginal and Torres Strait Islander Australians with an ABI, gaining access to DisabilityCare will likely rely on the ability to demonstrate impairments in function, particularly cognitive function, as this is often the most common impairment seen in ABI. Typically, establishing cognitive deficits requires a cognitive assessment. Whilst relatively straightforward in the non-Indigenous population, this is problematic for Aboriginal and Torres Strait Islander Australians, given that there are no scientifically validated instruments for determining cognitive impairment in adult Aboriginal and Torres Strait Islander Australians (Dingwall & Cairney, 2010). As one psychologist states:

Nearly all the sort of psychometric type tests that have been used are all based on European and English and to a lesser extent, American culture. And norms? So it's all normed on English and American populations although that's changed to some degree, for a lot of the formal tests, you know, like intelligence tests and all that sort of stuff. We do have Australian norms for a lot of that now. But we have no norms for Indigenous people. We do have norms for other cultures and I have a lot of tests that are actually in different languages, like Greek and Italian and so on. But you can't norm- those norms don't apply to Indigenous people either and the tests don't apply to them.

These findings are consistent with a recent study by (Dingwall et al., 2013). The study found that clinicians assessing cognition in Indigenous clients in the Northern Territory rely heavily on informal and modified assessments, observations, clinical judgement and contextual interpretation (Dingwall et al., 2013). There

was little consistency in the approach used to assess cognition, and many clinicians were inadequately prepared. These modified and informal approaches are highly susceptible to bias and are inconsistent with best practice in cross-cultural psychological assessment (van de Vijver & Tanzer, 2004). For this reason, any instrument used in assessments for DisabilityCare Australia must be shown to be reliable and valid for use with Aboriginal and Torres Strait Islander clients.

✓ Assessment of key areas of cognitive and functional impairment

For an assessment instrument to be effective, it must assess the key functions impaired in ABI. Significant research has been undertaken to develop 'core sets' for traumatic brain injury, which provides guidance in terms of the key areas affected by brain injury (Laxe et al., 2013). Our research sought to augment these core sets with information gained from consulting a variety of key stakeholders with expertise in assessing or caring for Aboriginal and Torres Strait Islander Australians with ABI.

Body Functions

- Higher-level cognitive functions
- Emotional functions
- Energy and drive functions
- Control of voluntary movement functions
- Memory functions
- Sensation of pain
- Attention functions
- Consciousness functions

Body Structures

- Structure of brain

Activities & Participation

- Carrying out daily routine
- Conversation
- Walking
- Complex interpersonal interactions
- Acquiring, keeping and terminating a job
- Self care
- Recreation and leisure
- Family relationships

Based on the World Health Organisation International Classification of Functioning, Disability and Health (ICF) Core Sets for traumatic brain injury (Laxe et al., 2013).

Note: There is no ICF Core Set available for non-traumatic ABI, however impairments for traumatic brain injury are comprehensive and cover areas of function affected by ABI.

Figure 3.1: Key areas of function impaired by brain injury

✓ Relevance to Aboriginal Australians

Activities conducted under Aim 1 revealed important factors that must be considered in terms of how the impacts of ABI should be assessed in Aboriginal Australians. In particular, consultations revealed that many instruments currently available for assessing ABI suffer from significant bias (van de Vijver & Leung, 2011, p. 23). Firstly, many of the constructs (e.g. work, leisure, relationships, spirituality) may be different in Aboriginal and Torres Strait Islander compared to non-Indigenous Australian populations. As one Aboriginal advocate put it:

In the western world we either work or we leisure. But I know when I go home to my mob, work and leisure are the same almost. So there is no separation between them because you're on the beach, digging for shells. You're having leisure but you're also working.

There are clear cultural differences in how Aboriginal and Torres Strait Islander Australians view health and wellbeing compared to non-Indigenous Australians. In the context of measuring health and wellbeing, this has been covered in the literature (Dingwall & Cairney, 2010; Drew et al., 2010; Haswell-Elkins, Sebasio, Hunter, & Mar, 2007). Importantly, Aboriginal and Torres Strait Islander Australians typically hold a holistic view of health and wellbeing that focuses not only on personal physical and mental health, but cultural connection, and family and community functioning. In many communities both urban and remote, the wellbeing of the collective (community) is indivisible from the wellbeing of the individual (Drew et al., 2010, pp. 192 - 194). The importance of the impact of ABI on families and communities was evident during consultations. Consistent with this, any assessment instrument used with Aboriginal people must adequately consider the important cultural, family and community impacts of ABI on the individual. As one rehabilitation clinician stated:

There are lots of demands on Indigenous people in communities in terms of their family and cultural relationships.

Many standard instruments for assessing daily functioning are not appropriate for many Aboriginal Australians, particularly those living in remote communities where there is a greater focus on community and communal living (Sheldon, 2010, p. 219). Also, most instruments based on WHO ICF domains focus on work and leisure as distinct areas of life, however our consultations revealed that this might not be appropriate for many Aboriginal individuals. The term leisure was not widely used, particularly in remote communities. Thus any instrument should assess family, community and social functioning, and place reduced importance on work/leisure distinctions. Interviewees complained that some standard instruments contained severe item bias, where Aboriginal participants are judged on their perceived ability to perform activities that may not be relevant to their everyday life (e.g. "Threads a sewing needle",

“climbs a six-foot ladder” – Inventory for Client and Agency Planning). Scoring on such items therefore reflect the relevance of that activity to participant more than their ability to perform that activity.

✓ Administration by non-clinical assessors

Determining the existence of cognitive deficits in ABI typically involves assessment by neuropsychologist. The specialist skill required to assess cognition and functioning in this population is typically possessed by a small number of clinicians (e.g. neuropsychologists) who are concentrated in metropolitan areas. This means that many more remote communities only have access to fly-in/fly-out assessment, which is expensive, may require long wait times, and is inconsistent with a model of culturally acceptable assessment based on trust and rapport. Taking this into consideration it was seen as advantageous by those interviewed if an instrument could be administered in a community setting, by non-clinical administrators who have undertaken appropriate training. Interviewees were also confident that assessments made by local staff would be more likely to be accurate. For example, it was seen as ideal if an assessment could be undertaken by someone who knows the Aboriginal person with suspected ABI (e.g. LAC, nurse, allied health worker).

✓ Enable collaborative decision-making

Those interviewed who were involved in assessment saw it as critical to involve carers, service providers and other informants in the assessment process. It will be common for Aboriginal and Torres Strait Islander participants to have an extended group of carers, and families and carers are key sources of information during any assessment (Haswell et al., 2009, p. 27) (see Chapter 2 for consultation findings on this topic). There must be collaboration and equality in decision-making between the participant, family and assessor. Several interviewees emphasised that collaboration and consultation with family members was necessary to gather collateral information. Interviewees suggested that the family should always be involved in assessments, and development of the support plan, given that the individual is often indivisible from the collective. As several interviewees noted:

When you'd interview somewhere, someone outback, invariably a lot of the family would come along to the assessment. So instead of having a private consultation with one person, you've got, you know, four or five people.

And the other issue is too, having other family involvement in the assessment...one day, she did, she undertook an assessment. She didn't see the person for the first two visits. It was all the family. Until there was that level of trust...And they said, yeah, you've got consent now.

There's a whole literature out there about brain injury doesn't happen to individuals. It happens to families and often times, families can be really involved and they really facilitate things because if we're trying to help somebody with a particular problem area, it's not just going to happen in the therapist's office.

Some of the instruments currently used to assess ABI in non-Indigenous contexts use clinician observation, which was deemed culturally unacceptable by those interviewed in the current study. Those interviewed endorsed approaches that enabled collaborative reporting and decision-making by the individual with ABI and their family. Delivering a culturally acceptable assessment may also involve local Aboriginal health workers in the assessment process, to assist the assessor in understanding local cultural protocols, making the client and family members more comfortable, explaining the purpose of assessment to clients, translating questions and answers, re-framing questions to be culturally relevant, and providing their own perspective.

✓ Brief and engaging

Consideration of alternatives to standard instrument administration is considered a key approach to overcoming bias in cross-cultural assessment (van de Vijver & Leung, 2011, p. 23). Cultural differences are known to influence reactions to the examiner and to instructions (e.g. “go as fast as you can”, “do your best” (Lezak, Howieson, Bigler, & Tranel, 2012, p. 145), providing the rationale for greater consideration of the assessment process and format. This was echoed in our consultations. As one psychologist noted:

So you know, you've gotta be flexible. I mean, we're supposed to be helping them, not putting them through more stress.

From all perspectives (clinical, allied health, community-based service provision), the use of brief and engaging assessments was seen as both culturally acceptable and critical to obtaining an accurate assessment of function whilst not causing distress for the client. The use of assessment instruments was considered a Western cultural standard, not an Aboriginal one, therefore many Aboriginal people are reluctant to engage in assessment, particularly if the purpose of the assessment is not adequately explained, if the assessment is arduous, or if the outcomes are not of interest to the individual. Instruments that were onerous to complete were seen as likely to produce inaccuracies due to response bias, as clients were more likely to respond ‘no problem’, to complete the assessment as quickly as possible. As one psychologist noted:

So the last thing you'd want to do is impose a structure so onerous that- and of course what happens is, if you pose something that is really onerous, no-one will do it. And then you'll have a great idea and a beautiful system, but no one will find that they'll be able to use it.

Assessments that were under ten minutes in length were seen as optimal. Approaches that facilitated yarning and storytelling were considered the exception to this rule, as allowing the individual and family member to tell their story of their experience with ABI, in a relaxed, conversational manner was seen as culturally acceptable. As one interviewee stated:

But if it's kept conversational, um, and enjoyable, like card games and things like that are enjoyable, and they don't see it as being a test, you can go for quite a length of time.

Many of those interviewed who were involved in assessment reported the need to obtain additional qualitative information to enable accurate assessment. For this reason, instruments that explicitly facilitate yarning and allow the information gained during yarning to be incorporated into the assessment were considered optimal.

In terms of cognitive assessment, many cognitive assessment tasks rely on the person being assessed following the directions of the assessor, with response speed often used as a key indicator of cognitive processing. Neuropsychologists reported that Aboriginal clients may not consider cognitive testing as relevant or important, and thus many standard paper and pencil assessments may not yield accurate assessment of cognitive function. Engaging approaches were seen as more useful, particularly problem-solving, game or technology-based approaches (e.g. iPad apps, card games), as assessments were intrinsically engaging and less intimidating than traditional paper-pencil tests. As one psychologist said:

So formal assessment is always confrontational. Tell me this. Tell me that. Remember this. Remember that. Draw this. Draw that. Whereas a computer assessment it's- as an assessor, it's you and the person against the computer... so I wouldn't for example have a test where a person has to sit there thinking before they do something. I'd have something that actually that the thing was engaged by the behaviour rolling out all the time. So like rather than a search task, like a trail-making test or something where you actually have to engage the test.

✓ Reduced reliance on English literacy and numeracy

English is often a second or third language for Aboriginal and Torres Strait Islander Australians, thus instruments that rely heavily on English literacy and numeracy are not considered appropriate. Many of those engaged in assessment commonly reported the need to simplify, translate or re-interpret

questionnaire items or tasks, due to heavy reliance on English literacy and numeracy. As one psychologist notes:

You know, some can speak several languages but English is the bottom of the list.

In terms of cognitive assessment, many neuropsychologists reported that using versions of tasks that were primarily verbal and pictorial, rather than written, was more effective and appropriate for Aboriginal clients. To obtain culturally acceptable and accurate assessments of function, instruments should use simple language, be translated into local language if necessary, and eliminate reliance on English literacy and numeracy skills.

✓ Strengths-based approach

Typically, assessment instruments developed by Western psychologists use a deficits-based approach (i.e. they seek to identify what the individual cannot do). On the other hand, strengths-based, positive approaches are recommended when measuring health in Aboriginal or Torres Strait Islander populations (Haswell-Elkins et al., 2007). Strengths-based approaches identify what an individual can do well, or subjective satisfaction, and aim to support this while at the same time identifying what an individual might need help with. This approach aligns well with Quality of Life disciplines of research and instrument development, which enable people to rate their own satisfaction or dissatisfaction with major areas of life. This may be particularly important in preventing stigmatisation due to disability. As two interviewees noted:

The concept of disability is also...a concept of weakness, same as mental health problems are regarded as madness.

For some communities and some mobs, they see disability as a shame factor...there's that side. The other side is, in some of our families disabilities become normalised. You know, like, he's always been that way.

Deficits-based assessment approaches may cause distress in Aboriginal and Torres Strait Islander Australians, which will likely be compounded if assessments only tap into Western constructs of health and wellbeing, while ignoring culturally relevant ones.

Aim 3. Evaluate the cultural acceptability of instruments currently used for assessing function and participation in ABI

Following the development of the evaluation framework, instruments were rated according to the framework, to determine their potential utility for assessing functioning, cognitive impairment, and the care and support needs of Aboriginal Australians with ABI. These results are shown in Appendix 3 and 4.

Assessing cognition

No cognitive instruments satisfied all the evaluation criteria (Appendix 3). Four instruments were found that had been developed specifically for assessing cognition in Aboriginal Australians; the Kimberley Indigenous Cognitive Assessment, Cognitive Assessment for Aboriginal People, the Q Test, and the CogState Assessment Battery. All three instruments have the advantages of being relevant to Aboriginal Australians and assessing cognitive functions relevant to ABI. The Kimberley Indigenous Cognitive Assessment was often used by those interviewed for assessing cognitive function in Aboriginal clients of all ages. Despite this, the Kimberley Indigenous Cognitive Assessment is validated only for use with Aboriginal people aged ≥ 45 years. The Cognitive Assessment for Aboriginal People, whilst developed for Aboriginal people, has never been validated, thus cannot be used reliably to assess cognition. The Q Test, developed for Aboriginal Australians, has been validated, however recent normative data are not readily available (Drew et al., 2010, p. 195). Lastly, the CogState Assessment Battery has been designed for Aboriginal people, assesses key functions impaired in ABI, and uses an engaging, game-based format. The battery has some demonstration of reliability in adolescent Aboriginal Australians (Dingwall, Lewis, Maruff, & Cairney, 2009), however, the battery has never been validated for the assessment of cognitive impairment or in adult Aboriginal or Torres Strait Islander Australians. Thus, while our research revealed some promising culturally acceptable instruments, none are valid and reliable for the purpose of assessing ABI or diagnosing cognitive impairment in Aboriginal Australians aged 18-45. Validation studies are urgently needed.

All instruments assessed key cognitive functions impaired in ABI, and a non-clinical assessor could administer all the assessments examined except the Q Test, which requires a psychologist skilled in testing. Most were brief and/or engaging, with the exception of the Behaviour Rating Inventory of Executive Function, which had 75 items and is thus likely to be impractical. Several of the tests relied heavily on English literacy (Montreal Cognitive Assessment, Frontal Assessment Battery, Behaviour Rating Inventory of Executive Function, and the Dysexecutive Questionnaire), and none used a strengths-based approach focused on personal satisfaction with function. Providing structured feedback about the assessment is rarely built in to administration of the cognitive tasks, however it is likely that this structured feedback of information about cognitive assessment would encourage a more strengths-based approach, given that the

client would then have the opportunity to discuss their own strengths and areas of impairment, which could be discussed in the context of the outcome of the assessment.

Assessing functioning and care and support needs

No instruments were found that satisfied all the evaluation criteria (Appendix 4). No instruments had been specifically designed for, or validated in Aboriginal or Torres Strait Islander populations. Key domains of relevance to ABI were included in all the instruments when their content was compared to the core ICF domains of relevance to ABI, though some examined these domains comprehensively, while others were more focused. Many of these instruments failed to emphasise functional domains in line with those identified as being important to Aboriginal people in the interviews and in the literature. In particular, cultural connection or spirituality and community participation were not included in most of the instruments. Similarly, a strong distinction between work and leisure was made in most instruments, however our respondents suggested that for many people this distinction was not of importance or meaningful. Family and relationships were a focus of many instruments, which was compatible with Aboriginal values, emphasising extended family relationships as important. Non-clinical interviewers could administer most instruments with training, and several enabled collaborative decision-making using key informants such as family members or the individual with ABI to report on functioning. Only one instrument, the Quality of Life After Brain Injury was strengths-based, enabling the individual to report their satisfaction with key life areas.

Aim 4. Development of culturally acceptable instrument toolkit for assessment of function and participation in Aboriginal Australians with an ABI

In response to evaluation of the currently available instruments, it was decided that several existing cognitive assessments show promise for assessment of ABI in Aboriginal Australians, in terms of their content and format. However none could be used reliably due to the paucity of normative data and validation studies. None of the instruments currently available for assessing functioning and care and support needs were adequate for assessment of ABI in Aboriginal Australians. It was decided to explore the following options with respect to assessment of ABI in this study:

- a) Develop a culturally acceptable My Access Checker.
- b) Develop a culturally acceptable cognitive assessment 'toolkit'.
- c) Develop a new culturally acceptable instrument to assess WHO ICF domains of function, activities and participation relevant to Aboriginal and Torres Strait Islander Australians with ABI.

The activities associated with Aim 4 were undertaken using a Continuous Quality Improvement approach. The first cycle involved a stakeholder workshop for review of the draft cognitive assessment 'toolkit', and

the development of the culturally acceptable instrument based on WHO ICF domains of function, activities and participation. Following the workshop, a-c were revised and subsequent pilot studies of the modified instruments were conducted with stakeholders and community members at several sites. Pilot studies are ongoing. The following pages detail the development and content of a-c.

a. Develop a culturally acceptable My Access Checker

The My Access Checker (DisabilityCare Australia, 2013) is intended to be the first point of contact for individuals seeking to access DisabilityCare. This online access checker asks individuals or informants to answer questions pertaining to the Disability Requirements of DisabilityCare. Stakeholders and investigators deemed the My Access Checker to need revision due to significant cultural bias, to ensure the language, content and format is culturally acceptable. Given that the My Access Checker may be many Aboriginal and Torres Strait Islander people's first encounter with DisabilityCare, it is critical that the screening mechanism does not lead to incorrect exclusion of people. To ensure this incorrect exclusion doesn't occur, it is critical that the instrument adheres to the evaluation criteria, particularly: relevant to Aboriginal and Torres Strait Islander people, reduced reliance on English, and use of a strengths-based approach. The investigators reviewed the My Access Checker and modification was necessary for the following reasons:

- Recommend removing 'and have a disability' from the initial screen – many Aboriginal people may be reluctant to engage in an assessment if the term 'disability' is used, as many Aboriginal individuals may not be familiar with the term or it may cause fear of stigmatisation.
- Recommend removing the question 'Do you have a disability?' – this is culturally unacceptable as many Aboriginal communities don't use the term 'disability'
- Recommend adding an option 'I'm not sure of my date of birth' as many Aboriginal individuals may not know their date of birth
- Recommend removing the question 'Is your disability likely to continue for the rest of your life?' - many Aboriginal individuals may not have had an assessment thus won't be able to answer
- Combine Education and Employment into one category (Work, study and training.). For example, working, getting a job, studying, or training
- The language used in domain names and descriptions within the 'Support Needs' section could be significantly simplified (e.g. Learning and doing, Everyday activities. Yarning, Moving around, Looking after yourself, Daily life. Relationships and behavior, Community and culture). The current category names use language derived from the World Health Organization International Classification on Functioning, Disability and Health, which is unlikely to be familiar to Aboriginal and Torres Strait Islander people.

- A strengths-based response dropdown box is recommended with the following options: “Yes, a big hand” (subsuming “With complete help” and “With almost complete help”), “Yes, some hand” (subsuming “With a lot of help” and “With a little help”) and “No” (subsuming “Without help”).
- The question regarding use of assistive technology may be confusing. Many individuals may have had little access to assessment and prior support, so it should not be assumed that individuals would know the answers to these questions.

Lastly, the validity and utility of a self-screen for individuals with ABI was questioned, since awareness of impairments is often impaired in ABI. For individuals with cognitive impairment, it is likely that a self-screen would need to be conducted with the assistance of a trained assessor and an informant (e.g. family member, friend, advocate), to ensure an accurate assessment is made.

For Aboriginal and Torres Strait Islander Australians, it was recommended that this assessment be conducted in person, in consultation with the individual, relevant informants and any local advocated (e.g. Local Area Co-ordinators, Disability Advocates).

b. Develop a candidate culturally acceptable cognitive assessment ‘toolkit’

Based on literature review, consultations, evaluation, and continuous quality improvement several cognitive tasks were selected to form part of a culturally acceptable toolkit of tasks for assessing cognitive impairment in the key cognitive domains relevant to ABI in Aboriginal Australians. These tasks are shown in Table 3.2 and assess primarily high-level cognitive functions that are primarily impaired in ABI: memory, attention, executive function, learning and processing speed. Given that brevity is important when assessing cognition in this population, it was decided that any battery should focus on assessing these functions. The tasks in the toolkit were found to meet the following evaluation criteria; key cognitive impairments in ABI should be assessed, the tasks should be brief and engaging, and there should be minimal reliance on English. The key stakeholders on the project have endorsed these tasks. It is important to note that none of these tasks have been validated with Aboriginal or Torres Strait Islander Australians. As mentioned previously, the paucity of normative data for Aboriginal Australians precludes these tasks being used to diagnose cognitive impairment or ABI in this group.

Given the brief time frame of the study, it was decided to pilot the readily available CogState assessment battery, which contains the following tasks: World list learning (verbal memory & learning), Card detection task (processing speed), Card identification task (visual attention), card learning task (visual memory), Groton Maze Learning task (spatial memory, learning & executive function). These tasks assess the functions relevant to ABI (memory, attention, executive function, learning and processing speed) using an engaging format (cards). See (Dingwall et al., 2009) for examples of the tasks in the assessment battery.

Pilot studies of the CogState assessment battery have been initiated in the following sites:

1. Community Rehab NQ (Townsville Mackay Medicare Local) – community-based rehabilitation facility for neurological disabilities
2. Royal Darwin Hospital Inpatient Rehabilitation Unit
3. National Critical Care and Trauma Response Centre (Royal Darwin Hospital)
4. Top End Remote Aged & Disability Program (Northern Territory Department of Health)
5. Cairns Base Hospital (Psychology department)
6. Redfern community centre, NSW
7. James Cook University (student sample)

At each site, the CogState assessment battery was presented to stakeholders. A focus group has been held with staff at sites 1-4 to determine the potential usability of the assessment battery in their practice. At each site, staff spoke positively about the assessment battery with respect to the potential usability, utility and cultural acceptability of the battery. Sites 1-4 expressed desire to pilot the battery and report back to the project team regarding its cultural acceptability and usability. An additional pilot study is underway (site 7), with a sample of Aboriginal and Torres Strait Islander Australian students. Several sites have also indicated their enthusiasm to participate in upcoming validation studies. Due to the short frame of the study, detailed piloting and evaluation was not possible. Despite this, pilot studies are in place and evaluation will be conducted in the coming months by the project team. Importantly, while the cognitive assessment toolkit validation studies are required before any of the tasks in the assessment battery can be used reliably with Aboriginal and Torres Strait Islander Australians with an ABI.

Table 3.1: Cognitive assessment toolkit

Task	Function measured	Task description	Available or development required	References
Word list learning task	Verbal memory & learning	Words are read aloud to participant. Participant is asked to recall as many words as possible. Several learning trials are conducted	<ul style="list-style-type: none"> • Available in a variety of existing tests • List needs to be developed for Aboriginal and Torres Strait Islander Australians 	<p>CogState (2013d)</p> <p>Randolph (2012)</p> <p>Wechsler (1997)</p>
Story Memory	Verbal memory	Story is told to participant. Participant is asked to recall information pertaining to the story.	<ul style="list-style-type: none"> • Component of a variety of existing tests • Aboriginal and Torres Strait Islander -specific story needs to be developed 	<p>Randolph (2012)</p> <p>Randolph ()</p> <p>Wechsler (1997)</p>
Card detection task (computer/iPad)	Processing speed	The participant is instructed to answer yes or no to the question "Has the card turned over?" A playing card is presented in the centre of the screen. The card will flip over so it is face up. As soon as it does, the participant must press "Yes".	<ul style="list-style-type: none"> • Developed for Aboriginal Australians • Familiar stimulus (cards) 	CogState (2013a)
Card identification task (computer/iPad)	Visual attention	The participant is instructed to answer yes or no to the question "Is the card red?" A playing card is presented in the centre of the screen. The card will flip over so it is face up. The participant must press "Yes" if the card is red and "No" if the card is black.	<ul style="list-style-type: none"> • Developed for Aboriginal Australians • Familiar stimulus (cards) 	CogState (2013c)

Card learning task (computer/iPad)	Working memory & learning	"Have you seen this card before in this task?" A playing card is presented in the centre of the screen. As soon as it does the subject must decide whether or not the same card has been seen before in this task and respond by pressing the "Yes" or "No" key.	<ul style="list-style-type: none"> • Developed for Aboriginal Australians • Familiar stimulus (cards) 	CogState (2013f)
N-back task	Working memory & attention	Items are presented one at a time and participants must identify the item that occurred "n" items before	<ul style="list-style-type: none"> • Used in variety of studies • Familiar stimulus could be used (cards) 	CogState (2013e)
Groton maze learning (computer/iPad)	Spatial learning, memory, executive function	The subject is shown a 10 x 10 grid of tiles on a computer screen. A 28-step pathway is hidden among these 100 possible locations. The subject learns the 28-step pathway through the maze on the basis of trial and error feedback. Once completed, they are returned to the start location and repeat the task	<ul style="list-style-type: none"> • Developed for Aboriginal Australians 	CogState (2013b) Pietrzak et al. (2008) Dingwall, Maruff, and Cairney (2011)
Colour trail making test	Executive function	Uses numbered coloured circles and numbers. The circles are printed with vivid pink or yellow backgrounds. The respondent rapidly connects numbered circles in sequence, but alternates between pink and yellow colours.	<ul style="list-style-type: none"> • Designed specifically for cross-cultural research 	D'Elia, Satz, Uchiyama, and White (2012)
Zoo map	Executive function	It involves plotting or following a route through a map that does not contravene a set of rules. The score is based on the successful implementation of the plan.	<ul style="list-style-type: none"> • Component of the Behavioural Assessment of the Dysexecutive Syndrome 	Wilson, Alderman, Burgess, Emslie, and Evans (2003) Wilson, Alderman, Burgess, Emslie, and Evans (2012)

c. Develop a new culturally acceptable instrument to assess WHO ICF domains of function, activities and participation relevant to Aboriginal and Torres Strait Islander Australians with ABI.

Based on literature review, consultations and evaluation, it was decided that none of the non-cognitive assessment instruments were comprehensive and culturally appropriate, thus a new instrument was required, specifically for assessing WHO ICF domains of function, activities and participation in Aboriginal Australians with an ABI. This instrument, developed by the investigators, aimed to integrate the ICF core sets (brief and comprehensive) for traumatic brain injury with the evaluation criteria developed through consultation. The key features of the instrument, as per the evaluation framework, are as follows

- Key ABI functions assessed: the instrument incorporates the WHO ICF Core Sets for Traumatic Brain Injury (Laxe et al., 2013). These core sets identify the key Body Functions and Structures, Activities, and Participation domains that are affected by brain injury. Both the Brief and Comprehensive Core Sets were thoroughly examined to identify domains relevant to Aboriginal Australians with brain injuries as revealed during consultations. Whilst there are no Core Sets for non-traumatic ABI, the Core Sets for traumatic brain injury are comprehensive and appear to include the domains relevant to ABI from non-traumatic causes.
- Relevance to Aboriginal people: Several changes were made to ensure enhanced relevance to Aboriginal people. Firstly, within the Spirituality and Religion domain (D930), two items addressing connection to culture and community were included. Additionally, work, study and training were combined into a single item, and the term 'leisure' was removed and replaced with 'things you enjoy'.
- Non-clinical administrator: To make assessment more accessible for Aboriginal and Torres Strait Islander Australians who may not have access to clinical assessment, the questionnaire is designed to be administered by non-clinical assessors. In the context of the NDIS, it is anticipated that Planners would be able to receive training to administer the instrument.
- Facilitate collaborative decision-making: Throughout the project, the importance of collaborative and transparent decision-making was emphasised by all stakeholders, involving family members and the individual with ABI in the assessment process. Observational assessments by assessors were never endorsed. As such, the instrument is designed to be administered collaboratively, with the assessor discussing each domain with the individual and their relevant family members, spokesperson or advocates.
- Brief and engaging: The instrument incorporates primarily the brief WHO ICF Core Sets for traumatic brain injury, thus enabling the key impacts to be addressed quickly. Additionally, the instrument is designed to facilitate yarning. By enquiring as to the individual's satisfaction with

their ability in each of the domains, the areas in which the individual may need ‘a hand’ or help with can be identified. The questionnaire items are designed to stimulate more in-depth conversations consistent with the yarning approach. It is intended that in future, a ‘yarning tool’ will be developed to match the instrument, so that key support needs can be identified and matched with areas of reduced satisfaction.

- Reduced reliance on English: The wording has been significantly simplified from the original WHO ICF domains. Additionally, the domain definitions have been simplified into plain English to make them more understandable to non-clinical, non-specialist administrators, as well as to individuals with ABI and relevant family members, spokespersons or advocates.
- Strengths-based approach: We sought to use a response scale that was strengths-based and focused on subjective ratings, consistent with a Quality of Life approach. Similarly, it is anticipated that this approach will help avoid bias associated with cross-cultural interpretation of behaviour. For each item, individuals report on how happy they are with the domain according to the following scale: very unhappy, a bit unhappy, neutral, a bit happy, very happy, doesn't apply to me

The items included in the questionnaire are shown in Table 3.2, along with their correspondence to the WHO ICF domains contained in the core and comprehensive sets for traumatic brain injury. Culturally acceptable definitions are also provided. Figure 3.3 provides an example of the instrument might look, the items and the response scale. The project team are concerned about the potential (mis)use of the instruments that have been developed in this project, given that they have not yet been validated. Hence, as a precautionary measure, this report — which, we understand, will be made publically available — does not include the instruments in their entirety. The project team will, however, be able to present the instruments to the team currently developing the DisabilityCare assessment toolkit and/or any individuals responsible for evaluating/reviewing this report — that is, on the assumption that the instruments will not be made public or used in any assessment process prior to validation (unless in the context of a validation study).

A variety of individuals involved in the study have reviewed and commented on the instrument, leading to its refinement, consistent with a Continuous Quality Improvement approach. Figure 3.3 shows an example of how the instrument might look when formatted. Importantly, validation studies are required before the instrument can be used reliably. Pilot studies have been initiated in the following sites:

1. Community Rehab NQ (Townsville Mackay Medicare Local) – community-based rehabilitation facility for neurological disabilities
2. Top End Remote Aged & Disability Program (Northern Territory Department of Health)
3. Royal Darwin Hospital Inpatient Rehabilitation Unit

A focus group has been held with staff at sites 1-3 to determine the potential usability of the assessment battery. At each site, staff spoke positively about the assessment battery with respect to the potential usability, utility and cultural acceptability of the battery. Sites 1-3 expressed desire to pilot the instrument and report back to the project team regarding its cultural acceptability and usability. Several sites have also indicated their enthusiasm to participate in upcoming validation studies. Due to the short frame of the study, detailed piloting and evaluation was not possible. Despite this, pilot studies are in place and evaluation will be conducted in the coming months by the project team.

Table 3.2: Questionnaire items, ICF domains, and culturally acceptable domain definitions

How happy are you with...	ICF domain	B/C*	Domain	ICF Domain definition**	Culturally acceptable definition of domain***
Your relationships with your family?	D760	B	Family relationships	Creating and maintaining kinship relationships, such as with members of the nuclear family, extended family, foster and adopted family and step-relationships, more distant relationships such as second cousins or legal guardians. Inclusions: parent-child and child-parent relationships, sibling and extended family relationships.	Maintaining relationships with family members, including between parents and children and with extended family members
Your relationships with your friends?	D750	C	Informal relationships with friends	Entering into relationships with others, such as casual relationships with people living in the same community or residence, or with co-workers, students, playmates or people with similar backgrounds or professions.	Creating and maintaining friendship relationships with friends and peers
Your connection to your culture?	D930	C	Religion and spirituality	Engaging in religious or spiritual activities, organizations and practices for self-fulfilment, finding meaning, religious or spiritual value and establishing connection with a divine power, such as is involved in attending a church, temple, mosque or synagogue, praying or chanting for a religious purpose, and spiritual contemplation. Inclusions: organized religion and spirituality	Engaging in cultural, religious or spiritual practices, for self-fulfilment, religious, cultural or spiritual value. Establishing connection with spiritual forces. Includes formal activities (e.g. attendance at church or ceremony) but also informal activities (e.g. contemplation, feeling of connection).
Your connection to your community?					

Doing your normal daily activities?	D230	B	Carrying out daily routine	Carrying out simple or complex and coordinated actions in order to plan, manage and complete the requirements of day-to-day procedures or duties, such as budgeting time and making plans for separate activities throughout the day. Inclusions: managing and completing the daily routine; managing one's own activity level.	Completing day-to-day routines and activities, such as scheduling and undertaking activities throughout the day
Doing things you enjoy (e.g. sport, hunting, fishing, art)?	D920	B	Recreation and leisure	Engaging in any form of play, recreational or leisure activity, such as informal or organized play and sports, programmes of physical fitness, relaxation, amusement or diversion, going to art galleries, museums, cinemas or theatres; engaging in crafts or hobbies, reading for enjoyment, playing musical instruments; sightseeing, tourism and travelling for pleasure. Inclusions: play, sports, arts and culture, crafts, hobbies and socializing	Engaging in recreation and leisure activities, including organised and informal activities. Includes physical fitness, amusement, hobbies, cultural activities, dance, music, hunting, fishing, art
Work/study/training?	D845, D850, D825, D830	B	Acquiring, keeping and terminating a job/ Remunerative employment/ Vocational training/ Higher education	Seeking, finding and choosing employment, being hired and accepting employment, maintaining and advancing through a job, trade, occupation or profession, and leaving a job in an appropriate manner. Inclusions: seeking employment; preparing a resume or curriculum vitae; contacting employers and preparing interviews; maintaining a job; monitoring one's own work performance; giving notice; and terminating a job Engaging in all aspects of work, as an	Getting and keeping a job. Includes seeking a job, preparing a resume, contacting employers, preparing interviews, maintaining and job, monitoring work performance, terminating a job. Engaging in work. Includes doing the tasks required of the job, attending work, supervising or being supervised. Engaging in vocational work or

				<p>occupation, trade, profession or other form of employment, for payment, as an employee, full or part time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups. Inclusions: self-employment, part-time and full-time employment</p> <p>Engaging in all activities of a vocational programme and learning the curriculum material in preparation for employment in a trade, job or profession.</p> <p>Engaging in the activities of advanced educational programmes in universities, colleges and professional schools and learning all aspects of the curriculum required for degrees, diplomas, certificates and other accreditations, such as completing a university bachelor's or master's course of study, medical school or other professional school.</p>	<p>training in preparation for employment</p> <p>Engaging in formal education in preparation for employment</p>
Joining in community events?	D910	C	Community life	<p>Engaging in all aspects of community social life, such as engaging in charitable organizations, service clubs or professional social organizations. Inclusions: informal and formal associations; ceremonies</p>	<p>Engaging in community social life. Includes formal activities (e.g. member of clubs, organisations), informal activities (attendance at events, ceremonies). Also includes cultural activities such as ceremonies, dances, music</p>

Yarning with people?	D350	B	Conversation	<p>Starting, sustaining and ending an interchange of thoughts and ideas, carried out by means of spoken, written, sign or other forms of language, with one or more people one knows or who are strangers, in formal or casual settings.</p> <p>Inclusions: starting, sustaining and ending a conversation; conversing with one or many people.</p>	Starting, carrying out and ending conversations with one or more people, either through written, spoken or sign language.
Walking?	D450	B	Walking	<p>Moving along a surface on foot, step by step, so that one foot is always on the ground, such as when strolling, sauntering, walking forwards, backwards or sideways.</p> <p>Inclusions: walking short or long distances; walking on different surfaces; walking around obstacles.</p>	Walking, including forwards, backwards and sideways, short or long distances, walking around obstacles, and on different surfaces
Getting around the community?	B760 D455, D465	C	Control of voluntary movements/ moving around/ moving around using equipment	<p>Functions associated with control over and coordination of voluntary movements.</p> <p>Inclusions: functions of control of simple voluntary movements and of complex voluntary movements, coordination of voluntary movements, supportive functions of arm or leg, right left motor coordination, eye hand coordination, eye foot coordination; impairments such as control and coordination problems, e.g. dysdiadochokinesia.</p> <p>Moving the whole body from one place to another by means other than walking, such as climbing over a rock or running down a street, skipping, scampering, jumping, somersaulting or running around obstacles.</p>	Control over and coordination of voluntary (deliberate) movement. Including functions of arms and legs, coordination between right and left side movements, hand-eye coordination, foot-eye coordination. Moving around the community. Includes crawling, climbing, running, jogging, jumping and swimming. Includes using equipment such as wheelchairs and walkers

				<p>Inclusions: crawling, climbing, running, jogging, jumping and swimming</p> <p>Moving the whole body from place to place, on any surface or space, by using specific devices designed to facilitate moving or create other ways of moving around, such as with skates, skis, or scuba equipment, or moving down the street in a wheelchair or a walker.</p>	
Washing your self?	D510	B	Self-care	This chapter is about caring for oneself, washing and drying oneself, caring for one's body and body parts, dressing, eating and drinking, and looking after one's health.	Looking after oneself, being able to wash and dry the body, take care of the body, dressing, eating and drinking, looking after one's health. Includes ability to manage own health (e.g. diet, exercise, maintaining physical health)
Going to the toilet?	D530	B			
Getting dressed?	D540	B			
Eating and drinking?	D550, d560	B			
Taking your medicine?	D570	B			
Keeping your self healthy?	D570	B			
Any pain?	B280	B	Sensation of pain	<p>Sensation of unpleasant feeling indicating potential or actual damage to some body structure.</p> <p>Inclusions: sensations of generalized or localized pain in one or more body part, pain in a dermatome, stabbing pain, burning pain, dull pain, aching pain; impairments such as myalgia, analgesia and hyperalgesia</p>	Feeling pain, including general body pain, pain in specific body areas, dull pain, stabbing pain, aching pain.
Fixing problems when they come up?	B164	B	Higher level cognitive functions	Specific mental functions especially dependent on the frontal lobes of the brain,	Complex brain processes including planning and carrying out plans,

Making decisions?		B		including complex goal-directed behaviours such as decision-making, abstract thinking, planning and carrying out plans, mental flexibility, and deciding which behaviours are appropriate under what circumstances; often called executive functions. Inclusions: functions of abstraction and organization of ideas; time management, insight and judgement; concept formation, categorization and cognitive flexibility.	decision-making, deciding what actions are appropriate in which circumstances, abstract thinking, and mental flexibility. Often called executive function
Planning and organising things?		B			
Keeping your mind on one thing?	B140	B	Attention functions	Specific mental functions of focusing on an external stimulus or internal experience for the required period of time. Inclusions: functions of sustaining attention, shifting attention, dividing attention, sharing attention; concentration; distractibility.	Being able to focus on what's going on outside the body or in the mind for the required time. Includes attention, concentration, distractibility.
Remembering things?	B144	B	Memory functions	Specific mental functions of registering and storing information and retrieving it as needed. Inclusions: functions of short-term and long-term memory, immediate, recent and remote memory; memory span; retrieval of memory; remembering; functions used in recalling and learning, such as in nominal, selective and dissociative amnesia.	Being able to store and remember information and retrieve it when needed.
Controlling your emotions?	B152	B	Emotional functions	Specific mental functions related to the feeling and affective components of the processes of the mind. Inclusions: functions of appropriateness of emotion, regulation and range of emotion; affect; sadness, happiness, love, fear, anger,	Being able to experience the normal range of emotions including sadness, happiness, love, fear, hate, anger, tension, anxiety, joy, sorrow. Being able to control emotions and have appropriate emotional

				hate, tension, anxiety, joy, sorrow; lability of emotion; flattening of affect.	responses
Behaving in a way that's normal in your community?	D720	B	Complex interpersonal relationships	Maintaining and managing interactions with other people, in a contextually and socially appropriate manner, such as by regulating emotions and impulses, controlling verbal and physical aggression, acting independently in social interactions and acting in accordance with social rules and conventions. Inclusions: forming and terminating relationships; regulating behaviours within interactions; interacting.	Behaving and interacting in ways that are appropriate for the circumstances. This includes regulating emotions and impulses, controlling aggression, acting in accordance with social rules and conventions
Looking after your money?	D860	C	Basic economic transactions	Engaging in any form of simple economic transaction, such as using money to purchase food or bartering, exchanging goods or services; or saving money.	Engaging in any form of simple economic transaction, such as using money to buy food or bartering, exchanging goods or services; or saving money.

*Indicates if the item was drawn from the brief (B) or comprehensive (C) core set for traumatic brain injury. Items included in the comprehensive core set but not the brief core set are marked 'C'.

** As per the original WHO ICF domain definitions

*** Culturally acceptable and plain English interpretations of the WHO ICF domain definitions

How happy are you with...	Very happy	A bit happy	Neither	A bit unhappy	Very unhappy	Doesn't apply to me
1. Your relationships with family?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Your relationships with friends?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Your connection to culture?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Your connection to community?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Doing your normal daily activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Doing things you enjoy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Work/study/training?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Joining in community events?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Yarning with people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Walking?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Getting around the community?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Washing your self?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Going to the toilet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Getting dressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Eating and drinking?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Taking your medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Figure 3.2: Example of items and response scale from the function, activity and participation instrument

Summary and recommendations

The instrument toolkit presented in this chapter represents the first effort to develop culturally acceptable instruments for the assessment of Aboriginal and Torres Strait Islander Australians with brain injuries. Within the brief study time frame, significant progress has been made in terms of: defining the content of the instrument, integrating the evidence-based literature with unique perspectives of Aboriginal and Torres Strait Islander Australians, identifying relevant tasks and questionnaire items, and piloting and evaluating this toolkit using Continuous Quality Improvement. As well as enabling development of the instrument toolkit, the study has mobilised key experts in the area of instrument development and Aboriginal and Torres Strait Islander health toward the important goal of ensuring that Aboriginal and Torres Strait Islander Australians have access to evidence-based assessment through DisabilityCare Australia.

The instrument toolkit requires significant further piloting in a variety of settings to further refine the instruments prior to undertaking formal validation studies. At this stage, the instruments should not be used as they represent a prototype toolkit rather than a validated set of instruments. In addition to further refinement and validation, development of associated protocols and training is required. This will ensure that the instruments satisfy the key theoretical, practical, standardisation, reliability and validity considerations prior to use.



Chapter 4: A framework for DisabilityCare Australia assessor training and organisational capacity building

DisabilityCare Australia staff will be required to consider carefully the nature, intensity and frequency of individuals' support needs. To do this effectively for those with brain injuries, assessors must be trained to understand the causes of ABI, symptoms and signs, and its impacts on the lives of individuals, families and communities. DisabilityCare Australia Planners and LACs must recognise the broad, dynamic and ongoing impacts of ABI, to evaluate the support needs of individuals adequately. Proper evaluation of these needs is necessary to enable people to be empowered toward social and economic participation and to reduce the current burden of unrecognised brain injury-related disability, which is currently borne largely by families (Aboriginal Disability Network New South Wales, 2007; Westerman, 2010).

DisabilityCare Australia Planners and LACs need to have sound understanding of the unique causes and consequences of ABI for Aboriginal and Torres Strait Islander Australians. There is very little empirical research investigating the causes or impacts of ABI, despite that fact that Aboriginal and Torres Strait Islander communities suffer more frequent incidences of ABI risk factors.

Whilst there is a service gap in the provision of Aboriginal and Torres Strait Islander-specific ABI training, the framework for staff training and capacity building protocols set out in this chapter are derived from consultations conducted by the research team across Australia. The following components were considered vital elements of a training and professional framework for DisabilityCare Australia frontline staff.

1. ABI training

1A: Knowledge of ABI: causes, symptoms and signs

1B: Training in the assessment of ABI

2. Aboriginal and Torres Strait cultural training:

2A: Cultural awareness training

2B: Cultural Competence skills-based monitoring and assessment

This training framework will ensure that, when working with Aboriginal and Torres Strait Islander Australians with an ABI, assessors are adequately skilled to:

- deliver accurate and culturally-appropriate assessment;
- identify appropriate care and support needs; and
- communicate effectively with Aboriginal and Torres Strait Islander clients.

4.1. ABI training

4.1A: Knowledge of ABI: causes, symptoms and signs

Symptoms of ABI are complex, and whilst many individuals experience overt physical impairments due to brain injury, many more experience cognitive and behavioural deficits that may not be recognised as being related to brain impairment. The research behind these guidelines revealed that ABI frequently goes unrecognized within Aboriginal and Torres Strait Islander communities, and cognitive and behavioural impacts of ABI are often ignored. Frequently, symptoms of ABI are often mistaken for mental health issues, and challenging behaviours arising from ABI can often lead to discrimination and exclusion of the individual. For these reasons, basic training in understanding ABIs is necessary for DisabilityCare Australia staff, to:

- increase awareness of the causes of ABI and its consequences on individuals, families and communities;
- assist staff to engage effectively with people with an ABI;
- understand the range of health and non-health SPs required by those with an ABI; and
- recognise appropriate early intervention and treatment options.

Available training courses are presented in Table 1.

4.1B: Training in the assessment of ABI

Assessors need to receive training regarding how to assess ABI because:

- ABI is complex, involving physical, cognitive and behavioural impairments;
- a variety of strategies may be necessary to accurately assess a person with ABI;
- it is vital that they understand culturally appropriate protocols prior to and during assessment;

This will ensure that staff:

- are proficient in the use of the recommended suite of instruments to undertake appropriate assessments;
- have a proficient knowledge of cognitive assessment to accurately interpret medical case history documentation; and
- have a sound knowledge of specialist services available to undertake highly specialized cognitive assessment.

4.2 Aboriginal and Torres Strait cultural training:

4.2A: Cultural awareness training

Cultural awareness, cultural competence and cultural safety are concepts enshrined in a raft of policy guidelines and frameworks that aim to address the health inequities experienced by Aboriginal and Torres Strait people. There is increasing recognition of the need for health practitioners and those responsible for delivering health services to take account of the historical, cultural, and environmental experiences and contemporary circumstances of Aboriginal people.

For DisabilityCare Australia staff to work effectively with Aboriginal and Torres Strait Islander Australians with an ABI, it will be critical that they understand Aboriginal and Torres Strait Islander history and culture, and have the practical skills to work with this group.

Cultural Awareness courses are available across Australia. They are frequently delivered to the staff of government, non-government and corporate organisations to equip people with the knowledge and skills to work effectively and challenge common stereotypes. Course content also varies but comprehensive training will guide trainees through a process to gain insight into their own beliefs, Aboriginal and Torres Strait Islander perspectives of significant historical events and theories, the impact of events on contemporary Australian society, and insight into Aboriginal and Torres Strait Islander ways of working.

Available training courses are presented in Table 2.

4.2B: Cultural Competence skills-based monitoring and assessment

DisabilityCare Australia is committed to a recruitment policy that will contract or directly employ, members of both Aboriginal and Torres Strait Islander communities as frontline employees. This is

consistent with the National Strategic Framework for Aboriginal and Torres Strait Islander Health, 2003-2013, which states that a competent health workforce is to be adequately resourced to employ:

- *Appropriate clinical, management, community development and cultural skills to address the health needs of Aboriginal and Torres Strait Islander peoples supported by appropriate training, supply, recruitment and retention strategies (Commonwealth of Australia, 2007, p. 21) ; and*
- *Skilled and supported staff to address mental health, social and emotional well-being and substance use issues for children, adults, families and communities across all Indigenous settings (Commonwealth of Australia, 2007, p. 23).*

The value of having locally known, respected and trusted representatives of DisabilityCare Australia, cannot be overstated.

For non- Aboriginal and Torres Strait Islander staff, an effective training and professional development protocol needs to contain a competency-based process for the ongoing monitoring and assessment of cultural competence. Ongoing education and practical capacity building through work shadowing, mentoring, personal and peer reflection, is needed. Non- Aboriginal and Torres Strait Islander staff should be 'buddied' to work with mentors who have an Aboriginal and/or Torres Strait Islander heritage, or a respected work history of practice with Aboriginal and/or Torres Strait Islander people. Work practices should be grounded in Aboriginal and Torres Strait Islander community settings on an ongoing basis. Formal cultural competency training is limited, see Tracey Westerman ("Indigenous psychological services,"), as a cultural competency training provider. It is important to recognise that despite training efforts, not all individuals will be suited to effective engagement with Aboriginal and Torres Strait Islander people (Bauman, 2007).

We emphasise cultural competency, because, there is an important distinction between cultural *awareness* and cultural *competence*. Interviewees were critical of cultural awareness training for non-Indigenous Australians for not 'going far enough.' From the perspectives of interviewees, cultural awareness training failed to produce culturally competent practitioners equipped with the skills for effective practice. Assessors and service providers may cause great harm within Aboriginal and Torres Strait Islander communities and undermine outcomes for individuals with disabilities if they do not have the required skills and attributes to work with these cohorts.

Cultural competence is a commitment to engage respectfully with people from other cultures. It builds people's cultural awareness and demonstrates a specialist set of communication skills which

are required to arrive at informed, transparent and sustainable decisions. “The manner in which any ‘agreement’ is entered into will have a bearing on its success, as will the engagement and communication skills of individuals involved on the ground to build mutually respectful and trusting relationships” (Bauman, 2007, p. 14).

A commitment to cultural competence is the beginning of an ongoing process that requires motivation and a willingness to improve cross-cultural communication and practice in both individuals and organisations. Cultural competence encompasses and extends elements of cultural respect, cultural awareness, cultural security and cultural safety. Cultural competence is a set of congruent behaviours, attitudes and policies that come together in a system, agency or among professionals and enable that system, agency or those professionals to work effectively in cross-cultural situations... It can be defined as the ability to identify and challenge one’s own cultural assumptions, one’s values and beliefs. It is about developing empathy and connected knowledge, the ability to see the world through another’s eyes, or at the very least to recognise that others may view the world through a different cultural lens. (Walker & Sonn, 2010, p. 161).

Cultural respect

Cultural respect as a fundamental element of cultural competence (Walker & Sonn, 2010). It involves the recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal and Torres Strait Islander peoples.

For DisabilityCare Australia, Aboriginal and Torres Strait Islander people’s cultural differences will be acknowledged and their cultural rights, practices and values will be legitimatised, to ensure that equitable disability support outcomes are achieved.

The national Cultural Respect Framework endorsed by the Australian Health Ministers' Advisory Council (AHMAC) aims to provide a nationally consistent approach to building a culturally competent health system that will improve access to and responsiveness of mainstream services for Aboriginal and Torres Strait Islander peoples. It recognises that the planning and delivery of culturally secure and appropriate health and mental health services has been challenging and that a commitment to cultural respect needs to be embedded across all sectors of the health system.

Translating this commitment to DisabilityCare Australia will engage the corporate, organisational and care delivery levels to uphold the rights of Aboriginal and Torres Strait Islander peoples to maintain, protect and develop their culture and achieve equitable disability support outcomes.

Cultural safety

The concept of cultural safety extends the concept of cultural appropriateness in health practices. Cultural safety in practice focuses on effective clinical practice for a person from another culture. Unrecognised miscommunication, or culturally unsafe practices are pervasive in Australian health settings and particularly in remote communities. “It is important to recognise that failure to instil culturally safe practices is a diminution and erosion of fundamental cultural and human rights for Indigenous peoples.” (Walker & Sonn, 2010, p. 162).

Cultural safety is about acting in ways that enhance rather than diminish individual and communal cultural identities and empower and promote individual and community wellbeing. To create a culturally safe space involves a high level of critical reflexivity(Walker & Sonn, 2010, p. 162).

Table 4.1: ABI training programs

	Source	Access	Brief information about the course	Type of course and completion	Accredited
Online					
	Family and Community Services, NSW Government	Online Free	Working with people with Acquired Brain Injury Self-study modules: 1. Introduction to ABI and 2. Working with people with ABI Extensive additional information resources online, although service information is NSW based Facilitated training workshops also available in NSW http://www.abistafftraining.info/	Competency based progression- self paced and can be completed at work or home Pre-test and Post-test	
			Also offered (and linked to the ABI training site) are 12 self study modules on working with people with traumatic brain injury. http://www.tbistafftraining.info/index.htm	As above	
	NVT Systems Australia South Australia	Online course Fee \$325.	Neurological Vision rehabilitation – offers online training - ABI in relation to vision impairments http://www.nvtsystems.com.au/products_services/online_training/ brochure: http://www.nvtsystems.com.au/resources/brochures/On_Line_Training_Course.pdf		
On-site with a Facilitator					
	Brain injury Australia		One day workshop Facilitating Psychosocial Adjustment After Brain Injury: Goal Planning And Self-Awareness Interventions	On site	
	ARBIAS		<i>Comprehensive training</i> Arbias offers professional training to develop and enhance the knowledge and skills required to work effectively with people who have an acquired brain injury Workshops are offered on-site (modules 1-4) modules 5-9 are offered at venues in NSW and Victoria http://www.arbias.org.au/training.html	On-site for modules 1-4 Participants go to locations in NSW and Victoria for modules 5-9	
	Acquired Brain Injury Outreach Service (ABIOS) Queensland	Trainer	Training offered through ABIOS –formal seminars and workshops, guest speakers, telephone conferencing, internet and mail. Information resources on website http://www.health.qld.gov.au/abios/asp/abi_education.asp	On-site training	

	Source	Access	Brief information about the course	Type of course and completion	Accredited
	Synapse	Trainer	<p>Customised corporate training</p> <ul style="list-style-type: none"> • Supporting Individuals with Complex and Challenging Behaviours (SICCB) • Positive Behaviour Support (PBS) • Understanding Acquired Brain Injury (UABI) • The Effective Support Person (TESP) • Customised Induction to specific Organisational requirements <p>http://synapse.org.au/our-work/training/customised-corporate-training.aspx</p>	Training can be delivered in either two or four hour blocks, or full day sessions.	
	Brain Injury Association of Tasmania	Trainer Mark Lamont Clinical Neuropsychologist	For Families, Carers & Friends and People living with Acquired Brain Injury Up to 7 modules available. Fee, workshop structure and location negotiable.	On or off-site training	
	Headwest (Brain Injury Association of Western Australia)	Trainer	<p>Training courses available to assist individuals when working with an ABI. Short to detailed, and tailored courses available.</p> <p>http://www.headwest.asn.au/</p>	On or off-site training	
	Brain Injury Association of New South Wales	Trainer	Training individuals and service providers. Programs can be customised to suit needs. Seminars, workshops and telephone conferencing available.	website	
	BrainLink (Victoria)	Trainer	<p>Training courses available to assist individuals with ABI and their families can carers. Fact sheets available</p> <p>www.brainlink.org.au</p>	website	

Table 4.2: Cultural competence training programs (National))

Source	Access	Brief information about the course	Type of course and completion	Accredited
National				
Indigenous Psychology Services (Dr Tracy Westerman)	Short course	<p>Cultural Competency Program for Supervisors of Aboriginal People (various course locations) (approx. \$1750.00)</p> <p>Two day workshop</p> <p>Better understand cultural competence and how to LEARNING OUTCOMES: This program which will enable Supervisors of Aboriginal people to:</p> <ul style="list-style-type: none"> • achieve focused, sustained shifts in core areas • Improve pre-training cultural competency skills via completion of the General Cultural Competency Test and training in all aspects of cultural competency • Understand the motivators and predictors of racial bias and skills associated with cultural empathy • Increasing participant's knowledge of Aboriginal health, history, government policies and culture and how this links with increased cultural competence <p>http://www.indigenousspsychservices.com.au/courseinfo.php?cid=33</p>		
Australian Indigenous Psychologists Association	Onsite short course	<p>Cultural Competence Course</p> <p>In person, two-day course for non-Aboriginal and Torres Strait Islander psychiatrists, psychologists, mental health nurses, social workers and mental health-trained occupational therapists</p>		
Centre for Cultural Competence Australia (CCCA)	Online short courses	<p>Aboriginal and Torres Strait Islander Cultural Competence Course</p> <p>Online learning (\$272.00), TAFE accredited</p> <p>Assist non-Aboriginal and Torres Strait Islander professionals to increase understanding of Australian Aboriginal and Torres Strait Islander cultures and help them become culturally competent at a personal and professional level.</p> <p>http://ccca.com.au/</p> <p>http://ccca.com.au/aboriginal-and-torres-strait-islander-cultural-competence-course#c5</p>	Competency Based Online Can be completed at own pace.	TAFE accredited
Centre for Cultural Competence Australia (CCCA)	Online short courses	<p>Aboriginal and Torres Strait Islander Cultural Competence Course</p> <p>Online learning (\$196.00), non-TAFE accredited</p> <p>Individuals, service providers, organisations, and state and federal departments</p> <p>Provide non-Aboriginal and Torres Strait Islander individuals, service providers and organisations with introductory knowledge of Australian Aboriginal and Torres Strait Islander cultures, the basis of effective and appropriate communication and engagement with Aboriginal and Torres Strait Islander communities.</p> <p>http://ccca.com.au/aboriginal-and-torres-strait-islander-cultural-competence-course-non-tafe#c14</p>	Competency based Online Can be completed at own pace	No
Royal Australian College of General	Online short Course	<p>Aboriginal and Torres Strait Islander cultural awareness in general practice for Medical personnel (free to RACGP members)</p> <p>http://www.racgp.org.au/yourracgp/faculties/aboriginal/education/cultural-awareness/</p>	Competency based Online	RACGP accredited

Source	Access	Brief information about the course	Type of course and completion	Accredited
Practitioners			(can be completed at own pace)	
Winangali Marumali Terranora, NSW	Short courses for non-Aboriginal and Torres Strait Islander service providers (fees)	<ul style="list-style-type: none"> • Program for Aboriginal and Torres Strait Islander Service Providers (5 days) • Program for Non-Aboriginal and Torres Strait Islander Service Providers (2 days) • Risk Management Workshop for Workers (2 days) • Aboriginal Cultural Awareness (2 days) • Healing Workshop (1 day) & (5 day) • Awareness Workshop (1 day) • Program for Aboriginal and Torres Strait Islander Inmates within correctional centres (5 days) http://www.marumali.com.au/formats	Training On site	
Why Warriors Pty Ltd (Arnhem Land)	Online short course (fees - \$77 per module)	<p>An introduction to cross-cultural awareness - Live streaming 4 modules over 2 days</p> <ol style="list-style-type: none"> 1. <i>Awareness of Cultural Dynamics</i> 2. <i>Entering the Cultural gap</i> 3. <i>Social and Political Systems</i> 4. <i>Introduction to effective communications</i> <p>http://www.whyywarriors.com.au/training/courses.php Has free online resources: Cultural Worlds - Working effectively with Aboriginal and Torres Strait Islander communities http://www.whyywarriors.com.au/online_training/index.php Will negotiate tailored courses that can be presented online.</p>	Training (online)	
Services for Australian Rural and Remote Allied Health (SARRAH)	Online course Free	<p>Short course Online module for remote and rural allied health practitioners to aid in developing culturally safe work practices http://www.sarrahrtraining.com.au/site/index.cfm?display=143690</p>	Cultural Awareness Online module can be completed in 20 minutes	
Felicity Ryan	Onsite (fee payable)	Short courses targeting non-Aboriginal and Torres Strait Islander people working within Aboriginal and Torres Strait Islander communities and individuals wishing to expand their cultural awareness.		
Symmetra Diversity Consulting	In person short course	First Australians Cultural Awareness Training. One day course aimed to develop participants cross cultural intelligence and capabilities relating to Aboriginal and Torres Strait Islander people. Fee payable http://www.diversityconsultingcompany.com/services_firstaus.html	Cultural Awareness short course	

Queensland					
	TAFE Cairns Campus	Short course (fees)	Course in Aboriginal and Torres Strait Islander Cultural Awareness (39269QLD) 2 units: Develop an Understanding of Aboriginal and Torres Strait Islander Australian History and Cultures Relevant to Work Contexts Employ appropriate protocols to work effectively with Aboriginal and Torres Strait Islander people Two day course – in 2013 these were scheduled 25 & 26 March and 6 & 7 May.	Training, awareness course	
	Tom Kirk Aboriginal and Torres Strait Islander Consultant	Training for organizations (from 2 hours to 7.5 hours) Cost according to training required)	<ol style="list-style-type: none"> 1. Introducing Aboriginal people (2 hours) 2. Culture, Kinship and community (4 hours) 3. Communicating across cultures (7.5 hours) http://tomkirktraining.com/programs	Awareness training	No
Western Australia					
	CSD Network Kim Bridge and Tim Muirhead	Onsite with Facilitator	Aim is to develop participant's abilities in engaging, communicating and forming partnerships with Aboriginal people. Two day workshop (\$895.00)	Awareness workshop	
	The Western Australian Council of Social Service	Training for Community Services Sector and Individuals Onsite	Communicating and Connecting with Aboriginal Clients Covers culture, history and includes a strong emphasis on strategies for engaging, communicating and working collaboratively with Aboriginal people and communities (\$278.00 non-member) http://www.wacoss.org.au/services/eventsbookingDetails/12-12-21/Communicating_and_Connecting_with_Aboriginal_Clients_-_Fri_12th_April_2013.aspx	Cultural Awareness training	
	Wangka Maya Pilbara Aboriginal Language Centre	Onsite training for individuals and organisations working with or deliver services to, Aboriginal people in the Pilbara region	Training can be customised, or a one-day workshop introducing the culture of Aboriginal people in the Pilbara. Short Course Fee payable http://www.wangkamaya.org.au/index.php?option=com_content&view=article&id=20&Itemid=383	Cultural Awareness training	

	Kart Koort Wiern Consultancy	Training for organisations	Cultural Awareness and Competence training offered through Kart Koort. Formal workshops including half-day, full-day and two-day workshops are available. (Fees payable) http://www.kartkoortwiern.com/#	Cultural Awareness and Competency training available	
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New South Wales					
	Ombudsman New South Wales	Onsite with Facilitator (fee payable)	Half day workshop aimed at providing organisations and staff with Cultural Awareness to assist in delivery of Service to Aboriginal and Torres Strait Islander people. http://www.ombo.nsw.gov.au/training-workshops-and-events/our-workshops/access-and-equity-training/aboriginal-cultural-appreciation	Awareness training	
	Aboriginal Health College	Onsite short course	Non-Aboriginal community and social services, health and allied health professionals and workers working with or likely to work with Aboriginal clients and communities. Course can be customised, aimed at preparing participants to work in a culturally safe way with Aboriginal people and provide an understanding of factors impacting the health and service delivery for Aboriginal people. Two day course	Cultural Awareness training	
South Australia					
	Emu Consulting	Onsite with Facilitator (fee payable)	This course provides companies, students, communities and individuals with an understanding of the importance of cultural practice. One day workshop http://www.healthinfonet.ecu.edu.au/key-resources/courses-training?fid=501	Awareness workshop	
	Rural Solutions		Cultural Competency Training – Working with Aboriginal people. Aimed at organisations and government departments Two day workshop (\$775.00) http://www.ruralsolutions.sa.gov.au/workshops/aboriginal_cultural_awareness_training_2013	Competency training workshop	

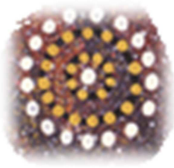
Tasmania					
	Riawunna Centre, University of Tasmania	Training for Medical Students and Health Practitioners	Cultural Awareness short course for medical students and health practitioners providing an introduction to Tasmanian Aboriginal and Torres Strait Islander cultures including in communicating effectively with different aboriginal cultures. (Free) http://www.staff.utas.edu.au/news/articles/come-walk-with-us-a-tasmanian-experience	Onsite short course	
	Tasmanian Aboriginal Centre, with Alcohol Tobacco and Other Drugs Council Tas Inc	Onsite for all personnel in the health and community sectors in Tasmania	Tasmanian Aboriginal culture and history (fee payable) http://atdc.org.au/	Cultural Awareness training	

Victoria				
Koorie Heritage Trust	Onsite short course	Cultural Awareness course for Staff of government, non-government and corporate organisations in Victoria, providing an introduction to Aboriginal cultures, can be customised. http://www.koorieheritagetrust.com/cultural_education/education	Cultural Awareness training	
Kangan Institute - Indigenous Education Centre	Onsite short course	Cultural Awareness course for Staff of government, non-government and corporate organisations in Victoria providing people with the knowledge and skills to work effectively with Victorian Aboriginal communities. Course also aims to eradicate apprehension or misconceptions about Aboriginal and Torres Strait Islander people. http://www.kangan.edu.au/assets/downloads/departments/Aboriginal and Torres Strait Islander-education-centre/ICAT-flyer.pdf	Cultural Awareness training	
Victoria Aboriginal Community Services Association (VACSAL)	Onsite short course	Aboriginal and Torres Strait Islander cultural awareness training aimed at government departments and non-government agencies in Victoria. http://www.vacsal.org.au/icat.html	Cultural awareness training	
McCaughy Health Centre	Onsite short course	Race, culture, indigeneity and the politics of disadvantage course. Professional development activity for those in research, policy or service delivery roles within Aboriginal and Torres Strait Islander health, social work, education and related areas. "This course provides access for those working/interested in a wide range of Aboriginal and Torres Strait Islander affairs to bodies of scholarship that address issues of cultural diversity, anti-racism, and identity politics. The course aims to change the way participants think about Aboriginal and Torres Strait Islander affairs." Two day course (\$660.00)	Cultural awareness and competency training	

Table 4.3: Other relevant training or professional development packages that might be useful (e.g. TAFE courses, Aboriginal and Torres Strait Islander mentoring programs)

	Source	Access	Brief information about the course
	Queensland Government – Training Queensland	Facilitator led	<p>Aboriginal and Torres Strait Islander Mentoring Program (IMP)</p> <p>Two competency based units from Community Services Training Package:</p> <ul style="list-style-type: none"> • CHCORG428A Reflect on and improve own professional practice (for mentoree) • CHCORG627B Provide mentoring support to colleagues (for mentor) <p>http://training.qld.gov.au/information/skilling-plans/community-services/Aboriginal and Torres Strait Islander-mentoring.html</p>
	Building Aboriginal and Torres Strait Islander Capacity (BIC)	Facilitator led	<p>Designs customised facilitation and training programs for Aboriginal and Torres Strait Islander mentors</p> <p>http://bicgroup.com.au/facilitation-and-training/</p>
	Synapse		<p>FSG (Freedom, Social Justice, Growth) Australia and Synapse introduced “The Deadly Connection” pilot program in July 2011, focussing on personal and professional development within a mentoring framework that benefits Aboriginal and Torres Strait Islander workers and volunteers from a broad range of industries and services.</p> <p>http://synapse.org.au/our-work/aboriginal-torres-strait-islander-support/deadly-connections.aspx</p>
	Mentoring Australia's Apprentices Project - MAAP	Facilitator led	<p>MAAP will target all industry sectors with the overarching aim of increasing the retention rates of Australian Apprentices in order to improve completion rates and support the supply of skilled workers in sectors/occupations with a current or emerging skills need. Aboriginal and Torres Strait Islander and people with a disability are mentioned as priority</p> <p>http://www.youthmentoring.org.au/program_details.php?pgDetails=NDg2</p>
	Nintiringanyi Cultural Training Centre	Facilitator led	<p>Various programs</p> <p>http://www.jaitn.com.au/member/nintiringanyi-cultural-training-centre</p>
	Tribal Warrior Aboriginal and Torres Strait Islander Mentoring Program	Facilitator led	<p>Designed to address recidivism rates in jail.</p> <p>http://tribalwarrior.org/training/Aboriginal and Torres Strait Islander-mentoring.html</p>
	Learning Network Queensland	Mobile delivery (facilitator led)	<p>Variety of courses</p> <p>http://www.lnq.net.au/category/aboriginal-torresstraitislander-courses/</p>
	Families4Families Network	Website	<p>Variety of resources available for further information on ABI including:</p> <ul style="list-style-type: none"> • Relevant websites • Relevant organisations • Resources List <p>http://families4families.org.au/resources/abi-relevant-resources/</p>
	Menzies School of Health Research	Website	<p>Variety of resources including:</p> <ul style="list-style-type: none"> • Flipcharts including Sniffing and the Brain, The Grog Brain Story, The Gunja (Yarndi) Brain Story, Sniffing Men's Flipchart, Sniffing Women's Flipchart and Mental Health Brain Story <p>http://menzies.edu.au/</p>

	Source	Access	Brief information about the course
	National Critical Care and Trauma Response Centre (Royal Darwin Hospital)	Website	DVD about mild head injury, translated into several NT Aboriginal languages. Currently being evaluated.
			http://www.adac.org.au/siteF/resources/brainstory/
	Acquired Brain Injury Outreach Service (ABIOS)	Website/DVD	ABIOS DVD Resource, "My Community, My Family - Three Aboriginal and Torres Strait Islander Families Share Their Knowledge of Brain Injury" http://www.health.qld.gov.au/abios/asp/atsi_program/atsi_resources.asp
	Brain Injury Matters (Victoria)	Website	Provides education for people with an ABI living in Victoria www.bim.org.au
	Brain Injury Network of South Australia	Website	Provides short videos on Brain Injury and Mild Traumatic Brain Injury http://www.binsa.org/



Chapter 5: Summary, conclusion and general recommendations

This project aimed to assist DisabilityCare to provide culturally relevant assessment to Aboriginal and Torres Strait Islander Australians with ABI. This document describes a culturally acceptable assessment framework, a culturally acceptable instrument toolkit, and a training and professional development framework for assessors. These components are intended to build the capacity for DisabilityCare staff to work effectively with Aboriginal and Torres Strait Islander people who are affected by ABI in the following ways:

- By enabling culturally acceptable assessment
- By providing managers with a framework for staff selection, training and professional development
- By providing a framework to operationalize the Principles of DisabilityCare for Aboriginal and Torres Strait Islander Australians with ABI

This project sought to engage key stakeholders from a variety of settings to participate in the development and review of the project deliverables. This participatory approach was highly successful, with individuals and organisations across QLD, NT and NSW engaging in the project, highlighting the urgent importance of ensuring that Aboriginal and Torres Strait Islander Australians have equal access to DisabilityCare. Despite the project's success, the brief time frame allocated for the conduct of the project meant that what was achieved represents only a fraction of what needs to be done in this important area. Also, having access to the DisabilityCare Assessment Toolkit would likely have significantly enhanced the project deliverables, and the investigators will review the deliverables once the DisabilityCare Assessment Toolkit becomes available.

Based on the results of the project, we make the following recommendations.

Assessment and planning framework

1. DisabilityCare should integrate the Planning and Assessment Framework into its Operational Guidelines
2. When conducting assessments with Aboriginal and Torres Strait Islander prospective participants, assessors should work in accordance with the four stages specified in the Planning and Assessment Framework: Engagement, Pre-Assessment, Assessment and Follow-up.

3. Training for assessors should be developed to ensure the Planning and Assessment Framework is reflected in practice

Instrument toolkit

4. DisabilityCare should remain committed to using valid assessment instruments. The culturally acceptable instrument toolkit described should be validated to enable culturally acceptable and accurate assessment of Aboriginal and Torres Strait Islander Australians with ABI.
5. The alignment of the instruments with the DisabilityCare Assessment Toolkit must be reviewed when the DisabilityCare Assessment Toolkit becomes available
6. Accredited training for assessors should be developed to ensure instruments are used appropriately with Aboriginal and Torres Strait Islander Australians with ABI
7. Further research should be conducted to develop instruments for Torres Strait Islander Australians

Assessor training and capacity building framework

8. DisabilityCare should ensure that all staff engage in training and ongoing formally accredited professional development in the area of cultural competence and awareness. Such training will assist in preparing service providers to deliver culturally competent assistance to Aboriginal and Torres Strait Islander Australians.
9. Accredited training must be developed to address the lack of training available for those working with Aboriginal and Torres Strait Islander Australians with ABI. Training must cover causes and impacts of ABI, and assessment and engagement protocols.

General recommendations

10. DisabilityCare should remain committed to employing or contracting Aboriginal and Torres Strait Islander Australian staff to undertake assessment of Aboriginal and Torres Strait Islander clients with ABI. This should include male and female individuals, and represent a variety of age groups, languages and cultures.
11. An Aboriginal and Torres Strait Islander review committee should be established, to hear appeals from Aboriginal and Torres Strait Islander prospective participants whose assessment for eligibility was unsuccessful. This is extremely important during the interim period in which no validated assessment instruments or approaches exist.

12. Awareness of ABI must be raised in DisabilityCare staff and Aboriginal and Torres Strait Island communities, to ensure that Aboriginal and Torres Strait Islander individuals with this disability are recognised and have access to DisabilityCare support.

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Appendix 1. Instruments assessing cognitive function

Name	Description	ABI specific	Availability	Reference (s)
Kimberley Indigenous Cognitive Assessment (KICA)	Created to assess cognitive function and identify dementia in Indigenous Australians aged >45. Includes sections on medical history, drug/alcohol use, depression, family report, caregiver report, and cognition, which fall under three sections, clinical information, cognitive data and information about the subject. The KICA-Cognition consists of 16 questions covering memory, comprehension, language abilities and executive functions.	N	Free	LoGiudice et al. (2006)
Montreal Cognitive Assessment (MoCA)	Assesses mild cognitive impairment. Includes short-term memory recall, visuospatial abilities, executive function, phonemic fluency, verbal abstraction, attention, concentration and working memory, orientation, and language. The MoCA is a 30-point, one page test administered.	N	Free	Nasreddine et al. (2005) Nasreddine (2013)
CogState assessment battery	Assesses cognitive function. Primarily a game-based computerized test consisting of tasks on both a computer and iPad. The CogState consists of seven tasks assessing attention, learning, reaction time and processing speed.	N	Must purchase	Dingwall et al. (2009)
Cognitive Assessment for Aboriginal People	Assesses cognitive function, the test was developed and used by the NT government. A questionnaire administered including questions relating to memory, orientation, environment, attention/sorting, money management, language skills, telephone use, safety and judgment, and perception.	N	Not freely available	Northern Territory Government ()
Frontal Assessment Battery	Created to assess dementias the Frontal Assessment Battery contains six simple tests of sequencing, behavioural inhibition, planning and frontal release signs.	N	Freely available	Dubois, Slachevsky, Litvan, and Pillon (2000)
Behaviour Rating Inventory of Executive Function (BRIEF)	The BRIEF-A is a standardized measure that assesses adult's executive functions and self-regulation in his or her everyday environment. Both a self-report and an informant report are used. 75 items within nine clinical scales: Inhibit, Self-Monitor, Plan/Organize, Shift, Initiate, Task Monitor, Emotional Control, Working Memory, and Organization of Materials.	N	Must purchase	(Roth, Isquith, & Gioia, 2012)
Dysexecutive Functioning Questionnaire	Component of the Behavioural Assessment of the Dysexecutive Syndrome (BADS). Was designed to assess dysexecutive functioning. It consists of a 20-item questionnaire describing behaviour associated with dysexecutive syndrome. Ratings of the frequency with which the particular behaviour occurs. Self-report and informant versions.	N	Must purchase	(Wilson et al., 2012)

The Queensland Test	Performance-based test of general cognitive capacity in Aboriginal Australians. The individual tests are constructed of portable coloured beads and tiles with the candidate required to construct, manipulate or recall a pattern. The six sub-tests are: sequential memory, visual memory, planning, abstract manipulation, pattern matching, design sequencing. Takes one hour to administer. Administered by a psychologist. Normative data not published.	N	Must purchase	Kearney and Davidson (2006) Value Edge (2012)
Behavioural Assessment of the Dysexecutive Syndrome (BADS)	Designed to assess components of the dysexecutive syndrome. Designed to assess brain injury. Six tasks and two questionnaires. The tasks require participants to plan, initiate, monitor and adjust behaviour in response to the explicit and implicit demands. Questionnaires do not contribute to the final score	Y	Must purchase	(Wilson et al., 2012)

Appendix 2. Instruments assessing functioning care and support needs

Name	Description	Mode of administration	ABI specific?	Availability	Reference (s)
Care and Needs Scale	Designed to measure care and support needs in Traumatic Brain Injury patients >16. The Care and Needs Scale is an 8-level categorical scale with two sections, Section 1 is a Needs checklist and Section 2 is a Support Level checklist measuring the extent of support needed.	Clinician report	Y	Available upon request	Tate (2011) Soo, Tate, Williams, Waddingham, and Waugh (2008) Soo et al. (2007) Tate (2004)
Inventory for Client and Agency Planning	Assesses level of care required for both children and adults with disabilities. A 16 page booklet completed by caregiver, parent, teacher, etc. Gains background information, measures Adaptive and Maladaptive behaviours with each item representing a statement of ability. A rating is given to determine level of support needed.	Trained assessor	N	Must purchase	"The Inventory for Client and Agency Planning" 2013)
Ongoing Needs Inventory (state based versions available, eg South Australia: Initial Needs Identification	Assesses mental health, functional ability and the degree of limitations associated with functional ability to determine the assistance the person requires. A two-tier assessment that begins with a screen before moving to an assessment. Functional Screening consists of 9 questions measuring domestic functioning, self-care functioning, challenging behaviour and cognitive functioning. Tier 2, Functional Assessment measures the same 4 domains using more comprehensive tools.	Trained Assessor	N	Available upon request	(University of Wollongong: Centre for Health Service Development)
Sydney Psychosocial Reintegration Scale	Assesses three functions of individuals after suffering a Traumatic Brain Injury, occupational skills, living skills and interpersonal relations. Two forms consisting of 12 item questionnaire, Form A assesses change since injury and Form B assesses current status.	Informant, clinician and self-report versions	Y	Available upon request	Tate, Hodgkinson, Veerabangsa, and Maggiotto (1999) Tate (2011) Kuipers, Kendall, Fleming, and Tate (2004)

Overt Behaviour Scale	Designed to measure the frequency, severity and impact of challenging behaviours as a result of ABI in patients aged >16. Behaviours are assessed through direct observation or interview with informant such as spouse or case manager. The behaviours are placed in 9 categories, verbal aggression, physical aggression against objects, physical acts against self, physical aggression against other people, inappropriate sexual behaviour, perseveration / repetitive behaviour, wandering / absconding, inappropriate social behaviour, lack of initiation.	Clinician by observation or through informant interview	Y	Freely available	Kelly (2010)
Functional Independence Measure and Functional Assessment Measure	Designed for rehabilitation settings to assess independence in motor (self-care, sphincter control, locomotion, transfers) and cognitive (communication/social cognition) functions. The Functional Independence Measure is an 18 item scale and the Functional Assessment Measure is a 12 item scale, a combined 30 item scale delivered four times to identify changes over the course of rehabilitation.	Trained Assessor, Clinician	N	Freely available	Wright (2000)
Brain Injury Community Rehabilitation Outcome Scales	Assesses patient independence with activity, social participation, and psychological components after returning to the community. Consists of three self-report questionnaires, Patient-Pre, Patient-Post, and Carer-Post to measure the patients function both pre and post brain injury.	Clinician, informant and self-report	Y	Available upon request	Powell, Beckers, and Greenwood (1998) Faleafa (2009)
Mayo Portland Adaptability Inventory-4	Designed to assist in the clinical evaluation of people during the postacute period following acquired brain injury. Consists of a 4 part 35 item scale completed by either the patient, professional staff or caregiver covering ability (physical, cognitive), adjustment (emotional), and participation (behavioural and social)	Clinician, informant and self-report	Y	Available upon request	Malec (2005)
World Health Organisation Disability Assessment Schedule	Designed to assess difficulties associated with health and disability. Three available versions, a 12 item, 24 item and 36 item self-administered questionnaire. The 36 item questionnaire covers Cognition, Mobility, Self-care, Getting along, Life activities and Participation.	Informant and self-report	N	Freely available	World Health Organisation (2013) Svestkova, Angerova, Sladkova, Bickenbach, and Raggi (2010)
Quality of Life in Brain	A 37 item self-report questionnaire using the likert scale to	Self-report	Y	Available	Truelle et al. (2010)

Injury	provide a profile of health-related quality of life covering six subscales, cognition, self, daily life and autonomy, social relationships, emotions and physical problems. The six subscales can be used separately or combined for an overall Quality of Life Profile.			upon request	von Steinbuchel et al. (2010)
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Appendix 3. Evaluation of cognitive instruments

Name	Validated for Aboriginal adults	Key ABI functions assessed	Relevance to Aboriginal people	Non-clinical administrator	Facilitate collaborative decision making	Brief and engaging	Reduced reliance on English	Strengths-based approach	Advantages	Disadvantages
Kimberley Indigenous Cognitive Assessment (KICA)	X	✓	✓	✓	✓	✓	✓	X	The only validated cognitive scale specifically for Indigenous Australians. Includes family report	Designed for older people (≥45 years). Ceiling effects when used with younger people
Montreal Cognitive Assessment (MoCA)	X	✓	X	✓	X	✓	X	X	Considered a good global cognitive screener by those interviewed.	Highly reliant on English literacy and numeracy.
CogState assessment battery	X	✓	✓	✓	X	✓	✓	X	Designed from work with Aboriginal people in Arnhem Land. Highly engaging game-based format	Requires a computer. Does not provide diagnosis of cognitive impairment.
Cognitive Assessment for Aboriginal People	X	✓	✓	✓	✓	✓	✓	X	Designed specifically for Indigenous Australians. Relevant to community life	Not validated.
Frontal	X	✓	X	✓	X	✓	X	X	Designed to be	Two tasks heavily

Assessment Battery									conducted easily at the bedside	reliant on English literacy. One task requires the administrator to touch the client.
Behaviour Rating Inventory of Executive Function (BRIEF)	X	✓	✓	✓	✓	X	X	X	Has ecological validity as refers to everyday functions. Allows self-report and informant ratings	Lengthy (75 items), some complex wording.
Dysexecutive Functioning Questionnaire	X	✓	✓	✓	✓	✓	X	X	Has ecological validity as refers to everyday functions. Allows self-report and informant ratings. Brief	Not freely available.
The Q Test	✓	X	✓	X	X	X	✓	X	Doesn't rely on English literacy and numeracy.	Not freely available. Out dated norms.
Waiting on information										
Behavioural Assessment of the Dysexecutive Syndrome	X	✓	X	✓	X	X	✓	X	Designed specifically for ABI	Relies on participant understanding a range of verbal instructions, lengthy (40 min)

Appendix 4. Evaluation of the functional and care and support needs instruments

Name	Validated for Aboriginal adults	Key ABI functions assessed	Relevance to Aboriginal people	Non-clinical administrator	Facilitate collaborative decision making	Brief and/or engaging	Reduced reliance on English	Strengths-based approach	Advantages	Disadvantages
Care and Needs Scale	X	✓	✓	✓	✓	✓	✓	X	Addresses relevant domains, brief	Clinician rated
Inventory for Client and Agency Planning	X	✓	X	✓	X	X	X	X		Lengthy, many irrelevant items, rigid structure
Ongoing Needs Inventory	X	✓	✓	✓	✓	X	✓	X	Comprehensive	Lengthy, some domains of relevance not captured, not ABI specific
Sydney Psychosocial Reintegration Scale	X	✓	✓	✓	✓	✓	X	X	Domains relevant to Aboriginal people, relevant community setting, brief	Some domains of relevance not captured
Overt Behaviour Scale	X	✓	✓	✓	X	X	✓	X	Relevant to ABI	Assesses challenging behaviour only
Functional Independence Measure and Functional	X	✓	✓	X	X	✓	✓	X	Brief	Deficits-based, clinician administered

Assessment Measure										
Brain Injury Community Rehabilitation Outcome Scales	X	✓	X	✓	✓	X	✓	X	Designed to be used in a community setting	Lengthy (38 items), many irrelevant items (e.g. writing letters)
Mayo Portland Adaptability Inventory-4	X	✓	✓	✓	✓	X	X	X	Comprehensive, Addresses relevant domains	Lengthy, deficits-based
World Health Organisation Disability Assessment Schedule	X	✓	✓	✓	✓	X	X	X	One question on subjective satisfaction with health. Addresses relevant domains	Lengthy, deficits-based
Quality of Life in Brain Injury	X	✓	✓	✓	✓	✓	✓	✓	Only instrument using a strengths-based subjective satisfaction rating	Some domains of relevance not captured