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# National NDIS Consultation Report

June – September 2012

*An analysis and record of the views and suggestions of key stakeholders across Australia on how best to ensure that the NDIS/NIIS eligibility and assessment processes will meet the needs of persons living with an acquired brain injury.*

**Prepared by Dr. Derek Brookes**

Policy Officer, Brain Injury Australia

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## Executive Summary

This report provides a [set of recommendations](#) on how the National Disability Insurance Scheme (NDIS) can ensure that it conducts fair, reliable and objective assessments of both the eligibility and support needs of people living with an [acquired brain injury \(ABI\)](#).

These recommendations are based upon the outcomes of a 4-month national consultation conducted by Brain Injury Australia and its member organisations. This process involved 192 consultees and 20 consultation sessions held in 5 states (including both urban and rural locations). A complete [record of these outcomes](#) and a [list of the consultees](#) can be found in the appendices.

This consultation has revealed a range of serious shortcomings in current approaches used to assess the eligibility and support needs of people living with ABI. Hence, the recommendations here—most of which are consistent with the [Productivity Commission's 2011 report](#)<sup>1</sup>—entail that the NDIS will need to remove or reform many existing practices.

For example, it is recommended that the assessment of a person with ABI should:

- involve a multi-disciplinary collaboration between all those involved in his/her life;
- consist of multiple tools that can be applied as needed;
- be undertaken periodically, over time, and in diverse functional contexts;
- be able to distinguish between ABI and mental health issues;
- be available within the criminal justice system;
- include an assessment of the ongoing support needs of carers;
- address the practical difficulties and costs associated with remote areas;
- be culturally appropriate for Indigenous people; and
- include an easy, clear, and transparent appeals process.

The consultations focused primarily on eligibility and assessment, however the consultees also raised a number of other issues about the NDIS (e.g. the impact of a market-based system). Recommendations relating to these issues are included in a separate section.

Brain Injury Australia and its member organisations are available both to discuss or clarify this report and have further input into the NDIS planning around assessment and eligibility.

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<sup>1</sup> Productivity Commission (2011): *Inquiry Report – Disability Care and Support*, No. 54 (Australian Government).

# 1. Introduction

The National Disability Insurance Scheme (NDIS) is a once-in-a-lifetime opportunity. It aims to provide long-term person-centred care and support to all Australians with a significant and ongoing disability. The NDIS therefore has the potential to meet the support needs of many Australians who have an acquired brain injury (ABI). Unfortunately, the experience of Brain Injury Australia and its member organisations is that the needs of people living with an ABI are often overlooked and misunderstood by disability services, health professionals and governments. For this reason, Brain Injury Australia and its member organisations have launched a campaign to make sure that decision-makers are informed about what it would take to get the NDIS right for people with an ABI.

There are many design issues that need to be addressed. But this campaign has focused on making sure that decision-makers are fully informed about *what it would take for the NDIS assessment process to be able to recognise, with accuracy and fairness, when a person living with an acquired brain injury requires NDIS-funded support, and the kind and level of supports they will need over time.*

There are good reasons for making this our priority. With an appropriate assessment that is sensitive to the needs of people with cognitive impairment, it will be possible to map out the right supports a person living with ABI is likely to need. The system will not rely so extensively upon crisis or acute care; and there will be less need to address the social and economic costs of untreated and unmanaged ABI, such as imprisonment, unemployment, homelessness, relationship breakdown, substance misuse, and mental health issues.

To this end, Brain Injury Australia and its member organisations have—over the past 4 months—conducted a national consultation on eligibility and assessment for people living with ABI. We have collected the views of [192 consultees](#) in New South Wales, South Australia, Western Australia, Victoria and Tasmania. This process involved 20 consultation sessions and a number of written submissions. Participants included people with an ABI and their carers, as well as disability services, support workers and health professionals who work directly with people living with ABI. The result has been a rich and detailed record of carefully considered, creative, passionate and often original suggestions.

Brain Injury Australia and its member organisations hope that the list of recommendations in this report—together with the recommendations contained in both of its submissions to the Productivity Commission—will be taken into account by decision-makers as they seek to design an eligibility and assessment process that meets the needs of every disability group.

## 2. Acquired Brain Injury

Acquired brain injury (ABI) refers to any damage to the brain that occurs after birth (with the exception of Foetal Alcohol Spectrum Disorder - FASD). That damage can be caused by an accident or trauma, by a stroke, a brain infection, by alcohol or other drugs or by diseases of the brain like Parkinson's disease.

ABI is common. Over 500,000 Australians have an ABI. Three out every four of them are aged under 65. As many as two out of every three of these people acquired their brain injury before they turned 25. Three out of every four people with acquired brain injury are men.

The leading cause of ABI is stroke—where the supply of blood to the brain is stopped by a clot or bleeding. It often results in physical disability as well as changes in a person's thinking and emotions. Around 60,000 new strokes occur every year - a number that's growing as Australia's population ages. Strokes normally occur in older age people, but around one in every five strokes happens to a person aged under 55. The next largest cause of ABI is an accident or trauma – known as traumatic brain injury, or “TBI”. Such an injury is a result of force applied to the head. Over 22,000 Australians were hospitalized as a result of a TBI in 2004-2005. Most of those Traumatic Brain Injuries—over two in every five—were caused by a fall, nearly one in three was due to a motor vehicle accident and one in six was caused by an assault.

Acquired brain injury is distinct from intellectual disability. People with a brain injury may have difficulty controlling, coordinating and communicating their thoughts and actions but generally retain their intellectual abilities.

Brain injury has dramatically different effects on different people. The brain controls every part of our being: physically, intellectually and emotionally. When the brain is damaged, some other part of ourselves will also be affected. Even a mild injury can result in a serious disability that will interfere with a person's daily functioning and personal activities, often for the rest of their life. While the outcome of the injury depends largely on the nature and severity of the injury itself, appropriate treatment plays a vital role in the level of recovery.

The significant changes in personality and behaviour of a person with a brain injury can be difficult for families to cope with. It can be hard for those not immediately affected to understand what a person with ABI and their family is going through. Family members often cope with the person's injury in different ways and some may not even acknowledge that the injury exists. Carers often find they have to support family members in addition to the person with an ABI. This can mean that it is harder for carers to deal with their own grief and personal needs. Carers may also be challenged by other family members about the care they are providing. Combined with the demands of caring for a person with a brain injury this can result in carers suffering chronic stress.<sup>2</sup>

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<sup>2</sup> The material in this section is adapted from Brain Injury Australia's website: [<http://goo.gl/r4Ci1>]

### 3. Consultation Method

Consultation sessions were arranged by the organisational members/member organisations of Brain Injury Australia's Executive Officer Network (EO Network): that is, the Brain Injury Association of NSW, Synapse (Brain Injury Association of QLD), the Brain Injury Network of SA Inc., the Brain Injury Association of Tasmania, BrainLink Services (Victoria), and Headwest (Brain Injury Association of WA).

Most regions held at least two sessions: one for people with ABI and their carers; and the other for professionals who were, in some way, involved in assessing the support needs of people with ABI and/or its consequences—although the meetings occasionally contained a mixture of both groups.

The sessions, each usually lasting from 2-3 hours, used the same procedure:

1. Following introductions, the facilitator, Dr. Derek Brookes, would set the context for the consultation by briefly introducing the government's NDIS design process and Brain Injury Australia's NDIS campaign.
2. The facilitator would then pose two discussion questions to the group, and type up their responses. This record would be immediately displayed up on a screen. This allowed the attendees to see exactly what had been recorded by the facilitator, and to make any corrections or additions to the record within the meeting itself.
3. At the end of the session, the facilitator would go through each point that had been recorded and ask the group if they would like to amend or add anything.
4. The consultation record was then emailed to all the attendees the session, again inviting them to amend or add to the record if they wished.

Many of the points that were 'voiced' in the consultation sessions were typed up virtually 'word for word' by the facilitator. However, for the most part, no individual names were attached to any single point nor were quotation marks used.<sup>3</sup> This approach was taken for the following reasons: first, many of the points arose out of a discussion, and so 'single person attributions' would have been incalculable or in any case unwarranted; second, no attendee indicated that they disagreed with the final version, and so each point could, with justification, be presented as the 'consensus position' taken by the relevant group (allowing, of course, for the possibility of 'unvoiced' or subsequent disagreements). The complete record of these consultation sessions is presented in [Appendix B](#).

Finally, a draft version of this report was emailed to all the consultees inviting them to suggest revisions—most of which were subsequently incorporated into the final text.

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<sup>3</sup> There were only a few exceptions: (1) In one case, the consultation session (a teleconference) was attended by two people with ABI. Because they related various aspects of their lived experience, their respective points were attributed to each person by using their initials. (2) Individual written responses were all given attributions and quotation marks.

## 4. Recommendations

The following is a list of recommendations that are directly based upon—and referenced to—the record of national consultation outcomes, as presented in [Appendix 2](#).

The purpose of this list is to make the ideas contained in the consultation record more readily accessible and useful to decision-makers and other readers. This has been done by:

- reducing the inevitable duplication;
- re-organising the record into distinct topics;
- adding context to aid understanding (e.g. filling out acronyms); and
- re-framing all the contributions into positive recommendations (i.e. what the NDIS should put in place, rather than what isn't being done at the moment).

In addition, these recommendations provide references to the Productivity Commission's views on eligibility and assessment (see [Appendix 3](#)). Where any aspect of a recommendation corresponds to (+) or conflicts (-) with the Productivity Commission's position, this is indicated by supplying a reference to the relevant text in [Appendix 3](#) (e.g. "PC: +7.2a").

Please note that each reference is 'hyperlinked', so that if the link is clicked, the reader can be taken directly to the relevant record in [Appendix 2](#). To return to the relevant recommendation, please right-click and select 'previous view', or press 'alt-left arrow' (for PCs), or 'command-left arrow' (for Macs).

Finally, the vast majority of contributions were focused upon eligibility and assessment. However, the consultees also made a number of valuable suggestions regarding more general issues relating to the NDIS. These are therefore included in the list of recommendations under 'General Issues'.

## ELIGIBILITY & ASSESSMENT

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### 1. Philosophy of assessment

#### RECOMMENDATION 1.1 — Hope and recovery

The assessment process needs to engender a sense of hope and recovery in the person with ABI and their family, enabling them to reclaim and re-discover their life, walking along side them as they do so. [5.18, 20.19b, PC: +7.2a]

#### RECOMMENDATION 1.2 — Quality of life

The assessment should include not merely the identification of ‘basic survival’ support needs, but also what a person needs to enhance their quality of life. [12.16, 14.17]

#### RECOMMENDATION 1.3 — Life goals and aspirations

The assessment should not be based upon the philosophy that ‘people should not expect too much out of life’. It should identify all those support needs that will ensure that people with ABI can reach their life goals and aspirations. [15.28, 18.20, PC: +7.1d]

#### RECOMMENDATION 1.4 — Person centred approach

The assessment should look at the person with a disability as a *person* first, not as a *disability*. Likewise, it should also look at the carers as *persons* first, not as *carers*. In other words, it should use a ‘person-centred approach’. [9.24, PC: +7.2d]

#### RECOMMENDATION 1.5 — Respect and dignity

People with a disability are some of the most vulnerable members of our society. A society is judged by the way it treats its most vulnerable members. In most cases, we are failing people with a disability miserably. So the NDIS needs to think in a way that will transform society so that people with a disability are able to be a part of society and to be treated with respect and dignity. [19.14, 19.15]

### 2. Raising awareness

#### RECOMMENDATION 2.1 — Ensure that access to the assessment process is equitable

People with ABI and their carers may not have the capacity or the information required to request or apply for an assessment. But every person with a disability should have the same opportunity to be assessed. Hence,

- (a) information about the assessment process should be made publicly available and in a form that is accessible by and specific to persons with ABI and their carers (e.g. taking into account memory loss, limited comprehension, the ‘lived experience’ of carers who are often struggling to survive on a day-to-day basis, and to cope with what has happened to their loved one, etc.); and

- (b) independent monitoring should be put in place to identify (i) individuals or groups who are not being assessed (e.g. people with ABI who are homeless or in prison) and (ii) any obstacles that are preventing equitable access to the assessment process. [1.5, 3.1, 5.20, 7.7, 8.15, 12.25, 14.2, 20.11, PC: 7.3di]

**RECOMMENDATION 2.2 — Raise awareness about ABI in the general population**

The general public needs to become better informed about:

- (a) the multiple causes of ABI (e.g. stroke, trauma);
- (b) the impact and consequences of ABI (e.g. loss of social skills, the differences between ABI and intellectual disability); and
- (c) the support needs that people with ABI are likely to have.

This is partly so that people who are currently unaware that they—or someone they know—have an ABI will be more likely to request a proper diagnosis or an assessment of their support needs. [12.23, 14.9, 18.27]

**RECOMMENDATION 2.3 — Educate health professionals about ABI and how to refer patients to an assessment**

Many in the medical profession do not understand ABI, confusing it with intellectual disability or minimising the symptoms (e.g. it's 'just concussion'). In addition, it is likely that GPs and other health professionals will become key points of referral to the NDIS for individuals with ABI. Hence, resources should be made available to ensure that GPs and other health professionals are equipped with:

- (a) the skills and understanding needed to identify the symptoms of ABI; and
- (b) an awareness of the procedures required to refer a patient to the NDIS for assessment [1.5, 3.11, 10.10, 11.28, 17.7, 20.11, 20.23]

**RECOMMENDATION 2.4 — Give support workers ABI-specific training and access to assessment outcomes**

Support workers do not have an adequate understanding of ABI. Consequently, they are not able to provide adequate rehabilitation, tending instead to focus on 'mere' attendant care (e.g. expecting muscle use to make the client 'stronger', when, because of the ABI, there is muscle wastage and the loss of coordination). Hence,

- (a) support workers for people with ABI should be given ABI-specific training;
- (b) the assessment of a person's functionality (not merely physical but also cognitive and behavioural) should be passed on to support workers. [3.4, 11.18]

**RECOMMENDATION 2.5 — Educate service providers about how ABI can lead to challenging behaviours**

Disability service providers—especially co-ordinators/managers—should be made aware of the 'challenging behaviours' or 'behaviours of concern' that can result from ABI, as this may impact on their assessment of eligibility for programs and services. [10.20]

### 3. Advocacy and assessment

**RECOMMENDATION 3.1 — Identify the need for advocacy**

Assessments should include identifying the person's need for independent advocacy—that is, someone who can 'stand beside and with the client'. [9.31]

**RECOMMENDATION 3.2 — Ensure that advocacy is adequately funded**

Systemic and individual advocacy can provide an independent means of monitoring and evaluating the NDIS assessment process, which is essential to safeguarding and enhancing its accuracy, objectivity and fairness. Hence, the government should ensure that, for each state and territory, there are independent sources of funding available to sustain effective systemic and individual advocacy for people with ABI. [2.19, 2.20]

**RECOMMENDATION 3.3 — Refer non-eligible clients to an advocacy agency if required**

If a person with ABI is deemed not eligible for NDIS funding, then they should be referred to an advocacy agency that can assist them if they wish to appeal. [20.7]

### 4. A multidisciplinary approach to assessment

**RECOMMENDATION 4.1 — Employ multi-disciplinary teams to conduct the assessment**

Multidisciplinary teams work best in carrying out an assessment of people with ABI, not individual assessors working in isolation. Hence, the assessment should involve an open collaboration between all those involved in the life of the person with ABI, including:

- (a) the person with ABI;
- (b) family, friends and others who know them well;
- (b) relevant health professionals (e.g. neuropsychologists, rehabilitation physicians, occupational therapists); and
- (c) service providers and organisations that have the specialist skills, knowledge and 'hands-on' experience in enabling people with ABI to meet their life-long goals and participate in 'real life' scenarios (e.g. return to work, community rehabilitation, education support, identifying adaptive strategies, etc.). [5.10, 7.1, 9.10, 8.20, 8.25, 11.25, 12.18, 12.19, 17.1, 17.8, 20.10, 20.25, PC: +7.2b, 7.2f]

**RECOMMENDATION 4.2 — Conduct a 'whole-of-life' assessment**

Without a comprehensive 'whole-of-life' assessment that has proper links to services, a person with ABI and their families are more likely to experience a 'second crisis' (e.g. relationship breakdown, alcohol and/or other drug dependence, debt problems, etc.). Hence, there should be a multi-disciplinary approach to assessment to ensure that:

- (a) the links between a person's cognitive, functional and physical impairments—as well as their actual and potential living environments—are captured; and

- (b) the support needs that result from this ‘whole-of-life’ assessment are properly resourced. [9.17, 10.2, 18.13, 20.16]

**RECOMMENDATION 4.3 — Give decision-making power to the multidisciplinary team**

The decision-making power in any assessment should reside with the multidisciplinary team, with the assessor playing an ‘oversight’ or ‘review’ role to ensure the accuracy and fairness of the decisions made. This would better reflect the person-centred philosophy behind the NDIS. [15.23]

**RECOMMENDATION 4.4 — Honour the recommendations of a multi-disciplinary team**

If recommendations are produced by a multi-disciplinary team—with access to all dimensions of the person with ABI’s life—then these should be honoured by NDIS decision-makers. [3.20, 3.23]

## 5. The assessor’s qualifications and skills

**RECOMMENDATION 5.1 — Ensure that assessors have ABI-specific training/qualifications**

To ensure that the assessment of people with ABI is accurate, assessors need to have specific training, education and (where available) accreditation in:

- (a) how to distinguish between ABI and intellectual disability;
- (b) how to measure cognitive impairment and its likely impact on a person’s functionality (but see Recommendation 5.2 below);
- (d) how to unearth the ‘hidden impact’ of ABI, including details that a person with ABI may not be aware of themselves (e.g. loss of initiative);
- (e) the ‘lived experience’ of people with ABI and their families; and
- (f) how to tailor the delivery of the assessment to meet the communication needs of the person with ABI; and
- (g) the range of ABI-specific services and health professionals available in the region.

It is not sufficient merely to provide ‘paper-based’ training or to include ‘instructions’ or ‘explanations’ for the assessor in the assessment form. [5.3, 5.11, 5.12, 7.25b, 8.19, 10.19, 11.26, 12.6, 12.20, 12.22, 13.4b, 14.14, 15.9b, 17.4, 20.22, PC: 7.4a]

**RECOMMENDATION 5.2 — Cognitive deficits and links to functionality must be assessed by qualified professionals**

Any assessment of a person’s cognitive deficits and/or the impact of cognitive limitations on their functionality must be carried out by qualified professionals, such as neuropsychologists, rehabilitation physicians and suitably skilled and experienced occupational therapists—rather than by ‘generic assessors’. [2.5, 6.4, 10.11, 20.25]

**RECOMMENDATION 5.3 — Assessors must be accredited health professionals**

Given the complexity and subtlety of ABI, assessors need to have the kind of background knowledge that will enable them to ask the right questions of health professionals. This means that any assessor of a person with ABI will need to be an accredited health professional, with specific training in ABI. [7.25a, 9.2, 9.5]

**RECOMMENDATION 5.4 — Set up a quality assurance framework for assessors**

To ensure the objectivity, consistency and reliability of the assessments, assessors should—in addition to training and accreditation—receive mentoring, monitoring, and limited appointment periods. [6.10, 11.10, 11.24, 13.4a, 17.11, PC: +7.4d]

**RECOMMENDATION 5.5 — Enable assessors to avoid imposing their own agendas and prejudices**

Those involved in the assessment of people with ABI should be made aware of and trained in how to identify and ‘neutralise’ the impact that their own agendas or prejudices may have on the outcome of assessments—in particular, the way in which:

- (a) certain assessment tools can be selected to achieve a desired outcome;
- (b) blame for (some aspect of) an ABI can be placed on pre-morbid issues, even when there is no evidence that it is causally related (e.g. a person with a pre-existing alcohol addiction acquires a brain injury as a result of a car accident);
- (c) administrative justifications can be illegitimately used to ‘screen people out’ (e.g. ‘out of catchment area’, ‘lack of resources’, ‘lost documentation’);
- (d) hidden prejudicial judgments and sweeping generalisations can distort the objectivity of the assessment (e.g. ‘they are all guilty until proven innocent’, a client is labelled as ‘violent’ due to an isolated incident in the acute stage); and
- (e) assessments can discriminate in favour of people with ABI who are easy to assess and support and against those who are more complex (e.g. clients with challenging behaviours, less of an ability to self-manage funding, or requiring long-term assistance and monitoring);
- (f) an assessor can easily impose their own values in the process of trying to identify the positive goals or outcomes the person with ABI is hoping to achieve [8.3, 8.13, 8.14, 9.29, 10.8, 12.12, 14.23, 16.11, 17.11]

## **6. The independence of assessors**

**RECOMMENDATION 6.1 — Financial rewards must not be given to assessors for reducing a client’s funding**

The remuneration of assessors should not be linked to the outcomes of their assessment. Specifically, assessors should not receive bonuses on the grounds that their assessments have led to a decrease in their clients’ NDIS funding packages. [1.3b]

**RECOMMENDATION 6.2 — Assessors must not be an employee of the client or any relevant service provider**

To avoid any conflict of interest, assessors should be financially and operationally independent of both the client and any organisation that is (or is likely to be) providing the client with a service as a result of the assessment. [1.4, 6.8, 8.5, PC: +7.4b]

**RECOMMENDATION 6.3 — Assessment reviews must be conducted by independent assessors**

When an assessment review is conducted, assessors from the same organisation are likely to protect each other by supporting the findings of previous assessments. An independent assessor should therefore be contracted to conduct any assessment review. [8.5, 11.24, 17.11]

## **7. The assessor's relationship to the person with ABI**

**RECOMMENDATION 7.1 — Assessors need to engage with clients over time**

An assessor of a person with ABI may need to engage with them over a long duration in order to produce a more reliable and effective assessment. For example:

- (a) to understand the responses of a person with ABI and pick up on issues such as exaggeration or underestimation, an assessor needs to understand the 'base-line' issues and the episodic nature of the person's ABI—which can only be gained by engaging with them over time;
- (b) a person with ABI may not be used to making decisions, creating long-term plans, or identifying their hopes and dreams; so an assessor must be prepared to take the time needed to enable them to achieve maximum control over their lives. [4.11b, 5.11, 5.24, 9.3]

**RECOMMENDATION 7.2 — Ordinarily, assessors should not have a pre-existing relationship with the client**

The principle of using assessors who do not have a pre-existing relationship with the person with disability should be applied 'across the board', given the potential for conflict of interest or unfair advantages (without losing the flexibility needed to allow for special cases). [16.13, PC: +7.4c]

## **8. The assessment tools**

**RECOMMENDATION 8.1 — Assessment tools must be evidence-based**

NDIS assessment tools for people with ABI must be designed and/or selected by neuropsychologists, rehabilitation physicians, occupational therapists with expertise and experience in ABI, and other relevant health professionals; and if there is sufficient evidence that a new tool is more effective than an existing tool—e.g. in terms of validity and/or reliability—then it should be included in the assessment process. [7.10, 13.10, 20.25, PC: +7.3a, +7.9, +7.10]

**RECOMMENDATION 8.2 — Assessment tools must be portable**

The assessment process must be fair and equitable: for example, it must be consistent across and portable between all states and territories. [3.24, 9.1, 10.4, 18.11, PC: +7.3d]

**RECOMMENDATION 8.3 — A tool that identifies the need for more specific assessments may be useful**

It may be useful to have a 'screening tool' that highlights basic cognitive, functional and physical issues that can then be referred to more specific assessments. [9.15]

**RECOMMENDATION 8.4 — The assessment should employ multiple tools as required**

Assessing the support needs of person with ABI requires a comprehensive clinical assessment, consisting of multiple tools that can be applied, as needed: that is,

- (a) functionality assessments, within relevant functional settings;
- (b) neuropsychological assessments;
- (c) pre-morbid assessments (i.e. of social problems, nutrition, etc.); and
- (d) assessment of change over time. [2.5, 6.5, 7.12, 7.15, 13.11, 15.2, 15.4, PC: +7.8a, -7.8b]

**RECOMMENDATION 8.5 — The assessment of functionality and participation should make use of OT assessments**

Neuropsychological assessments of people with ABI in the acute setting are essential. But they should not be the only (or the most important) kind of assessment used in a post-acute community setting. For example, relevantly skilled and experienced occupational therapists would be able to identify the impact of cognitive limitations on the person's everyday activity and participation experiences—and thus identify their associated support needs—through a combination of:

- (a) observing function in the home;
- (b) gathering interview data from the person and their family/support team; and
- (c) using specific portable OT assessment tools, such as the *Assessment of Motor and Process Skills* (AMPS) and the *Allen Cognitive Levels Screen* (ACLS). [2.21, 7.12, 7.13, 9.16, 12.11, 20.25]

**RECOMMENDATION 8.6 — Post-acute neuropsychological assessors should be employed by the assessing agency**

If a neuropsychological assessment has not already been carried out within acute care, then, where appropriate, it should be undertaken by neuro-specialists who are directly employed by the assessing agency for this purpose. [10.11]

**RECOMMENDATION 8.7 — Assessment tools must be ABI-specific**

The tools used to assess people with ABI must be specific to this disability, rather than generic. For example,

- (a) many diagnostic tools cannot identify particular types of ABI<sup>4</sup>;
- (b) generic disability assessment tools—such as the *Inventory for Client and Agency Planning* (ICAP)—tend to focus on physical and intellectual disability, and so are likely to ‘overlook’ aspects that are unique to ABI. [2.5, 2.17, 3.21, 5.4, 5.22, 5.23, 7.2, 12.10, 20.18c, PC: +7.8a, -7.8b]

**RECOMMENDATION 8.8 — Consideration should be given to using the MPAI in post-acute settings**

The *Mayo-Portland Adaptability Inventory* (MPAI)—alongside a range of other tools—should be considered as a tool for assessing people with ABI in a post-acute setting. A paediatric version is also available; and it fits with the *International Classification of Functioning, Disability and Health’s* participation domain.<sup>5</sup> [7.16, 9.13, PC: +7.1a]

**RECOMMENDATION 8.9 — Assessment tools must not be discriminatory**

The assessment tools must be tailored to ensure that they take into account age-related issues, gender and cultural and linguistic diversity—whilst also recognising that each individual must be taken ‘as they are’. [3.25, 9.32, 15.4]

**RECOMMENDATION 8.10 — Existing tools (e.g. FIM-FAM) are not sufficient for people with ABI**

In relation to people with ABI, the NDIS should not rely upon the use of existing assessment tools either in isolation or applied to every stage or context. For example:

- (a) the *Functional Independence Measure* (FIM) stops measuring the impact of ABI after 3 months (‘the ceiling effect’), so it is best used in an acute setting; there is evidence that the cognitive items on FIM are not accurate; and FIM is unable to capture changing support needs;
- (b) the *Functional Assessment Measure* [FAM] does not add much to FIM;
- (c) the *Functional Independence Measure for Children* [WeeFIM] reaches a ceiling at the age of 7, but the symptoms of ABI may not become apparent for many years;
- (d) the *Care and Needs Scale* [CANS] is ABI-specific, but it is not sufficient on its own;
- (e) the *Combined Application Process* (CAP) in WA is a ‘deficit’ model: it asks for a narrative and emotions that will exhibit the worse case scenario. [7.9, 7.14, 8.17]

**RECOMMENDATION 8.11 — Language should be adapted to meet the needs of the client**

The assessment tools and their delivery must take account of the varying degrees of education and understanding of the person with ABI and their families and other support persons. For example,

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<sup>4</sup> For example, the degree of microscopic injury in diffuse axonal injury—a frequent result of traumatic acceleration/deceleration or rotational injuries—commonly proves opaque to CT scans.

<sup>5</sup> See Productivity Commission (2011): pp. 309-11. Cf. Lexell J., Malec J.F., Jacobsson L.J. (2012) “Mapping the Mayo-Portland adaptability inventory to the international classification of functioning, disability and health”, *J Rehabil Med.* Jan; 44(1): pp. 65-72.

- (a) any relevant literature, including the assessment forms, must be available in Easy English versions, using simple dialogue, diagrams and photos; and
- (b) the assessors must be able to use easy-to-understand verbal dialogue (e.g. “I had to communicate with someone for whom communication was an overwhelmingly exhausting and confronting activity”). [20.11, 20.18b, PC: +7.3b]

## 9. Key elements to be identified in the assessment

### RECOMMENDATION 9.1 — Identify strengths, not merely deficits

Assessments should identify the strengths and abilities of a person with ABI, not merely their impairments or deficits. [2.12, PC: +7.2f]

### RECOMMENDATION 9.2 — Identify how much someone knows about their own situation

Assessments should identify the insight that people with ABI have into their own condition and experience. [5.9]

### RECOMMENDATION 9.3 — Identify supports and adaptive strategies that are comprehensive and aspirational

Rather than focusing on medical issues (e.g. bowel movements) or only one particular support need (e.g. accommodation), assessments should be comprehensive or holistic. They should provide precise details about the supports and adaptive strategies that are required to enable a person with ABI to achieve as fully as possible their own life-goals and aspirations (e.g. living independently, participating in the community, further study, work, sexuality, relationships, learning how to talk to their children again, etc.). [5.10, 8.10, 8.11, 9.3, 9.10, 11.4, 11.9, 12.3, 13.13, 14.8, 17.8, 18.4, 19.18, PC: +7.1c-d]

### RECOMMENDATION 9.4 — Identify the existence and impact of challenging behaviours

The assessment tool and the assessor must be able to measure not only functionality but also ‘challenging behaviours’ or ‘behaviours of concern’. Specifically, the assessment should identify:

- (a) if a person with ABI’s behaviour is preventing them from being able to access services (e.g. in a small rural area, a person with ABI may develop such a ‘bad reputation’ with the few services available, that they refuse to engage with them);
- (b) strategies that will ensure that they *can* access a service (e.g. providing a higher level of funding as an incentive for services, or linking the person with an advocate who can engage and educate the services on their behalf, etc.). [6.2, 15.4, 16.11]

### RECOMMENDATION 9.5 — Identify all support needs, even those currently met by carers

When assessing the support needs of a person with ABI, the assessor needs to identify what their holistic needs are *apart from* or *independently of* the support that is currently provided by existing carers. This ensures that if the carers (or their circumstances) change, the person with ABI will still be able to access the support needs they require, and they will not need to undertake a new assessment. [16.2, 18.6]

**RECOMMENDATION 9.6 — Identify necessary supports, even if previously unknown or unavailable**

The assessment should identify supports (e.g. equipment) that will improve a person's quality of life or help them to achieve their long term goals and aspirations, even if:

- (a) the person with ABI or their family/carers are unaware that these exist; and/or
- (b) those supports have not previously been available for whatever reason. [16.8]

**RECOMMENDATION 9.7 — Identify a person's need for someone who can act on their behalf**

The assessment process must be able to identify when a person with ABI may not have the capacity to acknowledge their disability, to be aware of their support needs, to initiate requests, to engage with medical/support systems and staff, and/or to give their informed consent. To manage such cases the assessment process should identify a 'key contact person' (with, if possible, the consent of the person with ABI) who has the following characteristics:

- (a) they are living with or have an ongoing relationship with the person with ABI;
- (b) they can be called on a regular basis by case managers or support services;
- (c) they can arrange, on behalf of the person with ABI, for them to undertake assessment reviews, receive support services, and so on;
- (d) they can engage with and are trusted by the person with ABI;
- (e) they have a good understanding of ABI;
- (f) they know how to navigate the system;
- (g) they are culturally appropriate for the person with ABI; and
- (h) they are actively monitored (e.g. by a Local Area Coordinator) to ensure that they are acting in the best interests of the person with ABI.

The funding for this person should not come out of the funding package that is required to meet the support needs of the person with ABI. People should not be disadvantaged *just because* they have this need. [10.21, 11.27, 14.4, 16.5, 16.6, 20.19d]

**RECOMMENDATION 9.8 — Identify travel costs**

The cost of travel to access a disability service (or to provide a service) should not be taken out of the funding required to meet a persons support needs. So:

- (a) the assessment should identify these travel costs and ensure that they are included in the total funding package; and
- (b) any NDIS regulation of 'unit costs' should factor in travel costs for the service provider. [16.14]

**RECOMMENDATION 9.9 — Identify the capacity to self-manage funding**

The assessment should be able to accurately and fairly identify when a person is unable—due to their disability—or unwilling to self-manage their funding. [16.16]

**RECOMMENDATION 9.10 — Identify preferences for the mix between family and paid care**

The assessment should identify ‘substitution possibilities’ in the provision of care: for example, if a person with a disability would prefer that a family member attend to certain kinds of needs (e.g. dressing), but that cannot be done unless activities that would otherwise be carried out by the family member are performed (e.g. cleaning), then it should be possible for the NDIS to fund someone to do the latter. [16.15]

**RECOMMENDATION 9.11 — Connect them to relevant support services**

The assessment process should assist the person with ABI and carers to locate services that will meet the needs that have been identified. [15.5, 17.3, 17.6]

**RECOMMENDATION 9.12 — Identify discriminatory situations and possible solutions**

The assessment should identify:

- (a) potential barriers to the person with ABI receiving ‘equal opportunities’ (e.g. access to rental properties, the cost of housing or car modifications, discrimination in the workplace or recruitment practices, etc.); and
- (b) how best to remove or avoid these barriers—for example, by linking up with an advocate. [17.13]

**RECOMMENDATION 9.13 — Identify ‘gaps’ that are preventing maximum independence**

Even when people with ABI are assessed as functioning well across a range of broad areas, there can remain small but significant ‘gaps’ in their capacity to access services and live as independently as possible (e.g. not being able to write an email). The assessment should ensure that these ‘gaps’ can be identified. [18.19]

**RECOMMENDATION 9.14 — Identify when health is at risk due to social factors**

The assessment tools should have the capacity to identify risk factors for poor social determinants of health, as this may reduce the risk of family breakdown, poverty and incarceration. [20.2]

**RECOMMENDATION 9.15 — Distinguish disability-related needs from socio-economic disadvantage**

The assessment must be able to distinguish between (a) support needs that are clearly linked to a person’s disability, and (b) needs that arise from pre-existing or otherwise unrelated socio-economic disadvantage. [13.6]

## 10. Assessing eligibility for NDIS funding

**RECOMMENDATION 10.1 — The determination of eligibility must be equitable**

The assessment/eligibility decision-making process should be fair and consistent, not favouring those who ‘shout the loudest’, as in the current system. [10.7]

**RECOMMENDATION 10.2 — Determining eligibility need not require a detailed assessment of support needs**

The basic facts about a person's condition should, in most cases, be sufficient to demonstrate that a person is *eligible* for NDIS funding (e.g. someone who has been run over by a train, lost both legs and has little cognitive capacity should not need to specify how these disabilities are affecting their life). In other words, the eligibility assessment should not be confused with the more detailed assessment of functionality required to determine the kind and level of support needs that a person will need over time. [8.18]

**RECOMMENDATION 10.3 — Avoid unreasonable eligibility re-assessments**

People should not be continually re-assessed to determine the presence of disabilities that have already been identified as 'permanent'. [9.22]

**RECOMMENDATION 10.4 — Eligibility must not be based merely upon diagnosis or the cause/time of injury**

NDIS funding must be based on the assessment of a person's current support needs rather than merely on the type or degree of injury or how long ago it occurred. For example, the eligibility criteria should avoid excluding people *just because*:

- (a) they did not have 'a post-traumatic amnesia of 7 days';
- (b) they have been diagnosed with 'minor' or 'moderate' ABI;
- (c) their injury was non-traumatic or did not involve hospitalisation (e.g. alcohol and other drug/alcohol-related brain injury, non-accidents, strokes, concussion, etc.);
- (d) they were only diagnosed with ABI many years after their injury. [9.34, 13.2, 14.10, 18.15c, 18.28, 20.1, 20.22]

**RECOMMENDATION 10.5 — Eligibility criteria should be made evident prior to an assessment**

To reduce the likelihood of misunderstanding or unrealistic expectations, the eligibility criteria for NDIS-funding must be made clear and transparent to people *before* they take the assessment. [14.20]

**RECOMMENDATION 10.6 — NDIS funding should be independent of income or assets**

A person with ABI (or their carers) should not be forced to choose between obtaining NDIS-funded support and pursuing life-goals, such as employment or education. For instance, if a person with ABI undergoes rehabilitation and begins to earn an income that should not *automatically* result in the loss or reduction of their NDIS funding. NDIS-funded support should always depend upon a proper assessment as to whether—or to what extent—the need for care and support exists, independently of that person's current income or assets. [14.22, 16.10]

**RECOMMENDATION 10.7 — Eligibility should be based on the combined outcome of multiple assessment tools**

Eligibility should not be based on the outcome of one assessment tool only, but a composite score taking into account the full range of tools used. [15.6]

**RECOMMENDATION 10.8 — Eligibility decisions must recognise how context can effect assessment outcomes**

The decision about whether a person with ABI is eligible for NDIS-funded support should take into account the fact that assessment tools are generally context-dependent. For instance:

- (a) there is likely to be a significant difference between an assessment that takes place in a structured and controlled environment—such as a hospital—and one that takes place in the community;
- (b) most tools only capture a person's condition *at a particular time*, rather than *over time*; however, a person with ABI may, at some future point, come to be affected by new co-morbidities, such as drug and alcohol misuse or a secondary ABI<sup>6</sup>; so, even if someone is initially assessed as not being eligible, this should not prohibit them from undertaking a re-assessment at a later time; [16.7]
- (c) after several years of funded support, a person with ABI might be doing quite well—but only because of the case management and external support services they have been receiving; however, if, *at this point*, they were re-assessed without taking the context into account (e.g. by not comparing the re-assessment with previous assessments), the assessor might *mistakenly* conclude that they were no longer eligible for NDIS-funded support; in other words, any re-assessment needs to take account of (a) improvement over time, and (b) the fact that this is likely to be dependent upon the presence of external support services. [18.15b]
- (d) an assessment of a person *at a particular point in time* might indicate normal functionality; but given the episodic nature of ABI, it would not follow from this kind of 'assessment' that no supports are necessary. [20.15, PC: +7.2c]

**RECOMMENDATION 10.9 — The eligibility re-assessment process must be made clear to those involved**

There should be a transparent process that specifies when a person with ABI who has not met the eligibility criteria can be 're-assessed' and the process that they would need to take to do so. [15.24]

**RECOMMENDATION 10.10 — The eligibility appeals process must be made clear to those involved**

If a person with ABI is deemed not eligible for NDIS funding, then they should be informed about and able to access a clear, fair and independent appeals pathway. [20.7]

**RECOMMENDATION 10.11 — Associated non-catastrophic injuries should be eligible for NIIS funding**

The *National Injury Insurance Scheme* (NIIS) should fund support needs that arise due to any non-catastrophic injuries that accompany the catastrophic injuries (e.g. when a person in an accident has a spinal injury with fractures, the NIIS should provide funding for both types of injuries.) [15.20]

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<sup>6</sup> Secondary ABI is damage that occurs at some time after the primary impact, and may include brain swelling (edema), increased pressure inside of the skull (intracranial pressure), epilepsy, intracranial infection, fever, hematoma, low or high blood pressure, etc.. See Mendelow, D. and Crawford, P. J. (1997) "Primary And Secondary Brain Injury" in *Head Injury: Pathophysiology and management of severe closed injury* (Chapman & Hall, London): Ch. 4.

**RECOMMENDATION 10.12 — Relevant carer support needs should be eligible for funding**

Families of people with ABI who have been assessed as experiencing depression, stress, or relationship breakdown as a result of—or related to—the person's ABI should be eligible for NDIS-funded support. [18.15a, PC: +7.7aii, 7.7bii]

**RECOMMENDATION 10.13 — Access to age-appropriate leisure should be eligible for funding**

Access to leisure is very important to a person with ABI's psychosocial improvement over time, and so support for this should be eligible for funding—for example, by funding transport or attendant care so that they can access age-appropriate leisure activities. For example, young people should be able to access sporting events on the weekend, and socialise with their friends after work hours. [18.15e, 18.17]

## 11. The context-dependency of assessments

**RECOMMENDATION 11.1 — The time frame of assessments should be responsive to individual need**

A person with ABI may need time to consider and formulate their long-term goals, future aspirations, and what is possible for them. Or again, their life circumstances may also be so chaotic or stressful that issues other than 'getting an assessment' or 'engaging with the system' are not their main priority. Yet people should not be excluded from accessing a NDIS assessment simply because they are unable (for legitimate reasons) to 'fit in' with the normal 'pathways'. Hence, the assessment process should be flexible and responsive to individual need, particularly in terms of the time frame for completing an assessment. [5.13, 17.14, 20.11]

**RECOMMENDATION 11.2 — Assessments should include diverse and 'aspirational' functional contexts**

The assessment should identify support needs that arise not merely within a person's current or predominant situations (e.g. home or hospital) or a small subset of functional contexts (e.g. cooking, but not shopping), but also those support needs that often only arise within potential or 'aspirational' contexts: for example, attending and reaching their full potential at school or university; accessing certain physical environments (like arts and cultural centres, national parks, etc.); engaging in a meaningful occupation; and participating in the mainstream community. [2.4, 8.27, 8.8, 9.18, 13.5, PC: +7.1c, +7.2f]

**RECOMMENDATION 11.3 — Assessments must recognise the impact of pre-morbidity**

The assessment of people with ABI should take into account how pre-morbid conditions (e.g. previous addiction to drugs or alcohol, pre-existing intellectual disability) impact upon the ABI and *vice versa*. However, where pre-morbidity issues may have resulted in or now exacerbate a person's disability, this should not be used as grounds to deny them access to NDIS-funded support. [8.12, 8.13, 9.35, 13.7, 14.5]

**RECOMMENDATION 11.4 — Assessments must be regular and ongoing**

The assessment of a person with ABI must be undertaken *periodically* and *over time*, rather than limited to a ‘one-off’ activity, given that:

- (a) their functionality will change over time and during key life-transitions; and
- (b) they might either exaggerate or underestimate their problems because the effect of the injury is episodic. [4.7, 4.11, 5.8, 7.17, 12.8, 14.3, 20.18f, PC: +7.2c]

**RECOMMENDATION 11.5 — Assessments must involve face-to-face contact with the client**

The assessment of a person with ABI must be conducted face to face, so that:

- (a) the person with ABI can see the assessor’s ‘non-verbal’ reactions and evaluate their attitude toward them (otherwise they will be less willing to trust the assessor and less able to understand the questions asked); and
- (b) the assessor is better able to take into account:
  - the extent to which the person with ABI has (or does not have) insight into various aspects of their disability;
  - the ‘non-verbal’ communication of the person with ABI; and
  - the ‘state’ of the person at the time of the assessment (e.g. whether they are under the influence of drugs or alcohol). [3.28, 5.16, 13.9]

**RECOMMENDATION 11.6 — Assessments must not be limited to a one-off interview**

A person with ABI may not require 24/7 physical care, but that does not mean they are ‘safe’ 24/7. Cognitive deficits can lead to inappropriate behaviour that can be dangerous. The presence of these behaviours can be difficult to identify in a short interview with the person with ABI. So to ensure that the assessment of a person with ABI is accurate, the assessor should take the time necessary:

- (a) to understand their background history or ‘personal narrative’;
- (b) to gain their trust and that of his/her ‘community of care’;
- (c) to listen to the day-to-day observations of those who live with them; and
- (d) to incorporate into the assessment medical documentation, neuropsychological assessments, information about their environment, social structures, family supports, and so on. [3.17, 3.18, 5.8, 11.25]

**RECOMMENDATION 11.7 — Take into account how ABI can impact on arranging and implementing the assessment**

People with ABI can have severe short-term memory loss and low levels of planning capacity and energy. So to ensure the accuracy and accessibility of assessments, the assessors need to ensure that (a) assessment times and places are not changed without consulting the person and giving sufficient advance notice; and that (b) consideration is given to whether each aspect of the assessment process might be too long or onerous. [3.28, 8.16, 11.2]

**RECOMMENDATION 11.8 — Assessors must recognise how ABI and family perspectives can impact on accuracy**

The assessments should take into account that what people with ABI say may not always be accurate. This can be due to confabulation, a lack of insight or an unwillingness to talk about their cognitive deficits, or not correctly interpreting the questions (e.g. due to receptive aphasia). Assessor should also be aware that family and carers might not have an accurate understanding about ABI, or have different goals to the client, or unrealistic expectations. On the other hand, the assessor should recognise that (a) the person with ABI is the expert on their 'lived experience' and (b) take seriously the day-to-day observations of those who live with the person with ABI (which may require undertaking independent assessments). [7.23, 9.30, 11.23, 11.25, 12.14, 14.7, 15.13b]

## 12. The issue of co-morbidities

**RECOMMENDATION 12.1 — The assessment must not conflate or confuse ABI with mental health issues**

The assessment process must be able to distinguish between *the symptoms of ABI* and *mental health issues* (whether pre-existing or a consequence of living with ABI). Assessors should not automatically classify any signs of a mental health issue as nothing more than a symptom of ABI without first conducting an evaluation as to whether both are present (i.e. a 'dual diagnosis'). [5.21, 7.22, 11.29, 12.24, 13.3, 14.6, 15.21, 20.10]

**RECOMMENDATION 12.2 — The assessment be able to identify ABI even when other disabilities are present**

The assessment must be able to distinguish between ABI and other disabilities—for example by employing the expertise of a rehabilitation physician—so that they will have access to the support that is required to meet the needs that arise from the ABI (e.g. at present, when the person has a spinal injury, funding bodies will not fund or are unlikely even to diagnose ABI support needs). [15.29]

**RECOMMENDATION 12.3 — Ensure that a person with ABI and a mental health issue receive care for both**

A person with ABI who is diagnosed as also having a genuine mental health issue should not, as a consequence, be excluded from receiving either a mental health service or NDIS-funded support. There should instead be a systemic relationship between mental health services and the NDIS. For example, if a person with ABI is assessed as having a mental health issue, then the assessor should ensure that:

- (a) they are referred to and/or given clear and accurate information as to how to access a mental health service;
- (b) crisis responses to mental health issues are effective;
- (c) a multi-disciplinary approach is used, e.g. with neuropsychologists and clinical psychologists working together on interventions. [2.18, 3.10, 8.7, 10.9, 11.29, 15.21, 20.10]

## 13. Assessment for early intervention

### RECOMMENDATION 13.1 — Make assessments available where early intervention would be beneficial

Assessments should not only be *made available* when the injury or its impact is so severe that significant and urgent support is required. Assessments should also be applied in cases where the injury will, if addressed early, be less likely to develop into a crisis (e.g. ‘mild concussion’). This will offer people with ABI the opportunity and the incentive to improve, as well as reduce their long-term need and costs. [7.18, 8.24]

### RECOMMENDATION 13.2 — Ensure assessments can identify needs that would benefit from early intervention

The assessment should have *the capacity to identify* different levels of need, including the functional needs and cognitive impairments of people with ‘minor’ to ‘moderate’ ABI. This will ensure that people living with ABI can be properly informed about the injury, its likely impact, and the available pathways to recovery or rehabilitation, and so take active steps to prevent or limit the spiral of symptoms, maladaptive strategies, a decline in their functional abilities, mental health problems and social welfare issues (e.g. imprisonment, homelessness, etc.). [1.4, 7.5, 9.11]

## 14. Assessments in the Indigenous community

### RECOMMENDATION 14.1 — Assessors of Indigenous persons should take into account privacy issues

It may be more culturally appropriate, in Indigenous communities, to use assessors who do not have a pre-existing relationship with the person with ABI or who are well known in the community (since they don’t want to share their ‘business’ or risk having it ‘spread around’ the community). However, there should be flexibility, since some people would prefer to talk to someone they know. [16.12]

### RECOMMENDATION 14.2 — Develop a culturally appropriate assessment process for Indigenous people

The NDIS should develop a culturally appropriate assessment process for Indigenous people with ABI. This should include a way of engaging Indigenous people with ABI so that they can ‘request’ or be encouraged to take part in any assessment process. [18.26]

### RECOMMENDATION 14.3 — Create a community-based role for linking Indigenous people to services

There needs to be an Indigenous project officer who—following an assessment—can create links between Indigenous people with ABI and the services that they need. [18.25]

## 15. Assessments in the criminal justice system

### **RECOMMENDATION 15.1 — Ensure that people in the criminal justice system can access assessments**

Assessments must be available to people with ABI who are inside or on the periphery of the criminal justice system. These assessments must be able to identify strategies, resources and support systems that will enable them to keep out of or not return to the criminal justice system (e.g. currently, many reporting requirements are impossible to keep for a person with ABI in this context). [9.33]

### **RECOMMENDATION 15.2 — Make neuropsychological assessments available to people in prison**

People with ABI who are imprisoned should have access to a neuropsychological assessment, where this is required for them to receive appropriate NDIS-funded support, and not merely when it is relevant to (or required by) their court case. [2.4, 8.27]

## 16. Assessment of children with ABI

### **RECOMMENDATION 16.1 — Ensure children with ABI are only assessed by persons qualified to do so**

Assessors need to be specifically trained in how to measure cognitive impairment in children to ensure accurate results. For example, assessors need to take into account:

- (a) the fact that, with children, the symptoms of ABI do not manifest until later; and
- (b) the possibility of the compounding effect of ABI at different ages and stages of development. [2.9, 2.10, 5.3]

### **RECOMMENDATION 16.2 — Assessments of children should include a prognosis and planned re-assessments**

The assessment of children with ABI (and sometimes their parents) should include a prognosis of what the impact of their ABI is likely to be in the future—for instance, by using the ‘life-plan model’. Re-assessments should then be carried out at key transition points in their development. This will enable them to understand their cognitive-behavioural impairments and so seek appropriate support. [8.9, 10.13, PC: +7.5b]

### **RECOMMENDATION 16.3 — Ensure that children’s assessments are held over time for comparison purposes**

A database system should be set up that starts from the time of the child’s injury and crosses into the transition made to the adult sector, so that long-term outcomes can be evaluated. [7.9]

### **RECOMMENDATION 16.4 — Assessments should identify supports needed within a school context**

The assessment should take account of the support needed to enable children with ABI to (a) develop relationships with other children, (b) establish new routines at school, and (c) manage bullying (e.g. by educating teachers on how to protect children with ABI). [11.20]

## 17. Assessment of carers

### **RECOMMENDATION 17.1 — Identify the support that family members are willing and able to provide**

The assessment should identify existing or possible informal supports, but not in a way that creates unreasonable expectations (e.g. in terms of both time commitments and financial costs) or does not take into account the willingness, the skills or abilities of carers to provide adequate support over the long-term. In other words, an ABI can make a family stronger and they will often ‘step up to the mark’, but this should not be taken for granted or ‘expected’ by the system. [8.21, 11.12, 11.22, 15.8, PC: +7.2h]

### **RECOMMENDATION 17.2 — Identify the support needs of carers**

Carers play a crucial role in supporting a person with ABI, given that the level of independence that is possible for a person with ABI is often far more compromised than other disabilities. So there should be proper and adequate assessment of the care and support needs of carers of a person with ABI, particularly carers who are aging or ill. This assessment should be ongoing, given the likelihood of changes in accommodation and/or deterioration in their capacity to provide support. [4.12c, 10.17b, 11.3, 12.15, 18.10, 18.21, 20.18d, PC: +7.6, +7.7ai]

### **RECOMMENDATION 17.3 — Take into account the fragility of relationships when identifying supports**

The assessment must take account of the fact that relationships are likely to fail or change over time. For instance, over half of all marriages in which one of the partners sustains an ABI break down within 6 years following the ABI. Hence, an assessor should:

- (a) always consider recommending additional support for a family in this situation;
- (b) avoid routinely identifying a marriage partner as being able to provide ‘life-time’ informal support; and
- (c) ensure that, if relationships do break down, there is a clear pathway for the person with ABI in terms of how they can then obtain the support that they need. [8.22, 11.11, 12.4]

### **RECOMMENDATION 17.4 — Identify the extent to which parental care can be sustained**

Assessments must be able to identify the capacity and long-term sustainability of parental care, given the evidence that parental abilities can deteriorate over time. [8.23, PC: +7.6]

### **RECOMMENDATION 17.5 — Help families to avoid imposing their own perspectives on the client**

The assessor should ensure that families are aware of the need not to impose their own aspirations and needs on the person with ABI. [9.29]

### **RECOMMENDATION 17.6 — Identify support needs that arise for siblings and children of the client**

The assessment should identify the care and support needs of siblings and children of people with ABI (e.g. “siblings often feel the need to exaggerate any illness or injury just to get some attention), [11.4, 12.2, PC: +7.7aii]

**RECOMMENDATION 17.7 — Identify support needs that exist for those who have no immediate informal support**

The assessment should identify the care and support needs of people with ABI who are single or live alone. [11.5]

**RECOMMENDATION 17.8 — Identify whether the carer can self-manage funding**

Carers should be assessed for their capacity to self-manage funding for the person with ABI—in particular children with ABI. The ‘Guardianship Board’ (in some situations) and the ‘Supported Decision-making’ model both work well in this respect. [5.25]

**RECOMMENDATION 17.9 — Identify how carers can meet their own needs and aspirations**

The quality of life experienced by carers of a person with ABI will strongly affect the quality of the care they are providing (and *vice versa*). So the assessment should try to identify ways in which the carers can meet their own needs and life-aspirations. This might include:

- (a) planning respite;
- (b) designing return to work or further education strategies;
- (c) planning a transition to independent living;
- (d) access to counselling; and
- (e) providing education about the disability. [16.9, 17.10, 18.8, 20.18e]

## **18. Assessment in regional, rural, and remote areas**

**RECOMMENDATION 18.1 — Identify and solve problems with accessing assessment and support in these areas**

Assessors must identify and seek to resolve the practical difficulties and costs involved for people with ABI who live in regional, rural, and remote areas so as to ensure that there is equitable *access* to both an assessment process and support services (e.g. appointment times should take into account the time it takes for a person with ABI to travel, locations should take into account accessibility issues for wheelchair dependent persons). [6.3, 10.17a, 11.14, 12.7]

**RECOMMENDATION 18.2 — Make specialist teams and services available in these areas**

Specialist teams in ABI need to be available to conduct assessments and offer specialist services in regional, rural, and remote areas, in partnership with local health teams. [7.20, 10.15, 18.14]

**RECOMMENDATION 18.3 — National ‘cost setting’ must recognise the additional cost of assessments in these areas**

The cost of assessments in regional, rural, and remote areas needs to be taken into account in any national ‘cost setting’. This is particularly relevant when the assessments are ongoing or when there is the need for ‘on site/home assessments’. [12.13]

**RECOMMENDATION 18.4 — Use a small panel of experts to decide how best to assess people in these areas**

Given the problems associated with accessing regional, rural, and remote areas and the large size of most states and territories, a rigid system of delivering assessments will not work. Hence, a small panel of experts should decide what would be the most appropriate way of assessing people with ABI. These ‘experts’ should be accredited and independent specialists who have a clear understanding of ABI. [7.19]

**RECOMMENDATION 18.5 — Make neuropsychological assessments available in these areas**

Neuropsychological assessments are typically only available in metro areas. So for people with ABI in regional, rural, and remote locations, the NDIS should (a) provide transport and accommodation (e.g. for 5 or 6 days), so that, where appropriate, these assessments can be accessed, and (b) build the capacity for more local access in these areas. [8.26, 10.3]

**RECOMMENDATION 18.6 — Recognise additional obstacles to phone interviews in remote areas**

Assessments of people with ABI should not be conducted by phone in remote areas, not only in view of the reasons given for face-to-face assessments cited in Recommendation 11.5, but also due to the number of obstacles that are likely to arise: for example, there is often no reception or landlines; the client’s credit may run out in the course of the assessment; their phone may have been loaned to someone else, and so the assessor will then need to leave a message that may or may not be delivered to the client. [3.26]

## 19. The impact of funding on assessment

**RECOMMENDATION 19.1 — Ensure that funding is indexed to unit costs**

Funding for the supports identified in an assessment must be indexed to current unit costs: that is, funding should increase if and when unit costs rise. [2.14]

**RECOMMENDATION 19.2 — Identify and assist with *all* support needs, even those not eligible for NDIS-funding**

The system must be able to identify the extent to which a person’s support needs are *not* being met by the NDIS. Hence, the assessment should not merely identify support needs that are eligible for NDIS funding or for which there is an available service. It should include *all* the support needs that a person with ABI actually has. And if any of their needs are not eligible for NDIS-funded support or if disability-specific services are currently insufficient, then the assessor should have the capacity to:

- (a) record this fact in the assessment; and
- (b) enable the person with ABI to access viable alternative sources of funding or assistance that *can* meet those needs (e.g. informal support networks or mainstream services). [2.15, 4.6, 6.9, 9.25, 9.37, 11.6, 14.21, 15.17, 15.18, 17.3, PC: +7.2g]

**RECOMMENDATION 19.3 — Do not apply rationing strategies to assessments merely to reduce expenditure**

The NDIS assessment process should be adequately funded to meet the appropriate needs of users, rather than depending upon rationing strategies, such as ‘waiting lists’ or rigid and arbitrary ‘cut off’ points (e.g. ‘only 4 hours per assessment’). [5.7, 9.9]

**RECOMMENDATION 19.4 — Do not distort assessment outcomes merely to reduce expenditure**

Assessments should not be used as a mechanism for budgetary control. For example:

- (a) the assessment outcomes should not be distorted as a means of reducing the number of people who can enter the system or have access to the kind and level of supports that they need (e.g. in the United Kingdom, the Department of Work and Pension has contracted out its Work Capability Assessments to the French multinational corporation ‘Atos Healthcare’, with devastating consequences for many people with a disability) [1.3a, 4.10, 15.7]; and
- (b) the evaluation of a person’s attendant care needs should not be compromised in order to off-set the expense of equipment, aids or modifications needs (or *vice versa*). [15.26, 15.27, 16.7]

**RECOMMENDATION 19.5 — Do not sacrifice a person’s long-term best interests merely to reduce expenditure**

The aim of an assessment should not be to identify the cheapest possible way of providing people living with ABI with what they need *at the expense of their long-term best interests*—for example, by

- (a) recommending that the person needs a cleaner, rather than an occupational therapist or physiotherapist who, over the long-term, will enable them to do their own cleaning;
- (b) recommending that the family can provide support when there is good evidence that, without outside attendant care, the family are likely to ‘burn out’ over time;
- (c) evaluating whether a young person can be placed in an aged care facility. [4.6a, 4.6b, 14.13]

**RECOMMENDATION 19.6 — NDIS must fund a neuropsychological assessment if it would otherwise be unavailable**

A neuropsychological assessment—together with tools measuring functionality in diverse physical and social contexts—is invaluable for assessing the support needs of people with ABI, and for some it is an essential tool. It will provide a far more detailed and accurate picture of cognitive impairments than more generic tools (e.g. FIM, FAM). However, the high cost of neuropsychological assessments can be prohibitive to private clients. So if a neuropsychological assessment has not yet been done (or a review is required) and State and Territory Departments of Health are unwilling or unable to resource this, then the NDIS should fund this kind of assessment. [2.6, 6.5, 15.13a, 16.18, PC: +7.8a, -7.8b]

**RECOMMENDATION 19.7 — Estimate the total cost of support and then explore reductions with carers**

The assessment should start with a realistic total estimate of the cost required to meet a person's needs. Carers can then explore and negotiate the extent to which they might be able to reduce this total estimate by their informal contributions. [6.6, PC: +7.2i]

**RECOMMENDATION 19.8 — Avoid assessment distortions by properly funding lower level and episodic needs**

The NDIS should provide adequate support for lower level and episodic (non-crisis) needs, otherwise people will be more likely to exaggerate their problems in the assessment process (e.g. "They ask you 'how are you coping?'—If you answer in the positive then the interview stops there. You have to be in an 'almost catastrophic state' before they will provide support"). [4.1, 4.5, 4.11a]

**RECOMMENDATION 19.9 — Create a national workforce capable of making assessments equitable and effective**

Given the increased number of people with ABI that will enter the system under the NDIS, workforce capacity must be addressed at a national level if the NDIS assessment process is to be effective and fair for people with ABI. This will include:

- (a) providing additional resources to universities to train neuropsychologists;
- (b) supporting the employment of relevant specialists in regional areas (e.g. rehabilitation physicians, occupational therapists, etc.); and
- (c) providing specialist training to support staff and other allied health workers 'on the ground' who are working with people with ABI. [10.5, 10.6, 20.20, 20.21]

## 20. Reviews and re-assessments

**RECOMMENDATION 20.1 — Ensure that assessment reviews can be requested without adverse repercussions**

People with ABI (or their carers) should be able to initiate or request a review of their support needs (a) without being penalized, and (b) in a way that does not negatively affect their relationship with the NDIS or service providers. [1.2, 4.4, 9.19, 10.14]

**RECOMMENDATION 20.2 — Ensure that relevant systems can recommend a review without adverse repercussions**

Where the person with ABI does not have the capacity to request a re-assessment, then other systems should have the capacity to recommend an assessment review for them (e.g. case managers, service brokers, DSOs, or LACs)—that is, (a) without being penalised and (b) in a way that does not negatively affect their relationship with the client. [9.19, 10.14]

**RECOMMENDATION 20.3 — Assessment reviews must not be restricted unfairly or arbitrarily**

The number and frequency of reviews should be determined by need, on a case-by-case basis. [1.2, 10.12]

**RECOMMENDATION 20.4 — Reviews should be used to identify changing needs, not merely to reduce funding**

Due to prior experience with funding bodies, people with ABI and their carers are likely to have an inherent fear of losing funding whenever reviews take place. This should be taken into account by reassuring them that NDIS-funding is ‘needs-responsive’. In other words, the purpose of the review is not merely to reduce funding but to ensure that a person’s needs are accurately and fairly identified and supported. For example, NDIS-funded support could *increase* if and when new needs are identified (e.g. a deterioration in their condition). [1.3b, 2.13, 16.4]

**RECOMMENDATION 20.5 — Any review must include a formal re-assessment, rather than mere ‘experimentation’**

Reviews must involve a formal assessment of the support that is likely to be needed in the future, rather than—as some agencies currently do—withdrawing a service to ‘see what happens’. [2.12]

**RECOMMENDATION 20.6 — Ensure that, where necessary, reviews can be held quickly and transparently**

The NDIS should have the capacity to conduct a review in response to a crisis or sudden change in circumstances (e.g. the person with ABI has been arrested or they have lost a primary carer). The assessment process must therefore be:

- (a) inherently flexible, quickly responding to changing needs rather than being delayed by ‘paperwork’ and ‘system-processing’; and
- (b) transparent about how long it will take before the re-assessment process can begin. [2.12, 9.21, 15.24]

**RECOMMENDATION 20.7 — Reviews should take place on a regular basis and after major life-transitions**

The NDIS should take a pro-active, anticipatory approach to the re-assessment of people with ABI, rather than being merely reactive (i.e. waiting until a crisis or a traumatic event occurs). In other words, re-assessments should occur *regularly* and *after key life-transitions*, with improvements or deteriorations being compared to the previous assessment. This is required for several reasons:

- (a) the capacity of family or friends to provide informal support will change over time;
- (b) the episodic nature of ABI means that some needs will be only be identifiable over time;
- (c) certain needs only emerge over time (e.g. due to improvement, change of circumstances, deterioration, etc.).
- (d) significant life-transitions are likely to require a re-assessment (e.g. after hospital discharge, school-leaving, employment, study options, moving home, aging). [3.9, 4.9, 5.5, 5.14, 9.10, 12.17, 14.15, 15.25, 16.3, 17.12, 18.29, 20.4, 20.14, PC: +7.5]

**RECOMMENDATION 20.8 — Make sure everyone involved knows, in advance, that there will be reviews**

The person with ABI and their family should be made aware at the outset that re-assessment(s) will occur. [12.17]

**RECOMMENDATION 20.9 — Clarify the status of pre-existing assessments for people who are moving into the NDIS**

Greater clarity is needed about the ‘assessment transition’ between people currently receiving services and the NDIS (e.g. Will they need to be ‘re-assessed’ by the NDIS? Will pre-existing assessments be sufficient? How will duplication be avoided?) [9.26, 10.15]

## 21. Assessing the assessments

**RECOMMENDATION 21.1 — Hold assessors accountable**

Assessors should be accountable for their decisions. This is particularly important for people with ABI, given the potential for challenging behaviours. [12.21]

**RECOMMENDATION 21.2 — Monitor the effectiveness and accuracy of assessments**

The follow-up to assessments should include checking on the progress and implementation of outcomes from the assessment, with accountability and evaluation built into the system. This should include opportunities for:

- (a) people with ABI and their families to review progress and modify goals;
- (b) community agencies, clients and families to improve and refine the validity and reliability of the assessment tools and ensuring the accuracy of the care plans; and
- (c) an independent review of the whole system to ensure that it is operating effectively for people with disability. [7.26, 9.36, 11.21, 20.4, 20.5, PC: +7.2j, +7.3a, +7.9, +7.10]

**RECOMMENDATION 21.3 — Those who decide to approve/reject assessments must be *relevantly* qualified**

Those who are making decisions about whether or not to approve the kind and level of support needs identified in the assessment should not only be trained or experienced in business and/or management. They should also be trained and have substantial experience in (a) the disability sector and (b) how to evaluate the quality of assessments. [10.16, 15.9a]

## 22. The role of a national NDIS database

**RECOMMENDATION 22.1 — Make assessment outcomes accessible to the client, assessors and support services**

The assessment outcomes should be held in a national NDIS database. These outcomes should be made accessible to both the client and—with the ‘one-off’ consent of the client—those involved in the assessment and care of the person with ABI, including state-based services. This is so that:

- (a) the outcomes are not ‘lost’;

- (b) the same information does not need to be repeatedly provided by the person with ABI or their families whenever they change or engage a new service;
- (c) change over time can be easily identified;
- (d) people with ABI will not be disadvantaged if they forget or do not have the capacity to convey various key aspects of their impairment;
- (e) the results of re-assessments/reviews can be kept up to date centrally, so that obsolete assessments do not prevent people from accessing a service; and
- (f) all those involved in providing a service can make decisions based upon the same information. [4.8, 8.1, 9.10, 11.15, 12.9, 14.19, 17.2]

**RECOMMENDATION 22.2 — Link assessment outcomes to relevant information in other databases**

The NDIS database should be integrated or linked with other relevant databases (e.g. e.Health), so that there is greater sharing of information between service providers, health professionals etc.—with the qualification that the information shared is essential for the purpose of service provision. For example, the assessment of a person with ABI’s functionality should be passed on to those who will be providing him/her with support and care. [9.27, 11.7, 11.18, 14.16, 17.2b]

## 23. Use of terms

**RECOMMENDATION 23.1 — Ensure that assessors understand the definition of ‘minor’ ABI**

The assessment process needs to be clear and consistent about the definition of ‘minor ABI’: the term ‘minor’ refers to the diagnosis or injury, not the level of cognitive-behavioural impairment, which can be profound and severe. [7.11]

**RECOMMENDATION 23.2 — Legal liabilities can unjustifiably prevent a diagnosis of ‘permanent and irreversible’**

Doctors can be reluctant to identify that a ‘minor’ ABI is ‘permanent and irreversible’ due to their legal liabilities. This should be addressed or taken into account by the NDIS so that people diagnosed with a ‘minor’ ABI are not disadvantaged or excluded. [8.4]

**RECOMMENDATION 23.3 — Raise awareness about the difference between ‘need’ and ‘want’**

The general public need to have an understanding of the definition of ‘need’ as distinguished from ‘want’, so that expectations about the NDIS are realistic. [9.28]

**RECOMMENDATION 23.4 — Clarify the meaning of ‘significant and permanent’**

It cannot be assumed that everyone will have the same understanding of what ‘significant and permanent’ disability means. So training for assessors, service providers and advocacy agencies will be essential if the scheme is to be equitable. [20.6]

## 24. Practical issues

### **RECOMMENDATION 24.1 — Ensure that taking part in an assessment is not prohibitively difficult**

The process of assessment needs to be ‘easy’ for the person with ABI and/or their carers, so that they are not ‘put off’ from undertaking, requesting or consenting to an assessment—for example:

- (a) not requiring information that was obtained in previous assessments;
- (b) being flexible about the time or place at which the assessment will take place;
- (c) restricting to whatever extent possible the number of locations in which different aspects of the assessment are carried out. [10.15, 11.15, 17.14, 20.18e, PC: +7.3a]

### **RECOMMENDATION 24.2 — Engage in respectful and prompt communications with the client and their family**

Those associated with conducting the assessment should provide feedback to any correspondence that the family or person with ABI sends to them (e.g. registering that they have received it, saying ‘thank you’); and they should not take an excessive duration to provide essential reports to the family (e.g. the results of neuropsychological assessments). [11.13]

### **RECOMMENDATION 24.3 — The NDIS should initiate and manage the assessment and support provision**

Both (a) the assessment process (including ongoing assessments) and (b) the provision of whatever support needs are thereby identified should be instigated, driven and managed by the NDIS—not the client or their carers—over the time of the person’s needs. [14.11, 14.18, 16.3]

### **RECOMMENDATION 24.4 — Ensure that people with ABI are assessed in acute care and monitored there onwards**

Some people are properly assessed only once they are in the community, in which case many of the problems of setting up within the community can be much more difficult (particularly for people with ‘minor’ ABI). There should be clear protocols from day one for people who have acquired a brain injury—from either traumatic or non-traumatic causes—to ensure they are properly assessed in acute care, and monitored through transition to their community. [9.12, 18.11]

## GENERAL ISSUES

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### 25. The impact of a market-based system

#### **RECOMMENDATION 25.1 — Maintain ABI-specific organisations**

The NDIS should ensure that ABI-specific organisations can be maintained, so that families, carers and people with ABI can receive specialist support and assistance:

- (a) to navigate the system (e.g. for people who have no experience of self-directed funding or the capacity to make complex decisions, the NDIS will be extremely difficult for them to manage);
- (b) to ensure that the assessment and planning process takes into account their whole-life context;
- (c) to become aware of and engage with disability services, so that appropriate services are in place once a person with ABI leaves acute care. [2.2, 3.1, 3.3]

#### **RECOMMENDATION 25.2 — Encourage and enable cooperation between disability organisations**

There is a danger that, under the self-directed funding model, disability organisations will take on a 'divide and conquer' orientation. The NDIS should seek to prevent this since it is more effective to work together, pooling resources, rather than working in silos. [2.1, 3.15, 9.8]

#### **RECOMMENDATION 25.3 — Ensure that smaller services with ABI expertise aren't taken over by generic services**

The NDIS should ensure that smaller services with a specialist expertise in supporting people with ABI are not swamped or taken over by bigger 'generic' organisations that do not offer the same specialist expertise—particularly in remote areas. For example, the differences between ABI and congenital disabilities (e.g. intellectual disability) are likely to be overlooked if there is a transition over time toward generic services. [3.13, 18.5, 18.24, 18.27, 20.19a]

#### **RECOMMENDATION 25.4 — Ensure that smaller attendant care agencies with ABI expertise remain accessible**

Currently, many smaller attendant care agencies do not have the capacity or resources to become accredited. Yet it is the smaller agencies that are more likely to offer a specialist service to people with ABI. So the NDIS should either (a) ensure that smaller agencies can become accredited or (b) permit people with ABI to access non-accredited attendant care agencies that have demonstrated skills and expertise in working with people with ABI. [18.15d]

#### **RECOMMENDATION 25.5 — Be aware that some disability organisations may not adopt a person-centred approach**

The NDIS should be aware that, even in a self-directed funding situation, some disability organisations are unlikely to be able to transition to a person-centred approach, given that they do not currently empower or enable people with ABI. [3.14, 3.16]

**RECOMMENDATION 25.6 — Ensure that there is a continuity of service and quality between contracts**

If the NDIS assessments are contracted out, there is a real danger that once one contract period expires a new round of tenders may result in a new provider and a potential loss of corporate knowledge and a loss of service improvement gains may result. Hence, consideration should be given as to how best to ensure continuity from the end of one contract to the beginning of the next contract. [20.9]

**RECOMMENDATION 25.7 — Provide incentives for services to expand capacity/focus so as to meet demand**

The disability sector is very reliant on NFP organisations, many of whom are community-based. But these organisations often have boards that are risk-averse or board members who are driven by needs of a family member. So rather than adopt a business model for the whole market, they adopt a narrow service focus. This leads to a lack of capacity building and often a lack of focus on more completely servicing the community in which the service is based. Hence, under the NDIS, there should be a ‘market signalling’ method about the need for a service in a particular area. Otherwise service providers may choose not to expand capacity to cater for extra demand. [20.13]

**RECOMMENDATION 25.8 — To ensure genuine choice, there will need to be an expansion in service provision**

When the NDIS is rolled out, existing services would need to be sustained and others initiated so that there is genuine choice under the self-funding model (e.g. there are few services in WA offering cognitive rehabilitation; and workplace rehabilitation services would need to be expanded.) [7.8]

**RECOMMENDATION 25.9 — Provide incentives for services to offer rehabilitation over the long term**

Substantial improvements toward independent living can be made even if the rehabilitation is provided many years after the brain injury. Hence, the NDIS should provide an incentive for service providers to engage in rehabilitation over many years, rather than the initial 3 months. [7.6, 18.16]

## **26. Support for persons with ABI in education and employment**

**RECOMMENDATION 26.1 — Ensure that schools understand and can offer ABI-specific support**

Schools need to be required to recognise ABI as requiring proper support and care. For instance, support aides are regularly unavailable for students with ABI in the school context. Teachers do not understand how children with ABI can ‘present well’ and yet have ‘episodic’ issues. [11.19, 17.9]

**RECOMMENDATION 26.2 — Create systemic changes that will increase the employability of people with ABI**

The NDIS should fund processes that will bring about the kind of systemic changes needed to make it possible for more people with ABI or any disability to be employed within any sector—for instance, by:

- (a) providing employers with assistance to pay for any insurance increase as a result of hiring a person with ABI;
- (b) making laws so that every company has to employ a minimum of 5% people with a disability to make up their workforce;
- (c) encouraging and enabling government departments and corporations to employ (i) 'specialist disability workers' to ensure that people with a disability are properly supported in the workplace, together with (ii) 'disability support managers' to manage these workers (on site or managing a multitude of sites). [17.13, 19.9]

## 27. Issues for regional, rural and remote areas

### RECOMMENDATION 27.1 — Address the low levels of service provision in these areas

People with ABI in regional, rural and remote areas might be eligible for (and even receive) NDIS funding, and yet be unable to access the kind and level of support they need. The NDIS will need to address the lack of services in these areas. For example:

- (a) transport to services is an ongoing issue for people with ABI in remote areas;
- (b) there is often no accommodation for people with ABI, given the lack of housing stock;
- (c) no ABI-specific service provider exists on a permanent basis in many rural areas;
- (d) there are no consistent allied health supports, given that they are unable to travel on a regular basis due to inadequate budgets;
- (e) workers and services are extremely transient in remote areas, and so service delivery is not consistent;
- (f) there is no well-supported process of education in ABI for people who work in these areas;
- (g) in regional areas, the limited funding means that there are not enough health professionals to manage the number of people who require a service (e.g. the waiting list for an OT for a person with ABI in one area was 18 months);
- (h) there is no 'step down care' rehabilitation for people with ABI once people move away from the city into rural areas. [3.2, 3.5, 3.6, 3.7, 3.8, 7.21, 11.8, 11.16, 20.24]

### RECOMMENDATION 27.2 — The criteria for approving support providers should be more flexible in these areas.

The NDIS needs to be flexible to meet people's needs in regional, rural and remote areas. For example, in a rural environment, it might be more cost effective to employ a friend or neighbour to meet their support needs. But this would require the system to:

- (a) recognise that some kinds of assistance do not require specialist training; and
- (b) allow people with a disability to identify the likely risks to themselves. [15.22]

## 28. Case managers, brokers and advocates

### **RECOMMENDATION 28.1 — Case managers should be offered whenever appropriate**

A case manager should be made available for every person with ABI for whom this need is recommended by their assessment, and if this is what the person wishes. [9.20]

### **RECOMMENDATION 28.2 — Ensure continuity of case management and client records**

Case management should either be the responsibility of one central person or there should be a framework in which the case management is quickly and comprehensively 'passed on' to other staff (i.e. where information about the client is handed on or is centrally accessible). [15.14]

### **RECOMMENDATION 28.3 — The choice of case manager should reside with the client**

The person with an ABI should be able to choose their own case manager and have the option to transfer to another one, rather than have them allocated. [15.16]

### **RECOMMENDATION 28.4 — Care and support should not be compromised to pay for case management**

The cost of case management should not be subtracted from the amount required to fund the support needs of a person with an ABI. It should instead be factored into the total package at the assessment stage. [10.18, 15.15, 16.6b]

### **RECOMMENDATION 28.5 — The role of case managers**

A case manager is not merely a coordinator who contacts them once every 12 months. Their role should be:

- (a) to oversee the assessment process, ensuring that it is undertaken either by the same person or that information is passed on to any additional assessors;
- (b) provide people with ABI and their carers with 'individualised' education;
- (c) help them to access services;
- (d) put in place long term strategies, etc. [9.20, 14.12, 18.18, 18.23]

### **RECOMMENDATION 28.6 — Case managers should be required to undergo performance reviews**

There should be measureable outcomes that case managers are required to achieve, so as to ensure quality, accountability and transparency. [15.11]

### **RECOMMENDATION 28.7 — Ensure that the required number and quality of case managers can be met**

There needs to be thought given now about the number of case managers that will be needed, and how best to ensure that they have the qualities, values and training required to implement a person-centred approach. [15.10]

## 29. Pathways and linkages

**RECOMMENDATION 29.1 — Link people with ABI to mainstream services to address other issues**

Greater clarity is needed around the linkages between the NDIS and mainstream services in cases of co-morbidities, dual diagnosis or additional social issues (e.g. homelessness, imprisonment, mental health, drug and alcohol abuse, stroke, etc.). In the discharge phase, social/health workers are unaware of where to send the person with ABI. There is a lack of information at this point and no assessment tool for case management to work through with the hospital. [9.23, 12.5, 15.21, 18.9]

**RECOMMENDATION 29.2 — Create a clear pathway of support from acute care onwards**

A more transparent way of connecting acute, primary care and the community would be very helpful in designing a system that works for people with ABI (e.g. “Navigation of the current system is overwhelming”). [7.4, 20.17]

**RECOMMENDATION 29.3 — Create a contingency plan in case existing informal support is withdrawn**

If the relationship of the carers breaks down, there should be a clear pathway for the person with ABI in terms of how they can now obtain the support that they need. [12.4]

**RECOMMENDATION 29.4 — Provide clarity about how people will transition out of the NDIS**

There should be clarity about the process by which people who are funded by the NDIS will ‘exit’ the scheme. [13.12]

**RECOMMENDATION 29.5 — Establish protocols for pathways and linkages between government and NGOs**

Agreements between government departments and the not for profit/community sector would facilitate more streamlined pathways, effective early intervention and coordinated treatment across the health department (hospitals & acute rehabilitation), allied health, HACC, not for profit, community and disability sectors. [20.3]

**RECOMMENDATION 29.6 — Establish procedures to help someone who doesn’t know that they need a service**

If a person with ABI has suffered significant frontal lobe dysfunction they may lack the insight necessary to see a need for any service. In such cases, a clear pathway is needed to enable them to return to or engage with a service. [20.8]

# Appendices

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## A. List of Consultees

In total, there were 20 consultation sessions and several written submissions, involving a total of 192 consultees—as listed below:

Name	Role and/or Organisation	Session
1. Deborah Farrell	Manager, Complex Care	Melbourne, Vic
2. Rodney Harris	CEO, Motor Neurone Disease Association of Victoria	Melbourne, Vic
3. Peter Trethewey	CEO, AQA Victoria Ltd	Melbourne, Vic
4. Sharon Strugnell	CEO, BrainLink Services (Victoria)	Melbourne, Vic
5. Dr. Di Winkler	Occupational Therapist, Founder & CEO of Summer Foundation	Melbourne, Vic
6. Marc Paradin	Policy Officer, Victorian Coalition ABI Service Providers	Melbourne, Vic
7. Nicole Telfer	Manager, ABI Services at Melbourne Citymission	Melbourne, Vic
8. Tanya Carroll	Person with ABI	Cairns, QLD
9. Jennifer Cullen	Synapse: Brain Injury Association of Qld	Brisbane, QLD
10. Virginia Downton	Manager, Disability Services at St John's Community Care	Cairns, QLD
11. Donna Engel	Assessment & Planning Manager, Synapse	Brisbane, QLD
12. Kelly May	District Director of Social Work, Cairns Base Hospital	Cairns, QLD
13. Gail Rogers	Speech & Language Pathologist, Specialised Speech Services	Cairns, QLD
14. Rhonda Baker	Person with ABI	Adelaide, SA
15. Leah Hobson	NDIS Engagement Project Officer, Australian Federation of Disability Organisations	Adelaide, SA
16. Joseph Lamarca	Father and carer of a person with ABI	Adelaide, SA
17. Robert Lamarca	Person with ABI	Adelaide, SA
18. Mariann McNamara	CEO, The Brain Injury Network of SA	Adelaide, SA
19. Trevor Andrews	Department for Communities and Social Inclusion, SA	Adelaide, SA
20. Cherie Archer	Occupational Therapist at Neuroadapt Occupational Therapy Services for Stroke and Brain Injury Rehabilitation, Adelaide SA	Adelaide, SA
21. Cathryn Blight	Manager Regional Services, Novita Children's Services, SA	Adelaide, SA
22. David Callahan	Department for Communities and Social Inclusion, SA	Adelaide, SA
23. Kirsten Deane	EO, National Disability and Carer Alliance	Adelaide, SA
24. Chris Farrand	The Brain Injury Network of SA	Adelaide, SA
25. Steven Garner	Coordinator, Community Mental Health Programs - Metro Options	Adelaide, SA
26. Brian Gillan	EO, Equol Consulting, Pty.	Adelaide, SA
27. Alicia Fidock	Research Officer, Julia Farr Association	Adelaide, SA
28. Mary Hall	Disability Worker, City of Port Phillip	Adelaide, SA
29. Tina Hampton	Department for Communities and Social Inclusion, SA	Adelaide, SA
30. Elizabeth Logan	Department for Communities and Social Inclusion, SA	Adelaide, SA
31. Lyle Rimon	Manager, Home and Community Care, Community and Home Support SA	Adelaide, SA
32. Peter Rovira	Brain Injury Rehabilitation Service, Australia	Adelaide, SA
33. Nicky Titchener	Team Leader, Acquired Disability Program, Novita Children's Services	Adelaide, SA
34. Faith Thorley	Person with ABI	Adelaide, SA
35. Tim Valente	Director at Senior Helpers, SA	Adelaide, SA
36. Amy White	Policy Officer. National Disability Services, SA	Adelaide, SA
37. Suzanne Wilson	Community Relations Coordinator at Senior Helpers Australia	Adelaide, SA
38. Victoria Zelipski	The Brain Injury Network of SA	Adelaide, SA
39. Lee-Anne Bressell	CEO, Headwest: Brain Injury Association of WA Inc., Psychologist	Perth, WA
40. Carol Franklin	Carer, Chair of Carers WA (outgoing), Vice Chair Young People in Nursing Homes Alliance, Advocate with PWD	Perth, WA
41. Brenda Hogg	Lawyer, Commercial Law Solutions	Perth, WA
42. Ardis Hood	Consumer representative, lived experience ABI	Perth, WA
43. David Hounsom	Chair, Board of Headwest: Brain Injury Association of WA Inc.	Perth, WA
44. Dr Shew-Lee Lee	Clinical Psychologist, Princess Margaret Hospital for children	Perth, WA
45. Alicia Mason	Health Planning and Improvement Manager - Perth Primary Care Network	Perth, WA
46. Yvonne Patterson		Perth, WA
47. Shirley Van Schagen	Management Consultant, private practice	Perth, WA
48. Alison Brady	Headwest: Brain Injury Association of WA Inc.	Perth, WA
49. Robyn Fitzgerald	Advocate and Educator, Headwest: Brain Injury Association of WA Inc.	Perth, WA
50. Dr Kim Fong	Head of Department Rehabilitation Medicine, Royal Perth Hospital	Perth, WA
51. Dr Anna Gubbay	Department of Paediatric Rehabilitation, Princess Margaret Hospital for Children, Perth	Perth, WA
52. Amanda Halfpenny	Rehabilitation Consultant / Social Worker, Lighthouse Health Group	Perth, WA
53. Dr Kate Langdon	Paediatrician, Princess Margaret Hospital	Perth, WA
54. Jenny Lawrence	General Manager, Brightwater Care Group (Perth)	Perth, WA

55.	<b>Kathy McCoy</b>	Executive Officer, The Neurological Council of WA	Perth, WA
56.	<b>Samantha Parker</b>	CRS Australia	Perth, WA
57.	<b>Sue Shapland</b>	General Manager, Member Services, MS Society WA (Inc.)	Perth, WA
58.	<b>KristyLee Shays</b>	Brightwater Brain Injury Rehab.	Perth, WA
59.	<b>Janet Wagland</b>	Manager Services For Younger People, Brightwater Care Group	Perth, WA
60.	<b>Denise Butler</b>	Advocate, Psychologist, Headwest: Brain Injury Association of WA Inc.	Perth, WA
61.	<b>Sophii La Cey</b>	Advocate, Headwest: Brain Injury Association of WA Inc.	Perth, WA
62.	<b>Rachel Balmer</b>	Area Manager, Anglicare Tas	Hobart, Tas
63.	<b>Jodi Bentley</b>	Anglicare Tas	Hobart, Tas
64.	<b>Kate Bierefelt</b>	Aspire: A Pathway to Mental Health, Inc.	Hobart, Tas
65.	<b>Lea Brady</b>	McKinstry Brady Disability Specialists	Hobart, Tas
66.	<b>Deborah Bryne</b>	EO, Brain Injury Association of Tasmania	Hobart, Tas
67.	<b>Ros Calvert</b>	Dementia Tas/Housing Options Providing Extra Support	Hobart, Tas
68.	<b>Debra Drew</b>	Headway Rebuilding Lives	Hobart, Tas
69.	<b>Jason Hall</b>	Headway Rebuilding Lives	Hobart, Tas
70.	<b>Sue Hodgson</b>	Family member/ Housing Options Providing Extra Support	Hobart, Tas
71.	<b>Ellen Kiernan</b>	Community Liason Officer, Disability, Housing and Community Services	Hobart, Tas
72.	<b>Mary Langdon</b>	Client Service Manager, MS Society	Hobart, Tas
73.	<b>Amanda Street</b>	Comorbidity Sector Development Officer, Alcohol, Tobacco & Other Drugs Council (Tas)	Hobart, Tas
74.	<b>Darren Osborn</b>	Headway Rebuilding Lives	Hobart, Tas
75.	<b>David Pearce</b>	Advocacy Tasmania/Glenorchy City Council/Housing Options Providing Extra Support	Hobart, Tas
76.	<b>Jill Ranson</b>	Infinite Development	Hobart, Tas
77.	<b>Robert Schnierer</b>	Aspire: A Pathway to Mental Health, Inc.	Hobart, Tas
78.	<b>Mark Lamont</b>	Neuropsychologist/Committee Member, Brain Injury Association of Tasmania	Hobart, Tas
79.	<b>Dario Tomat</b>	Whetstone/Vice President and Treasurer Brain Injury Association of Tasmania	Hobart, Tas
80.	<b>Leanne Whitney</b>	ABI Co-ordinator Veranto/Committee Member, Brain Injury Association of Tasmania	Hobart, Tas
81.	<b>Fiona Bardenhagen</b>	Psychologist, Launceston General Hospital	Launceston, Tas
82.	<b>Amanda Bendt</b>	Mental Health Clinician, Department of Health and Human Services	Launceston, Tas
83.	<b>Jacqueline Brown</b>	Advocate, Advocacy Tasmania Inc	Launceston, Tas
84.	<b>Kerry Finch</b>	Member, Legislative Council	Launceston, Tas
85.	<b>Pam Hesketh</b>	Clinical Nurse Consultant, Spinal Continence	Launceston, Tas
86.	<b>Chris Hill</b>	CEO, Motor Accidents Insurance Board	Launceston, Tas
87.	<b>Eric Ind</b>	Vice President, Tasmanian Acquired Brain Injury Services	Launceston, Tas
88.	<b>Allan Johnson</b>	Mission Australia Mental Health	Launceston, Tas
89.	<b>Linda Jomartz</b>	Case Manager, Community Options Service	Launceston, Tas
90.	<b>Liz Leslie</b>	Disability Support & Aged Care Services	Launceston, Tas
91.	<b>Maggie McKenzie</b>	Physiotherapist, West Tamar Physiotherapy	Launceston, Tas
92.	<b>Steve Rouse</b>	Family Based Care North	Launceston, Tas
93.	<b>Hannah Rubenach</b>	Client Service Provider, Tasmanian Acquired Brain Injury Services	Launceston, Tas
94.	<b>Mel Szczyпка</b>	Disability Support & Aged Care Services	Launceston, Tas
95.	<b>Russell Walker</b>	Services Coordinator, Tasmanian Acquired Brain Injury Services	Launceston, Tas
96.	<b>Leanne Wease</b>	Mission Australia North West	Launceston, Tas
97.	<b>Moira Wellman</b>	Client Service Provider, Tasmanian Acquired Brain Injury Services	Launceston, Tas
98.	<b>Pat Wrigley</b>	Area Services Coordinator North, Primary Health	Launceston, Tas
99.	<b>Beverley Taylor</b>	Training and Development Manager, Brain Injury Association of NSW	Coffs, NSW
100.	<b>Karren Alford</b>	Carer /Father of person with ABI	Coffs, NSW
101.	<b>John Alford</b>	Carer /Mother of person with ABI	Coffs, NSW
102.	<b>Matthew Alford</b>	Young person with ABI	Coffs, NSW
103.	<b>Maggie Heffernan</b>	Carer /Mother of person with ABI	Coffs, NSW
104.	<b>Helen Wisi</b>	Person with ABI	Coffs, NSW
105.	<b>Mark Collis</b>	Person with ABI	Coffs, NSW
106.	<b>Elaine Baxter</b>	Hastings Valley Community Options Program	Coffs, NSW
107.	<b>Clare Brennan</b>	Macleay Community Care	Coffs, NSW
108.	<b>Teresa Chard</b>	Case Manager, Northern Community Care	Coffs, NSW
109.	<b>James Charles</b>	Northwest Regional Community Care, Community Care Options	Coffs, NSW
110.	<b>Stephen Comerford</b>	Tweed Community Options Program	Coffs, NSW
111.	<b>Leonnie Davidson</b>	Mid North Coast Community Care Options	Coffs, NSW
112.	<b>Marion Dwyer</b>	Coordinated Veterans' Care Community Support	Coffs, NSW
113.	<b>Colin Everingham</b>	Hastings Valley Community Options Program	Coffs, NSW
114.	<b>Jacque Goodhen</b>	Northwest Regional Community Care, Community Options Program	Coffs, NSW
115.	<b>Jasmin King</b>	Northwest Regional Community Care, Community Care Options	Coffs, NSW
116.	<b>Jamie Lawler</b>	Northwest Regional Community Care, Community Care Options	Coffs, NSW
117.	<b>Elise Merzlikoff</b>	GLM Community Care Options	Coffs, NSW
118.	<b>Katherine Miller</b>	Mid North Coast Community Care Options	Coffs, NSW
119.	<b>Kathy Newton</b>	Mid North Coast Community Care Options	Coffs, NSW

120.	<b>Fran Pearce</b>	Hastings Valley Community Options Program	Coffs, NSW
121.	<b>Jason Pell</b>	Mid North Coast Community Care Options	Coffs, NSW
122.	<b>Daire Phillips</b>	Coordinated Veterans' Care Community Support	Coffs, NSW
123.	<b>Jan Roads</b>	Tablelands Community Support Options: Uralla	Coffs, NSW
124.	<b>Joanne Watters</b>	Tweed Community Options Program	Coffs, NSW
125.	<b>Catherine Winn</b>	Mid North Coast Community Care Options	Coffs, NSW
126.	<b>Kathryn Vaughan</b>	Manager Hunter Brain Injury Service (BIS)	BIRD, NSW
127.	<b>Matt Frith</b>	Manager Kaleidoscope Paediatric Brain Injury Rehabilitation Team Newcastle	BIRD, NSW
128.	<b>Marion Fisher</b>	Coordinator Paediatric BIRT Sydney Children's Hospitals Network, Randwick Campus	BIRD, NSW
129.	<b>Dr Angie Morrow</b>	Rehabilitation Specialist, The Children's Hospital Westmead	BIRD, NSW
130.	<b>Dr Adeline Hodgkinson</b>	Director and Chair ACI Brain Injury Rehabilitation Directorate and Liverpool Brain Injury Rehabilitation Unit	BIRD, NSW
131.	<b>Mandy De Roover</b>	A/Manager New England BIRS	BIRD, NSW
132.	<b>Denise Young</b>	Manager Mid West BIRP	BIRD, NSW
133.	<b>Narelle Miller</b>	Manager Dubbo BIRS	BIRD, NSW
134.	<b>Liesel Younger</b>	A/Manager North Coast BIRS	BIRD, NSW
135.	<b>Irene Gordon</b>	Manager Illawarra BIS	BIRD, NSW
136.	<b>Jane Murtagh</b>	A/Manager South West BIRS	BIRD, NSW
137.	<b>Jeremy Gilchrist</b>	Manager Southern Area BIS	BIRD, NSW
138.	<b>Barbara Strettles</b>	ACI Network Manager BIRD	BIRD, NSW
139.	<b>Phillip Behr</b>	Director, Just Better Care, St George office	Param., NSW
140.	<b>Colin Brodie</b>	Parent of son with ABI	Param., NSW
141.	<b>Anne Fahey</b>	Parent of son with ABI	Param., NSW
142.	<b>Glennen CC Fahey</b>	Person with ABI	Param., NSW
143.	<b>Jim Grainda</b>	Person with ABI	Param., NSW
144.	<b>Mark Hammond</b>	Just Better Care	Param., NSW
145.	<b>Robyn Hosking</b>	Person with ABI	Param., NSW
146.	<b>Julia Frost</b>	Person with ABI	Param., NSW
147.	<b>Nerida Johnston</b>	Quality Manager, Brain Injury Association of NSW	Param., NSW
148.	<b>Patricia Lynch</b>	Carer of son with ABI	Param., NSW
149.	<b>Naty Millarez</b>	Person with ABI	Param., NSW
150.	<b>Paul Raciborski</b>	Person with ABI, Coach & Project Manager, President of BINSW board	Param., NSW
151.	<b>Jenny Rossini</b>	Just Better Care	Param., NSW
152.	<b>Rob Wansbrough</b>	Person with ABI	Param., NSW
153.	<b>Gillian Woodcock</b>	Carer of sister with ABI	Param., NSW
154.	<b>Cathy Bouvy</b>	Operations Manager, Heartbeat Nursing Agency NSW	Param., NSW
155.	<b>Stephanie Challer</b>	Heartbeat Nursing Agency	Param., NSW
156.	<b>Samantha Frain</b>	Northcott Disability Services	Param., NSW
157.	<b>Lara Friedman</b>	Person with a disability, Presenter and Trainer at Person Centered Insights	Param., NSW
158.	<b>Wendy Hill</b>	Premier Care	Param., NSW
159.	<b>Jane-Maree Hurley</b>	Private Rehab	Param., NSW
160.	<b>Anthea Karatasoulis</b>	Information, Referral and Brokerage Manager, Brain Injury Association of NSW	Param., NSW
161.	<b>Cheryl Lynn</b>	Premier Care P/L	Param., NSW
162.	<b>Kathy Prasad</b>	Occupational Therapist, Northcott CATS	Param., NSW
163.	<b>Anne Reidy</b>	Quality Manager & Business Development, Julie Warner Community Care	Param., NSW
164.	<b>George Samuel</b>	HACC Development Officer, Inner South-West Community Development Organisation	Param., NSW
165.	<b>Lindy Williams</b>	Rehabilitation Consultant / Occupational Therapist, Lighthousehealth Group	Param., NSW
166.	<b>Max Hill</b>	Carers NSW Dubbo Branch	Dubbo, NSW
167.	<b>Roslyn Leonard</b>	Carers NSW Dubbo Branch	Dubbo, NSW
168.	<b>Gail Carling</b>	Grandmother of a person with ABI	Dubbo, NSW
169.	<b>Natalie Coad</b>	Mother of a person with ABI	Dubbo, NSW
170.	<b>Cassie Gardner</b>	Carer/parent of person with ID	Dubbo, NSW
171.	<b>Kylie Hacker</b>	Carer and a staff member of the Dubbo Brain Injury Rehabilitation Program	Dubbo, NSW
172.	<b>Iain Morgan</b>	Person with ABI	Dubbo, NSW
173.	<b>Andrew Murray</b>	Person with ABI	Dubbo, NSW
174.	<b>Cecily Murray</b>	Carer/parent of person with ABI	Dubbo, NSW
175.	<b>Isabel Wallace</b>	Carer/parent of person with ABI	Dubbo, NSW
176.	<b>John Wallace</b>	Carer/parent of person with ABI	Dubbo, NSW
177.	<b>Arienne Bourne</b>	Case Manager, Diverse Community Care	Teleconf., NSW
178.	<b>Bronwyne Chapman</b>	Disability Advocacy NSW	Teleconf., NSW
179.	<b>John Roach</b>	Manager, Headway Illawarra	Teleconf., NSW
180.	<b>Robyn Russell</b>	Coordinator, Headway Illawarra	Teleconf., NSW
181.	<b>Vicki Solomon</b>	Occupational Therapist, Port Macquarie Brain Injury Rehabilitation Service	Teleconf., NSW
182.	<b>Dallas Tanner</b>	Case Manager, Eurobodalla Shire Council	Teleconf., NSW
183.	<b>Greg Williams</b>	Hunter Region Co-ordinator, Disability Advocacy NSW	Teleconf., NSW
184.	<b>Pankaj Khanna</b>	TBI 2011 through pedestrian MVA – non compensable	Teleconf., NSW

<b>185. Colin Murdoch</b>	TBI as a child – non compensable	Teleconf., NSW
<b>186. Steve Hindle</b>	Rehabilitation Coordinator, Southern Area Brain Injury Service Goulburn NSW	Written, NSW
<b>187. Chris Lee</b>	Carer of person with ABI	Written, NSW
<b>188. Linda Ferguson</b>	Carer of person with ABI	Written, NSW
<b>189. Denis Ginnivan</b>	Director at South West Brain Injury Rehabilitation Service, Albury NSW	Written, NSW
<b>190. Rachel Merton</b>	Chief Executive Officer Brain Injury Association of NSW Inc.	Draft revisions
<b>191. Nick Rushworth</b>	Executive Officer, Brain Injury Australia	Draft revisions
<b>192. Dr Miranda Jelbart</b>	Rehabilitation Physician, Medical Director SA Brain Injury Rehabilitation Service Hampstead Rehabilitation Centre, Northfield SA	Draft revisions

## B. Record of Consultation Outcomes

### 1. Melbourne, Victoria: 11-12.30pm, June 26<sup>th</sup> 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and BrainLink	<b>Attendees:</b>	Derek Brookes, Deborah Farrell, Rodney Harris, Peter Trethewey, Sharon Strugnell
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by the attendees in this consultation meeting.*

#### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in Victoria? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' for this region? What should be included in the new scheme?

- 1.1 65 + are included in disability services in Victoria
- 1.2 Reviews should be client-initiated, not restricted by number or timing

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

- 1.3 Based upon Transport Accident Commission (TAC) experience:
  - a. if issues of scheme sustainability arise, then the first recourse will be to tighten up eligibility and assessment (since this is the only budgetary control available in an entitlement/insurance approach);
  - b. even once a person is considered eligible, there are likely to be additional barriers to receiving funding (e.g. a 'maximum' placed on services, restricted number or timing of reviews, using reviews to reduce funding, bonuses provided to assessors if they reduce funding).
- 1.4 Assessors who are also providing the relevant service are more likely to recommend unnecessary services (since they directly benefit). To avoid such conflicts of interest the two should be independent, as in the PC's report.
- 1.5 People with a disability are often not informed about services or funding that is available, due to a lack of awareness by e.g. medical staff, GPs, etc. The 'public information roll-out' recommended in the PC report therefore needs to include health professionals explicitly.

- 1.6 Experience of 'one-stop-shop' advisors (providing information to people with a disability) suggests that this model is inadequate—i.e. in terms of individualising the information for the person in question. Hence, relying solely upon an 'NDIS advisor', as apparently suggested in the PC's report, is problematic.
- 1.7 Most of the disability-specific information that an 'NDIS advisor' would need is 'owned' by existing disability services/organisations. The NDIS would therefore need to enter into some kind of 'contractual arrangement' to access this information.
- 1.8 If someone has cognitive problems that have not yet tipped into 'functional need', where will the funding come from to ameliorate this progression for as long as possible? Many disability groups currently perform this role, but it remains unclear whether (or how) they will continue to receive funding under the NDIS.
- 1.9 It is not clear from the PC report how much people with a disability will need to contribute to services themselves, i.e. from their own assets.
- 1.10 Possible model for including over 65s in the NDIS (suggested by Rodney Harris):
  - a. If a person with a disability is over 65, then their support needs should be funded by aged care.
  - b. However, once they have exhausted their aged care package (or the limits of available aged care funding), then—and only then—they would become entitled to NDIS-funding (assuming they are assessed as meeting the criteria for NDIS-funded support).
  - c. This ensures that aged care NDIS-funding is provided as a 'top-up' to or 'extension' of aged care funding (e.g. for higher level equipment, flexible respite).
  - d. The *advantages* of this approach would be that: (i) over 65s are included within the NDIS; and (ii) it would minimize the risk to the NDIS, since aged care will provide core funding.
  - e. The *risk* would be that aged care could place 'artificial' limits on available funding so that cases can be shifted to the NDIS.

## 2. Melbourne, Victoria: 1-3pm, June 26th 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and BrainLink	<b>Attendees:</b>	Derek Brookes, Di Winkler, Marc Paradin, Nicole Telfer, Sharon Strugnell
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in Victoria? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' for this region? What should be included in the new scheme?

- 2.1 It works well when services have positive relationships with each other: they are more likely to be able to work collaboratively for better outcomes for the individual with ABI. But how would this be done if services are only funded to carry out specific tasks (via 'self-directed' funding)?
- 2.2 It works well when there are organisations that (a) help families, carers and people with ABI navigate the system, that (b) ensure assessment and planning takes into account their whole-life context; and that (c) engage disability services, so that appropriate services are in place once a person with ABI leaves acute care. But if this sits in Tier 2, who—other than existing disability-specific organisations—will have this kind of knowledge (i.e. of ABI, MS, etc.)?
- 2.3 In Victoria, we have worked hard to maintain ABI-specific services—which means we have been able to meet the specific needs of people with ABI.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

- 2.4 People with ABI within the criminal justice system not being recognised/assessed, nor able to receive the right kind of support when they are diagnosed.
- 2.5 Cognitive impairments may not be obvious to a generic disability assessment. ABI requires a specific neuropsychological assessment by a specifically trained assessor (a neuropsychologist).
- 2.6 The cost and accessibility of neuropsychological assessments can be prohibitive.

- 2.7 People with ABI are presenting with a range of other issues (homelessness, mental health issues, etc.). This makes it difficult (a) to attribute ABI as 'the cause' of their functional needs, and (b) to determine the source of funding required to meet their needs.
- 2.8 The impact of making 'blanket decisions' based upon generic criteria (e.g. is the disability 'permanent?').
- 2.9 The needs of children with ABI is radically different from adults. They are currently placed in a generic disability service model, rather than offered specialist ABI support. Early intervention is especially crucial, and yet currently inadequately funded.
- 2.10 For children with ABI, it is not until key developmental milestones are reached that the symptoms of ABI manifest; and these are often attributed to non-ABI causes.
- 2.11 Children with ABI do not have access to Integration Aid Support (which does not currently assess specifically for ABI).
- 2.12 The TAC model does not include streamlined access; it has poor responsiveness; the unit costs do not cover services; it tends to withdraw services and 'see what happens'; it encourages a focus on what the person cannot do rather than their strengths and abilities.
- 2.13 The process around accessing resources is so complex and so difficult that once a person with a disability gains access they are unlikely to 'let go' in case they need the support at a later stage.
- 2.14 How unit costs are determined by the department is flawed – clients need to sacrifice basic needs because the unit costs are less than the service costs.
- 2.15 Assessment and planning must take account of the actual resources and funding available.
- 2.16 There tends to be a hierarchy of support needs: high physical support needs are ranked as more important than mild to moderate cognitive needs (e.g. organisational, planning, decision-making) or complex medical needs (the impact of which can increase the severity of ABI).
- 2.17 Assessments for many people with ABI are very complex, and will not fit within a standard generic form of 'care and support needs' assessments.
- 2.18 There needs to be a systemic relationship between mental health services and ABI services, so that referrals and crisis responses are effective and meeting the needs of individuals (e.g. crisis assessment treatment teams in mental health).
- 2.19 Self-directed funding will not fund systemic advocacy.
- 2.20 Victoria is not specifically funded to carry out systemic advocacy for people with ABI. So if the NDIS relies upon independent funding for systemic advocacy, then this may not work in Victoria.

- 2.21 Neuropsychological assessments do not always assess functional needs (the extent to which a person can function in the real world). It depends on the assessor: who was engaged and involved, the interpretation, the purpose for which the assessment was carried out, etc..

### 3. Cairns, QLD: 12-3pm, July 13th 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Network - FNQ	<b>Attendees:</b>	Derek Brookes, Tanya Carroll, Jennifer Cullen, Virginia Downton, Donna Engel, Kelly May, Gail Rogers.
<b>Type of Meeting:</b>	Consultation		
<b>Facilitators:</b>	Donna Engel & Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

#### Discussion questions:

What are the potential risks for people living with ABI in Far North Queensland (FNQ) when the NDIS/NIIS is introduced?

- 3.1 Lack of access to information about the services available (e.g. as provided in the workshops run by Synapse).
- 3.2 Workers and services are so transient in FNQ, service delivery is not consistent—and so genuine choice for clients is unlikely to be available.
- 3.3 For people who have no experience of self-directed funding or the capacity to make complex decisions, the NDIS will be extremely difficult for them to manage.
- 3.4 An ongoing issue is the lack of training of workers. They are not paid well, and yet are expected to have a good understanding of the issues facing ABI. So they are not able to provide adequate rehabilitation, tending instead to focus on 'mere' attendant care.
- 3.5 Transport and access to services is an ongoing issue, given the remoteness of people or homelessness issues.
- 3.6 A person with ABI in FNQ may have a funding 'package' and yet services are not available (e.g. no accommodation, given the lack of housing stock; or no service provider exists in their region on a permanent basis).
- 3.7 There are no consistent allied health supports, given that they are unable to travel on a regular basis due to inadequate budgets.
- 3.8 Disability services only focus on under 18; adults fall under health, but health has no community rehabilitation (so there is limited physiotherapy, OT, speech, social work, dietetics; limited funding for HACC).
- 3.9 Because people with disability are living longer, they will need regular reviews to determine the change of their support needs over time (e.g. people with ABI are more likely to develop cognitive degeneration as they age, such as dementia).

- 3.10 In cases of dual diagnosis (e.g. ABI plus mental illness), it is not clear who will fund their support needs—health or NDIS.
- 3.11 Many in the medical profession still do not understand ABI, confusing it with intellectual disability.
- 3.12 The goal of rehabilitation for people with ABI should not necessarily be employment, e.g. where the only employment possible is unsatisfying and/or poorly paid.
- 3.13 There is a danger of service monopolies emerging, particularly in remote areas.
- 3.14 Some disability organisations are unlikely to be able to adapt to a person-centred approach, given that they do not currently empower or enable people with ABI.

What is the current situation as regards the assessment of the support needs of people with ABI in FNQ? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' for this region? What should be included in the new scheme?

- 3.15 People are starting to realise that they cannot work in silos: organisations have to pool their resources if they are to be used more effectively.
- 3.16 Instead of looking at 'service-centric outcomes', it works best when we look at what the client wants (i.e. focus on 'person-centric outcomes').

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

- 3.17 People cannot be assessed in, say, 45 minutes—given the level of background history, the need to gain trust from the client and his/her community, etc..
- 3.18 The assessments must include more than an interview with the client. They should incorporate medical documentation, neuropsychological assessments information about their environment, social structures, family supports, etc..
- 3.19 The language used and information provided must accessible to people with ABI (e.g. they should be able to understand easily the assessment questions, the process and the results).
- 3.20 Recommendations about care and support should not be decided upon by people who are not involved in (or have no direct access to) the client's lived experience.
- 3.21 The current tool (ICAP) is not adequate for the ABI client group.
- 3.22 The assessment should be able to discriminate between different levels of need, i.e. not excluding those with 'mild' to 'moderate' ABI.

- 3.23 If recommendations are produced by a multi-disciplinary team—with access to all dimensions of the person with ABI’s life—then these should be honoured by the NDIS decision-makers.
- 3.24 The assessment tool should be portable between states.
- 3.25 Assessments should be culturally appropriate.
- 3.26 Conducting assessments by phone in remote areas is problematic (e.g. there is often no reception, the client’s credit runs out, their phone has been loaned to someone else, there are no landlines, the assessor often needs to leave a message that may or may not be delivered to the client).
- 3.27 Capacity (to give consent for an assessment to take place or to be assessed directly) needs to be assessed accurately and fairly, so that inappropriate decisions are not made on people’s behalf.
- 3.28 Disability services that work with a range of disabilities do not always understand the needs of people with ABI (e.g. the effect of changing schedules, esp. without consulting or no warning); and this issue would also apply to any assessment process.
- 3.29 The assessor should ask the person with ABI ‘how does this effect you?’, ‘what kind of structures would you like?’, etc..
- 3.30 Assessments must be face-to-face (rather than by phone):
  - a. so that the person with ABI can see their ‘non-verbal’ reactions and evaluate their attitude toward them—otherwise they will be less willing to trust the assessor and less able to understand the questions asked;
  - b. so that the assessor can confirm that the person with ABI has (or does not have) insight into various aspects of their disability.

## 4. Adelaide, SA: 11-1pm, July 17th 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Network of SA Inc.	<b>Attendees:</b>	Rhonda Baker Derek Brookes, Leah Hobson, Joseph Lamarca, Robert Lamarca, Mariann McNamara
<b>Type of Meeting:</b>	Consultation		
<b>Facilitators:</b>	Mariann McNamara and Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation in South Australia as regards the assessment of the support needs of people with ABI? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in South Australia? What should be included in the new scheme?

4.1 When I get into crisis I get 6 hours of support, but getting support should not depend upon crisis.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

4.2 Key terms in the assessment were not explained (e.g. 'moderate').

4.3 The follow-up to the assessment was poor (i.e. lack of professional support).

4.4 When a re-assessment was requested, it did not come.

4.5 They ask you 'how are you coping?' – if you answer in the positive then the interview stops there; you have to be in an 'almost catastrophic state' before they will provide support.

4.6 The assessment must be objective and accurate, rather than determined by the level of existing resources: for example

- a. their aim is to find the cheapest possible way of providing you with what you need—rather than what will be in your long-term best interests (e.g. a cleaner rather than an OT/physio who will enable you to do your own cleaning);
- b. they seem happy to burn your family out, rather than get someone in who can help you.

- 4.7 The assessment must take into account the episodic nature of brain injury (i.e. a person might respond positively to a question about 'how are you coping?' one week, but not the next).
- 4.8 There should be one database holding all the assessments so that (a) the same issues are not repeatedly assessed, and (b) change over time can be easily identified.
- 4.9 The assessment of the kind and level of supports a person needs must take into account the fact that informal supports (family, etc.) will change over time.
- 4.10 Assessors need to be monitored to ensure that their results are objective and not influenced by organisational 'directives' (e.g. to save resources).
- 4.11 The assessors need to be aware of the reason why people may either exaggerate or underestimate their problems: i.e. to obtain the resources they need or because the affect of the injury is episodic.
  - a. If the system provided adequate support for lower level or episodic (non-crisis) needs, then this 'corruption' of the assessment process would be far less likely.
  - b. If the assessor has (i) a longer-term relationship with the person and (ii) has a proper understanding of cognitive impairment, then they will know the 'base-line' issues and the episodic nature of brain injury. So they will be more likely to understand their responses and pick up on issues such as exaggeration or underestimation and so intervene at earlier stages.
- 4.12 We need to make sure that there is a proper and adequate assessment of:
  - a. a person with ABI's eligibility for NDIS-funded support;
  - b. a person with ABI's life-time care and support needs;
  - c. the needs of carers of a person with ABI.

## 5. Adelaide, SA: 2.30-4.30pm, July 18th 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Network of SA Inc.	<b>Attendees:</b>	Trevor Andrews, Cherie Archer, Cathryn Blight, Derek Brookes, David Callahan, Kirsten Deane, Chris Farrand, Steven Garner, Brian Gillan, Alicia Fidock, Mary Hall, Tina Hampton, Elizabeth Logan, Mariann McNamara, Lyle Rimon, Peter Rovira, Nicky Titchener, Faith Thorley, Tim Valente, Amy White, Suzanne Wilson, Victoria Zelipski
<b>Type of Meeting:</b>	Consultation		
<b>Facilitators:</b>	Mariann McNamara and Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation in South Australia as regards the assessment of the support needs of people with ABI? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as ‘best practice’ in South Australia? What should be included in the new scheme?

5.1 n.a.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be ‘carried over’ into the new scheme?

5.2 Assessment of prognosis—especially with respect to children with ABI—will need to be considered carefully.

5.3 Assessors need to be specifically trained in how to measure cognitive impairment to ensure accurate results for people with ABI. This is particularly necessary for children, because of the possibility of the compounding effect of ABI at different ages and stages of development.

5.4 There seems to be a lack of assessment tools that are designed specifically to capture the support needs of people with ABI.

5.5 There needs to be reviews over the duration of a person’s life, due to the episodic nature of ABI and the ever changing needs over the long term of people with ABI.

5.6 At what point will there be a transition from an existing intensive, multidisciplinary rehab service to ‘slow stream’ rehab (i.e. when a child is no longer needing rehab on a 3-4 times a week basis, stepping down to once a week or once a fortnight)?

- 5.7 The rationing strategy currently used is 'waiting lists'. The assessment capacity of services should be enhanced so as to avoid this 'strategy' and produce a quality that is appropriate to the needs of users.
- 5.8 The assessment should take into account the 'lived experience' of people with an ABI. This would require sufficient time to enable the assessor to record the 'personal narrative' of the person with ABI and identify their strengths.
- 5.9 The insight that people with ABI have into their own condition and experience needs to be adequately captured in the assessment. This is best done by a specialist in ABI.
- 5.10 Currently, assessments tend to focus on the 'front end' medical model (e.g. bowel movements), rather than quality of life outcomes (e.g. living and participating in the community). The latter approach requires 'person-centred' planning, involving the client's 'community of care' (family, friends, other agencies involved, etc.).
- 5.11 The assessor must (a) know the person being assessed; and (b) have the specialist skills required to assess a person with ABI.
- 5.12 Assessors need to know how to 'dig' for information that the person with ABI may not be aware of themselves.
- 5.13 The timing of the assessment is critical: the person with ABI may need time to consider and formulate their long-term goals, future aspirations, what is possible, etc..
- 5.14 Assessment must be ongoing, given that people's needs change over time (e.g. supervision).
- 5.15 There should be no 'dead ends' in terms of the provision of support needs.
- 5.16 Assessments should be carried out face-to-face.
- 5.17 There would need to be assessments (and monitoring) of the extent to which people with ABI have the capacity to self-manage their funding and engage in long-term planning. (e.g. the Flinders Model, PCP, CANS, self-assessment, etc.). A range of tools needs to be used in the context of a long-term relationship.
- 5.18 The assessment process needs to engender a sense of hope and recovery in the person with ABI, enabling them to reclaim and re-discover their life, walking along side them as they do so.
- 5.19 'Wellness planning' and 'relapse prevention planning' should be driven by the client.
- 5.20 It is important to ensure that there is publically available information about the assessment process. This is critical to empowering people living with ABI.
- 5.21 The assessment process (and assessors) must able to distinguish between ABI and intellectual disability.

- 5.22 Generic disability assessment tools tend to focus on physical and intellectual disability, and so are likely to 'overlook' aspects that are unique to ABI.
- 5.23 Many diagnostic tools cannot identify particular types of ABI (e.g. if a patient with diffuse axonal injury only receives a CT scan, their brain injury is unlikely to be identified).
- 5.24 The limitations of a functional assessment tool for people with ABI must be recognised. Assessors need to understand the person and engage in a long-term relationship so as to enable them to achieve maximum control over their lives (e.g. people with ABI will not be used to making decisions, or making long-term plans, identifying their hopes and dreams, etc.).
- 5.25 Carers should be assessed for their capacity to self-manage funding for the person with ABI—in particular children with ABI. The 'Guardianship Board' (in some situations) and the 'Supported Decision-making' model both work well.
- 5.26 How will the transition to adulthood be managed in the NDIS (esp. in terms of self-managed funding)?

## 6. Perth, WA: 5-7.30pm, 19 July 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Headwest	<b>Attendees:</b>	Derek Brookes, Lee-Anne Brensell, Carol Franklin, Brenda Hogg, Ardis Hood, David Hounsome (Chair), Dr Shew-Lee Lee, Alicia Mason, Yvonne Patterson, Shirley Van Schagen
<b>Type of Meeting:</b>	Consultation		
<b>Facilitators:</b>	Lee-Anne Brensell and Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

6.1 n.a.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

6.2 The assessment tool and the assessor must be able to measure not only functionality but also 'difficult behaviours' (e.g. non-compliance, poor planning), given that these are likely to be the primary cost-driving characteristics of people with ABI with respect to required staff support.

6.3 There is a distinction between assessment tools that assess functionality and tools that estimate the cost required to meet the needs identified. It is the latter that will be most problematic in relation to equity of access (e.g. Will the estimates take into account the fact that services in some states/regions will be more expensive than others?)

6.4 If the decision about the eligibility of a person with ABI depends upon diagnosis, then it must be based upon a thorough neuropsychological assessment, carried out by a trained neuropsychologist—not a 'generic assessor'.

6.5 A neuropsychological assessment—together with additional tools measuring functionality—is essential for assessing the care and support needs for people with ABI. If a neuropsychological assessment has not yet been done (or a review is required) and Health is unwilling or unable to resource this, then the NDIS must be able to fund this kind of assessment.

6.6 The assessment should start with a realistic total estimate of the cost required to meet a person's needs, and then the carers can explore and negotiate the extent to

which they might be able to reduce this total estimate by means of their informal (i.e. unpaid) contributions.

- 6.7 The system must have sufficient resources to be able to ensure that (a) people whose needs are changing/increasing over time are not denied the support they need because (b) people who do not yet have any funding are given priority. (Currently, this is due to the fact that CAP is the only 'way in'.)
- 6.8 Support needs should be identified by an independent assessor, not by the client or the service provider—given (a) the potential for conflict of interest and (b) the lack of objectivity and reliability (but the views of the client should, of course, be taken into account).
- 6.9 The assessment should be objective and not influenced or distorted by the budgetary constraints or policy objectives of the funder. In other words, the decision about what support needs will be funded (i.e. what is 'reasonable and necessary') should be separate from the assessment of what support needs a person actually has (some of which may not therefore receive NDIS-funding).
- 6.10 There should be built-in safeguards to ensure the quality of the assessments: for example, mentoring, monitoring, formal training and accreditation, limited appointment periods, etc..

## 7. Perth, WA: 9-10.30am, 20 July 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Headwest	<b>Attendees:</b>	Derek Brookes, Alison Brady, Lee-Anne Brensell, Robyn Fitzgerald, Kim Fong, Anna Gubbay, Amanda Halfpenny, Kate Langdon, Jenny Lawrence, Kathy McCoy, Samantha Parker, Sue Shapland, KristyLee Shays, Janet Wagland
<b>Type of Meeting:</b>	Consultation		
<b>Facilitators:</b>	Lee-Anne Brensell and Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

7.1 Multidisciplinary teams work best in carrying out the assessment of people with ABI, not individuals working in isolation.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

7.2 Currently there is no system that uses assessment that is targeted for people with ABI. All are standardised around people with an intellectual disability, using Americanised language (e.g. the ICAP).

7.3 The use of the FIM-FAM after 3 months for people with ABI reaches a ceiling effect (i.e. it stops measuring the impact of ABI after this point). The cognitive aspects are also not strong.

7.4 A more transparent way of connecting acute, primary care and the community would be very helpful in designing a system that works for people with ABI.

7.5 It would be useful to identify people with 'mild' ABI, so that they could be informed about the injury, its likely impact, pathways to recovery/rehab, etc.. This would avoid the spiral of symptoms, maladaptive strategies, and mental health problems.

7.6 There should be an incentive for service providers to engage in rehab over many years, rather than the initial 3 months.

7.7 People need to be informed about the services available to them, otherwise they will not access effective support. This is particularly problematic for people with ABI, so support services need to offer specialised, ABI-informed assistance.

- 7.8 When the NDIS is rolled out, existing services would need to be sustained and others initiated so that there is genuine choice under the self-funding model (e.g. there are few services in WA offering cognitive rehabilitation; and workplace rehab services would need to be expanded.)
- 7.9 In relation to assessment in paediatrics: (a) the ABI may not be apparent for many years; and (b) the WeeFIM reaches a ceiling at the age of 7; (c) it would be good to set up a data-base system that starts from the time of injury and crosses into the transition made to the adult sector, so that we can evaluate long-term outcomes.
- 7.10 This design process of the NDIS should be engaging with neurologists or health in the development of the assessment process.
- 7.11 The assessment process needs to be clear and consistent about the definition of 'mild ABI': the 'mild' refers to the diagnosis or injury, not the level of cognitive-behavioural impairment.
- 7.12 Neuropsychological assessments are focused on impairment, not functionality and participation. A multidisciplinary approach to the assessment of people with ABI is essential.
- 7.13 Neuropsychological assessments in the acute setting are essential, but should not be the only (or the most important) kind of assessment used in a post-acute community setting.
- 7.14 In relation to the use of FIM, FAM and CANS to assess people with ABI: (a) FIM is best used in an acute setting (given the ceiling effect); (b) there is evidence that the cognitive items on FIM are not accurate; (c) the FAM does not add much to FIM; and (d) CANS is not sufficient on its own. In short, we don't currently have adequate assessment tools for people with ABI.
- 7.15 There is no single assessment tool that is valid and accurate. What is required is a 'comprehensive clinical assessment', consisting of multiple tools: i.e.
- a. functionality assessments, within a relevant functional setting;
  - b. neuropsychological assessments;
  - c. pre-morbid assessments (i.e. of social problems, nutrition, etc.);
  - d. assessment of change over time.
- 7.16 The Mayo-Portland Adaptability Inventory works well for people with ABI in post-acute (although it needs to be 'tightened up'); a paediatric version is also available; and it fits with ICF classification under participation.
- 7.17 Assessments must not be a 'one-off' activity, given that functionality changes over time (and potentially rapidly).
- 7.18 Assessments should be tied to the need to pursue more extended early intervention, offering people the opportunity and incentive to improve. This would be likely reduce their long term need and costs.

- 7.19 A rigid system of assessment will not work over a large size region such as WA (e.g. given remote areas). A small panel of experts should decide what would be the most appropriate way of assessing the client. These 'experts' should be accredited and independent specialists who have a clear understanding of ABI.
- 7.20 Specialist teams in ABI need to be available to conduct assessments and offer specialist services in remote regions, in partnership with local health teams.
- 7.21 There should be a well-supported process of education in ABI for people who work in remote regions.
- 7.22 There needs to be an assessment of people with ABI that is cohesive enough to incorporate mental health issues.
- 7.23 Assessments should not rely only upon the self-assessment of people with ABI. It should include the views of people who know them well (e.g. using the 'life-care plan' model). But there should be caution about the views of the family, who may not have a clear understanding of ABI, and so misconstrue or misidentify the needs of the client.
- 7.24 'Better Start' may provide a good model of assessment.
- 7.25 Any NDIS assessor of the support needs of people with ABI should:
- a. be an accredited health professional, and
  - b. have a specialist education in ABI.
- 7.26 The NDIS should include an outcome assessment, with accountability and evaluation built into the system.

## 8. Perth, WA: 12-3pm, 20 July 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Headwest	<b>Attendees:</b>	Derek Brookes, Lee-Anne Brensell, Denise Butler, Robyn Fitzgerald, Sophii La Cey
<b>Type of Meeting:</b>	Consultation		
<b>Facilitators:</b>	Lee-Anne Brensell and Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

8.1 E.health is working well, since it will provide the patients entire medical history—particularly for people with ABI, who may forget (or not have the capacity) to convey various key aspects of their impairment to a health professional.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

8.2 Currently there is enormous variation in the quality of assessments of people with ABI (e.g. accuracy and comprehensiveness).

8.3 Neuropsychologists have different agendas which can influence the outcome of their assessment (e.g. certain assessment tools can be selected to achieve the desired outcome).

8.4 Doctors can be reluctant to identify that a 'mild' injury is 'permanent and irreversible' due to their legal liabilities.

8.5 When assessment inaccuracies are 'suspected', reviews are not necessarily effective, given that assessors tend to back up what previous assessors have said (i.e. to cover each other's backs). The assessment process should therefore be independent of service provision.

8.6 There can be poor follow-up care to assessments, even when support needs are clearly identified.

8.7 In WA, if the primary diagnosis is ABI, then someone with the dual diagnosis (mental health & ABI) will be 'screened out' of receiving any mental health service.

- 8.8 The assessments often only cover a subset of a person's functions (or functional contexts – e.g. they can cook, but find it difficult to shop).
- 8.9 The assessment of children with ABI (and sometimes their parents) should include a prognosis of what the impact of their ABI is likely to be in the future (e.g. 'life-plan model'); and re-assessments should be carried out at key transition points in their development. This will enable them to understand their cognitive-behavioural impairments and so seek appropriate support.
- 8.10 The assessments should provide precise detail on the supports a person with ABI would need to in order to achieve particular life-goals and aspirations – such as further study, work, sexuality, relationships, etc.. This support should include specialist assistance with developing adaptive strategies that will enable them to participate as fully as possible in key life-contexts (e.g. the workplace, education).
- 8.11 The assessments should acknowledge life-transitions.
- 8.12 Pre-morbidity issues should be taken into account because we need to know about linkages and context (people in their lives, previous addiction to drug and alcohol, etc.) – but it should not be used to deny a person access to care and support. Otherwise this 'no-fault' scheme could 'unofficially' exclude 'at-fault' people with ABI who present with pre-morbid issues that may have led to or now exacerbate their disability.
- 8.13 Pre-morbid issues can seriously affect the accuracy of assessments, due to the personal social/ethical beliefs or 'prejudicial labelling' of the assessor (e.g. blame for unrelated disabilities can be placed on, say, drug and alcohol addiction; or clients can be labelled as 'violent' due to isolated incidents that may have occurred in the acute stage).
- 8.14 Assessments can 'screen people out' using reasons that do not refer explicitly to prejudicial judgments (e.g. violent, alcoholic, etc.), such as 'out of catchment area', 'lack of resources', etc.
- 8.15 People with ABI may not have the capacity or knowledge to 'apply' to be assessed for eligibility. The system should therefore ensure that these obstacles are taken into account, so that *everyone* has the same opportunity to be assessed for eligibility.
- a. There should be independent monitoring, so that 'gaps' (i.e. who is not being assessed) and 'obstacles' (i.e. 'what is preventing this') are identified.
  - b. Information about and support to access the assessment process and services should be made readily available at the points when they are most needed.
- 8.16 Most people are too exhausted (or it is too onerous) for people to put in a CAP application for funding.
- 8.17 The CAP application is a 'deficit' model: they want a narrative and emotions that will exhibit the worse case scenario.
- 8.18 So much information is needed to prove why a person needs funding. Sometimes the basic facts of a story are more than enough to demonstrate their eligibility for support (e.g. someone who has been run over by a train, has lost both legs and has

- little cognitive capacity – they should not need to specify how these disabilities are affecting the person’s life).
- 8.19 Assessors need to have a more detailed specialist understanding of the typical basic impact of ABI on a person’s functionality: this should not need to be explained to them in the application form.
- 8.20 If the assessment orientation or philosophy is that the client (or their carers) is the primary and authoritative source of information about the kind and level of need that they require, then the assessments of people with ABI are likely to produce erroneous results— given that people with ABI (and often their carers) are not fully or accurately aware of their own cognitive-behavioural impairment.
- 8.21 The assessment should identify existing or possible informal supports, but not in a way that creates unreasonable expectations or does not take into account the willingness or abilities of carers to provide adequate support over the long-term.
- 8.22 The support for carers must be long-term and take account of the fact that relationships are likely to fail or change over time (e.g. the assessment can identify a marriage partner as being able to provide ‘life-time’ informal support – even when there is strong evidence that this relationship is unlikely to survive in the long-term or under those conditions).
- 8.23 Assessments must be able to identify the capacity and long-term sustainability of parental care, given the evidence that parental abilities can deteriorate over time.
- 8.24 Assessments should not only be applied when the injury (or its impact) is so severe that significant and urgent support is required. Assessments should also be made available in cases where the injury will, if addressed early, be less likely to develop into a crisis situation (e.g. ‘mild concussion’).
- 8.25 The experts who are invited to contribute to the assessment process must include not only health professionals, but also organisations that have specialist skills, knowledge and ‘hands-on’ experience in enabling people with ABI to meet their life-long goals and participate in ‘real life’ scenarios within the community (e.g. return to work, community rehabilitation, education support, identifying strengths and adaptive strategies, etc.).
- 8.26 In WA, neuropsychological assessments can only be done in the metro area. So for people with ABI in remote locations, the NDIS should provide transport and accommodation (e.g. for 5 or 6 days), so that these assessments can be accessed.
- 8.27 People with ABI who are imprisoned are unlikely to have access to a neuropsychological assessment unless it is relevant to (or required by) their court case.

## 9. Hobart, Tasmania: 9.30-12.30pm, 23 July 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Association of Tasmania	<b>Attendees:</b>	Derek Brookes, Rachel Balmer, Jodi Bentley, Kate Bierefelt, Lea Brady, Deborah Bryne, Ros Calvert, Debra Drew, Jason Hall, Sue Hodgson, Ellen Kiernan, Mary Langdon, Amanda Street, Darren Osborn, David Pearce, Jill Ranson, Robert Schrierer
<b>Type of Meeting:</b>	Consultation		
<b>Facilitators:</b>	Deborah Bryne and Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		
		<b>Apologies:</b>	Elise Archer, Mark Lamont

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

9.1 The (reformed) Gateway model is one that can be built on, but it would require (a) additional resources to function effectively, (b) accountability, (c) clear pathways and (d) consistency across all states and territories.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

9.2 The assessors need to have a relevant health background (i.e. with specific training in ABI)—otherwise they will not be able to ask the right questions of health professionals, particularly given the subtleties of ABI.

9.3 The assessment must take account of the person's whole of life experience.

9.4 The assessor needs to have personal experience of the person with ABI.

9.5 If the assessors have only a health background, then this may place too much emphasis on the medical aspects of an assessment.

9.6 There is currently little understanding or awareness of the impact that the NDIS is likely to have on local government.

9.7 The NDIS needs to be aware of the gap between 'theory' and 'implementation'.

9.8 There is a danger of different organisations setting up different groups to look at issues (with a 'divide and conquer' orientation). We need to work together, rather than in silos.

- 9.9 If there are insufficient resources to fund the NDIS assessment process, then short-cuts are likely to be used (e.g. using rigid and arbitrary ‘cut off’ points, such as ‘4 hours per assessment’).
- 9.10 Given that resources are unlikely to allow a lengthy assessment process, the assessment should prioritise the ‘lived experience’ or functionality of the person with ABI—using a process that involves:
- a. open collaboration with all parties involved (carers, health professionals, neuropsychologists),
  - b. drawing upon information that already exists (e.g. using e.health), and
  - c. with ongoing reviews.
- 9.11 The assessment should cover the functional needs and cognitive impairments of people with ‘mild to moderate’ ABI, so that they can access early intervention so as to prevent a decline in their functional abilities and other social welfare issues (e.g. homelessness).
- 9.12 There should be a clear pathway (i.e. protocols) from day one for people with head injuries (e.g. ensuring they are properly assessed in acute care, and monitored through transition to their community).
- 9.13 The Mayo-Portland assessment tool is a useful model for people with ABI, in conjunction with (or as one among) a range of other tools.
- 9.14 Assessment tools should be applied appropriately to the scale of the impact of a brain injury.
- 9.15 It may be useful to have a tool(s) that functions as a ‘screening tool’, i.e. able to highlight basic cognitive, functional and physical issues that can then be referred to more specific assessments.
- 9.16 In terms of care and support needs, assessing functionality is more important than cognitive impairment (e.g. someone may know how to make a cup of coffee, but not be able, in situ, to make one). However, a neuropsychological assessment remains essential, because there is a link between cognitive deficits and recovering functionality.
- 9.17 There should be a multi-disciplinary approach to assessment, to ensure that (a) the links between a person’s cognitive, functional and physical impairments—as well as their actual and potential living environments—are captured; and (b) the support needs that result from this ‘whole of life’ assessment are properly resourced.
- 9.18 Assessments of a person’s functionality within ‘living environments’ should include not only (a) their actual or predominant situations (e.g. home, hospital), but also (b) potential or ‘aspirational’ situations (e.g. work, travelling, etc.).
- 9.19 The initial assessment should specify whether the person is likely to require ongoing assessment. However, the system should ensure that—even if this is not done—additional assessments are carried out as and when required. For example,

- individuals should be able to 'flag' this need, but where the person does not have this capacity, then other systems should be put in place (e.g. case managers, service brokers, DSOs, LACs could play this role).
- 9.20 Every person with a disability—especially for people with ABI—should be assigned a case manager (i.e. not merely a coordinator who contacts them once every 12 months).
- 9.21 Assessments need to be done in a timely manner. Sometimes needs change overnight. People cannot wait for the administration processes of government agencies or services, which are typically designed to prioritise organisational needs, rather than the needs of the client. Any assessment process must therefore build in maximum flexibility—in particular, the capacity to respond quickly to changing individual needs, i.e. without becoming entrenched in paperwork and 'system-processing'.
- 9.22 People's ongoing disabilities need to be recognised: people should not be continually assessed to determine the presence of disabilities that have already been identified as 'permanent'.
- 9.23 Greater clarity is needed around the linkages between the NDIS and mainstream services in cases of dual diagnosis or additional social issues (e.g. homelessness, imprisonment, mental health, drug and alcohol abuse, etc.)
- 9.24 The assessment should look at the person with disability as a person first, not as a disability (i.e. using a person-centred approach). Likewise, it should also look at the carers as persons first, not as carers.
- 9.25 Assessments should not only look at the needs that can be met using NDIS-funding, but include needs that could be met using alternative resources. For instance, informal (unpaid) social support networks and generic or mainstream (paid) services.
- 9.26 Greater clarity is needed about the 'assessment transition' between people currently receiving services and the NDIS – i.e. Will they need to be 're-assessed' by the NDIS? Or will pre-existing assessments be sufficient? How will duplication be avoided?
- 9.27 There should be greater sharing of information between service providers, health professionals etc. under the NDIS— with the qualification that the information shared is essential for the purpose of service provision.
- 9.28 The general public need to have an understanding of the definition of 'need' (as distinguished from 'want'), so that expectations are realistic.
- 9.29 The assessment should include identifying the positive goals or outcomes the person with a disability is hoping to achieve. But the assessor should take great care not to impose their own values on this process. Likewise, families should be aware of the need not to impose their own aspirations and needs on the person with a disability.
- 9.30 The assessments must take into account the fact that the person with a disability and their family/carers are the experts on their lived experience.

- 9.31 Assessments should include identifying the person's need for advocacy (i.e. someone who can 'stand beside and with the client').
- 9.32 The assessment process must be tailored to ensure that it meets the needs of particular cultures and ethnic groups, whilst also recognising that cultures are not homogenous: each individual must be taken 'as they are'.
- 9.33 Assessments must be available to people with ABI who are inside (or on the periphery) of the criminal justice system. These assessments must be able to identify early intervention strategies, resources and support systems that will enable them to keep out of (or not return to) the criminal justice system (e.g. currently, many reporting requirements are impossible for a person with ABI to keep).
- 9.34 The system needs to recognise that there will be a variety of different points of entry into the system (e.g. some people with ABI may only be diagnosed many years after the injury).
- 9.35 The assessment should be able to take account of how pre-morbid conditions impact upon the ABI (and vice versa).
- 9.36 There must be an independent review of the whole system to ensure that it is operating effectively for people with disability.
- 9.37 The assessment to be able to identify not only those needs that the assessor knows can, realistically, be met—but also unmet needs (i.e. where the existing funding or services are currently insufficient).

## 10. Launceston, Tasmania 1.30-4.30, 24 July 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Association of Tasmania	<b>Attendees:</b>	Fiona Bardenhagen, Amanda Bendt, Derek Brookes, Jacqueline Brown, Deborah Bryne, Kerry Finch, Pam Hesketh, Chris Hill, Eric Ind, Allan Johnson, Linda Jomartz, Liz Leslie, Maggie McKenzie, Steve Rouse, Hannah Rubenach, Mel Szczypka, Russell Walker, Leanne Wease, Moira Wellman, Pat Wrigley
<b>Type of Meeting:</b>	Consultation		
<b>Facilitators:</b>	Deborah Bryne and Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		
		<b>Apologies:</b>	Christine Buxton, Clinton Gillam, Linda Sheedy

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting, including subsequent written submissions (as noted).*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

- 10.1 The current MAIB assessment process is very good.
- 10.2 Outpatient rehabilitation in Launceston General Hospital is working well for people with ABI: it is a multi-disciplinary team, patient-centered model.
- 10.3 In some cases, Gateway provides in-home assessments to people in rural/remote areas who cannot travel to the city [written submission].

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

- 10.4 The assessment process must be fair and equitable: e.g. there should be consistency between assessments on a national level (must be the same for everyone everywhere).
- 10.5 There needs to be a sufficient number of therapists with neuro training to be involved in the assessment and support needs of an increased number of people with ABI entering the system under the NDIS.
- 10.6 Workforce capacity must be addressed at a national level if the NDIS assessment process is to be effective and fair for people with ABI. This will include:
  - a. providing additional resources to universities to train neuropsychologists,

- b. supporting the employment of neuro specialists in regional areas, and
  - c. providing specialist training to support staff and other allied health workers 'on the ground' who are working with people with ABI.
- 10.7 The assessment/eligibility decision-making process should be fair and consistent, not favouring those who 'shout the loudest' (as in the current system).
- 10.8 The assessment process must not exclude or discriminate against people with ABI who may be considered to have been 'at fault' (in terms of the origin of their ABI).
- 10.9 In cases of dual diagnosis (e.g. ABI and mental health), there should be a multi-disciplinary approach to intervention—i.e. neuropsychologists and clinical psychologists should work together with interventions.
- 10.10 Medical and allied health staff need to have a greater awareness and understanding of the symptoms of ABI, so that referrals are more likely to be made to the NDIS assessment process.
- 10.11 A neuropsychological assessment should be carried out either within acute care if appropriate or, if it is not picked up at this stage, by neuro specialists who are directly employed by the assessing agency for this purpose (e.g. Gateway).
- 10.12 There should be assessment reviews, the frequency and need for which should be evaluated on a case-by-case basis.
- 10.13 There should be a (re)assessment at significant transition points in a person's life (e.g. childhood to adult).
- 10.14 Service providers should have the capacity to recommend an assessment review for a client (a) without being penalised and (b) in a way that does not negatively affect their relationship with the client. Likewise, the client should have this same capacity, again with (a) and (b) as qualifications.
- 10.15 The process of assessment needs to be 'easy' for the client, so that they are not 'put off' from undertaking, requesting or consenting to an assessment (e.g. not duplicating information obtained from previous assessments, ensuring that clients living in remote areas can access an assessment process).
- 10.16 The management of assessment agencies should be trained to evaluate assessments (not merely, e.g., managers who are only trained in business).
- 10.17 The assessment process must not merely identify the care and support needs of the person with a disability, but also:
- a. ensure that the practical difficulties and costs involved for them in *accessing* the necessary support services are resolved (e.g. clients living in remote areas); and
  - b. include in the assessment the care and support needs of ageing or ill carers [written submission].

- 10.18 The cost of brokerage, case management or advocacy should not reduce the 'dollar value' of the package (i.e. so that people are not trading support for these services).
- 10.19 The people administering the NDIS assessment process must have training and experience in working with people who have a disability, and specifically people with ABI—rather than a generalist training. (This is a problem that has been identified as existing in Gateway).
- 10.20 Disability service providers—especially co-ordinators/managers—should be made aware of the behaviours that can result from ABI, as this may impact on their assessment of eligibility for programs and services [written submission].
- 10.21 The assessment process must be able to identify when a person with a disability may not have the capacity to acknowledge their disability, to be aware of their support needs, or to give their informed consent. To manage such cases, the following is recommended:
- a. a person should be employed by the NDIS specifically to engage in active monitoring (e.g. the LAC); and
  - b. the assessment process should identify a 'key contact person' who (i) is living with or has an ongoing relationship with the person with a disability, who (ii) they can call on a regular basis and who (iii) can arrange, on behalf of the person with a disability, for them to e.g. undertake assessment reviews, receive support services, and so on.

## 11. Coffs Harbour, NSW: 9.30-12.30pm, 9 Aug 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Association of NSW	<b>Attendees:</b>	Karren Alford, John Alford, Matthew Alford, Derek Brookes, Maggie Heffernan, Helen Wisi, Mark Collis
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

11.1 The brain injury rehab team were very good – they have tried so hard, and they really understand. But they kept coming across the same 'brick walls'.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

11.2 When I was assessed I felt that everyone was criticising me ('Helen you should do this/do this better'). Looking back it was fine, but at the time I felt like I couldn't do anything that pleased anyone. Some of them were a bit 'snarly' (not all of them). Some of the tests I couldn't do because they were so hard (even my husband said he would find it hard to do some of them).

11.3 The assessment didn't focus enough on the roles and responsibilities that would have to be taken on by the carers/family—and the care and support that they would need.

11.4 The assessment didn't focus on areas that really matter: e.g. learning how to talk to your children again, whether the home environment is suitable (such as stairs), the need to provide support for siblings.

11.5 There is no support for siblings, families and single people at all in regional areas (e.g. siblings often feel the need to exaggerate any illness or injury just to get some attention; after we left the hospital we were left on our own).

11.6 If there isn't a service available, the medical profession will simply leave the issue 'unassessed'.

- 11.7 Different medical professionals won't communicate with each other, because each has their own little turf and don't want to 'lose business'. They are on the same email system in the same health system, so the fact that they don't communicate doesn't make sense.
- 11.8 There does not seem to be a 'brain injury specialist' in the area that can identify whether certain medications or therapies will 'work'.
- 11.9 There was too much focus on the medical side and not the human side.
- 11.10 The assessment seems to be very subjective – it depends upon who is conducting the assessment, what sort of day they happen to have had. It needs to be more objective and reliable.
- 11.11 Most marriages (where there is either a child with ABI or a partner with ABI) break up within the first 6 years. Therefore it is even more critical that support be provided to the family.
- 11.12 An ABI can make a family stronger and they will often 'step up to the mark', but this should not be taken for granted or 'expected' by the system.
- 11.13 The health system should provide feedback to any correspondence that the family or person with ABI sends to them (e.g. registering that they have received it, saying 'thank you', and not take an excessive duration to provide essential reports to the family—e.g. the results of neuropsychological assessments).
- 11.14 There is no understanding about or consideration given to the distance that a person with ABI has to travel (e.g. not giving appointment times that take into account the time it takes to travel, delays to the appointment).
- 11.15 One problem is the number of different places you need to go to get the assessment completed—this should be centralised. And often there is no communication between them, so you need to repeat information given. This is not time-efficient. If they worked together they would achieve a lot more.
- 11.16 In regional areas, the limited funding means that there are not enough health professionals to manage the number of people who require a service. E.g. the waiting list for OT for a person with ABI was 18 months. So the parents had to try to teach them (because they have to do something), but they don't have the training or expertise and so are constantly unsure of whether they are 'doing the right thing'.
- 11.17 The block funding arrangements don't work because when the funding for the organisation runs out, the service is no longer available to the person with ABI.
- 11.18 People who are responsible for helping people with ABI don't seem to have a proper understanding of ABI (e.g. expecting muscle use to make them 'stronger', when, because of the ABI, there is muscle wastage and the loss of coordination). This includes school-teachers, OTs, physios, GPs, etc. So:
  - a. there should be better education in ABI across the board; and

- b. the assessment of a person's functionality (not merely physical but also cognitive and behavioural) should be passed on to those who will be providing support and care.
- 11.19 Schools need to be required to recognise ABI as requiring proper support and care (cognitive deficits do not fit in to any boxes). For instance, students with intellectual disabilities have support aides, but students with ABI do not have adequate support in the school context. Teachers don't understand how children with ABI can 'present well' or have 'episodic' issues.
- 11.20 Assessment doesn't take account of the support needed to enable children to (a) develop relationships with other children, (b) establish new routines at school, (c) manage bullying (e.g. by educating teachers on how to protect children with ABI).
- 11.21 The follow-up to assessments is pathetic (e.g. there's no feedback, no checking on the progress or implementation of outcomes from the assessment).
- 11.22 The assessment should make sure that the kind and level of care and support provided by family members is both (a) 'reasonable' (e.g. in terms of both time commitments and financial costs) and (b) done 'willingly'.
- 11.23 Cognitive injuries are 'invisible' to most people—will the NDIS assessments recognise the fact that what people with ABI say may not be accurate (e.g. because of confabulation, lack of insight or an unwillingness to reveal or talk about cognitive deficits)? Will the assessor prioritise what the family/carers say about the person with ABI over the person with ABI?
- 11.24 If there is only one assessor and they take a dislike to the family or person with ABI, that should not affect the outcome. It must be an objective process, with the ability to review the outcome with independent assessors.
- 11.25 A person with ABI may not require 24/7 physical care, but that doesn't mean they are 'safe' 24/7. Cognitive deficits can lead to inappropriate behaviour that can be dangerous (e.g. "There are times when I don't have an 'edit button' that stops me from saying or doing things."). The presence of these behaviours can be difficult to identify in a short face-to-face interview with the person with ABI. So the assessment needs to take into account the day-to-day observations of those who live with the person with ABI (i.e. the assessor needs to listen to the family and take it seriously rather than only taking into account medical reports or the views of health professionals).
- 11.26 Assessors of people with ABI need to have a specialist understanding of ABI.
- 11.27 Often family do not want to ask for help, but when they do they don't know who to ask. And many services 'pass on' the problem to other agencies ('we can't help you, but such-and-such can'). There needs to be one central agency or case-worker who can help to find all of the support that's needed.
- 11.28 GPs don't always understand ABI, and even when they do, they don't know how to access support.

11.29 The mental health team are not willing or able to distinguish between (a) genuine depression, OCD or other mental health issues and (b) the symptoms of ABI. They automatically classify any signs of mental health issues as a consequence of ABI (i.e. without conducting any proper assessment). As a result, a person with ABI who has mental health issues is not able to get access to funding for psychological care and support.

## 12. Coffs Harbour, NSW: 2.45-4.00pm, 9 Aug 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Association of NSW	<b>Attendees:</b>	Elaine Baxter, Clare Brennan, Derek Brookes, Teresa Chard, James Charles, Stephen Comerford, Leonnie Davids, Marion Dwyer, Colin Everingham, Jacquie Goodhen, Jasmin King, Jamie Lawler, Elise Merzlikoff, Katherine Miller, Kathy Newton, Fran Pearce, Jason Pell, Daire Phillips, Jan Roads, Bev Talyor, Joanne Watters, Catherine Winn
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

12.1 n.a.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

12.2 The needs of carers and children are not given enough attention in the assessment process.

12.3 The assessment focuses entirely upon the clinical aspects of the person with ABI, rather than their functionality (relationships, day-to-day experiences, behaviour, etc.)

12.4 When the relationship of the carers breaks down, there is no clear pathway for the person with ABI in terms of how they can now obtain the support that they need.

12.5 In the discharge phase, social workers are unaware of where to send the person with ABI. There is a lack of information at this point.

12.6 Assessors of people with ABI require specific training or education in (a) ABI and (b) the range of services and health professionals available in the region.

12.7 There is often inequality in regional areas. Resources that are available in urban areas are, in isolated areas, either not provided or they are prohibitively expensive. This can mean that assessments are not carried out (e.g. due to the lack of footpaths for wheelchair dependent persons).

- 12.8 Because needs and circumstances change over time, the assessment process should be ongoing, not limited to a one-off, initial assessment.
- 12.9 The assessment outcomes should be held in a common, national data-base that is available to disability services, so that they are not 'lost' and do not need to be repeated when the person with ABI changes or engages a new service.
- 12.10 The assessment should not be so generic that it fails to capture needs that are specific to particular disabilities—e.g. brain injury.
- 12.11 The assessment should include all parts of a person's functioning, not merely IQ.
- 12.12 The assessment process should not discriminate between clients who are (a) easy to assess and support, and those who are (b) more complex—e.g. clients with challenging behaviours, less of an ability to self-manage funding, or requiring long-term assistance and monitoring.
- 12.13 The cost of assessments in rural areas needs to be taken into account in any national 'cost setting'. This is particularly relevant when the assessments are ongoing or when there is the need for 'on site/home assessments'.
- 12.14 The person with ABI and their carer should be assessed independently, given the possibility that there will be disparity between the two (due to, e.g. lack of insight).
- 12.15 The assessment of carers should be ongoing, given the likelihood of changes in accommodation and/or a deterioration in their capacity to provide support.
- 12.16 The assessment should be (a) 'informative' (i.e. informing who needs to know what needs to be done, what needs to happen.), (b) very helpful and (c) rewarding and comforting to the person with ABI (e.g. not telling them that they will 'end up in a nursing home').
- 12.17 The requirement for re-assessment should be 'built in' to the assessment process, rather than merely reactive (e.g. after given time period, a re-assessment should be automatic); and the person with ABI and their family should be made aware at the outset that re-assessment(s) will occur.
- 12.18 The assessment should be holistic —medical, social and functional.
- 12.19 Those who are involved in the assessment 'circle of support' also require specialist training and education in ABI.
- 12.20 Assessors need not only a 'paper-based' knowledge of ABI, but also a good understanding of the 'lived experience' of people with ABI and their families.
- 12.21 Assessors should be accountable for their decisions. This is particularly important for people with ABI, given the potential for challenging behaviours.
- 12.22 How the assessment is delivered should be flexible, i.e. tailored to the communication needs of the person with ABI.

- 12.23 Under Tier 1, the general public needs to be informed about the specific symptoms and needs of people with ABI. This is partly so that people who are currently unaware that they have an ABI will be more likely to request a proper diagnosis.
- 12.24 The assessment process will require the specific tools necessary to:
- a. identify co-morbidities (e.g. mental health, drug and alcohol, etc.) and
  - b. avoid misdiagnosis, which might thereby exclude them from eligibility to NDIS-funding.
- 12.25 The assessment process must be able to engage those who have not yet been diagnosed and who are unlikely to put themselves forward (e.g. homeless, prisoners, etc.).
- 12.26 There needs to be a process that enables a person with ABI to challenge the outcome of an assessment.

### 13. BIRD Directors/Officers', NSW: 10.30-11.15am, 10 Aug 2012

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<b>Type of Meeting:</b>	Consultation	<b>Attendees:</b>	Derek Brookes, Mandy De Roover, Marion Fisher, Matt Frith, Jeremy Gilchrist, Irene Gordon, Dr Adeline Hodgkinson, Dr Angie Morrow, Narelle Miller, Jane Murtagh, Nick Rushworth, Barbara Strettles, Kathryn Vaughan, Liesel Younger, Denise Young
<b>Facilitator:</b>	Dr. Derek Brookes		
<b>Notes Taken By:</b>	Dr. Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

#### **Discussion questions:**

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

13.1 N.a.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

13.2 People with 'mild' to 'moderate' ABI should be included within the scheme.

13.3 The assessment should be able to distinguish between ABI and co-morbidities.

13.4 Assessors must be trained and approved/accredited in ABI so as to ensure that

- there is consistency in how the tool is applied, and
- cognitive impairment will be properly identified.

13.5 The assessment should take account of the fact that certain aspects of a person's functionality can only be identified when they are in a complex environment (e.g. workplaces).

13.6 The assessment must be able to distinguish between (a) support needs that are clearly linked to a person's disability, and (b) needs that arise from pre-existing or otherwise unrelated socio-economic disadvantage.

13.7 The aetiology of the ABI must not be a barrier to receiving NIDS-funded support.

13.8 People with co-morbidities (e.g. drug and alcohol misuse) should not be able to 'double dip'.

- 13.9 The assessment needs to take into account the 'state' of the person at the time of the assessment (e.g. are they under the influence of drugs or alcohol?).
- 13.10 The assessment should not be limited to the tools that are currently available. If there is sufficient evidence that a new tool is more effective than an existing tool—e.g. in terms of validity and/or reliability—then it should be included.
- 13.11 The assessment process should not rely upon one 'generic' tool, but should include a range of tools that can be applied, as needed, over time. This should include tools that are specific to cognitive impairment.
- 13.12 There should be clarity about the 'exit' process for the NDIS.
- 13.13 Social/community participation is an essential aspect of a person's support and care needs, and so should be taken into account in any assessment process.

## 14. Paramatta, NSW: 9.30-12.30pm, 13 Aug 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Association of NSW	<b>Attendees:</b>	Phillip Behr, Colin Brodie, Derek Brookes, Anne Fahey, Glennen CC Fahey, Jim Grainda, Mark Hammond, Robyn Hosking, Julia Frost, Nerida Johnston, Patricia Lynch, Naty Millarez, Paul Raciborski, Jenny Rossini, Rob Wansbrough, Gillian Woodcock
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Dr. Derek Brookes		
<b>Notes Taken By:</b>	Dr. Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as ‘best practice’ in your region? What should be included in the new scheme?

14.1 n.a.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be ‘carried over’ into the new scheme?

In the following responses, ‘assessment’ refers to both (a) the assessment of the condition (diagnosis) and (b) the assessment of a person’s support and care needs:

14.2 Many clients are not even aware of what is happening, in terms of how to access funding or care and support. For example, they are being cared for by family members, and are not aware of the availability of an assessment process that might lead to funding their support needs. So, under an NDIS, there should be greater transparency about and clear and specific information (i.e. documentation) provided to people with ABI about the fact that an NDIS assessment process exists. This ‘communication’ of information should take into account the cognitive impairments of people with ABI (e.g. memory loss) and the ‘lived experience’ of carers (e.g. often struggling to survive on a day-to-day basis, and to cope with what has happened to their loved one).

14.3 The assessment process needs to take into account the transitions that people with ABI move through—i.e. ensuring that the assessment is undertaken *periodically* and *over time*, rather than only as a one-off event.

14.4 There are situations where a person with ABI has no one who can ‘drive’ the assessment (ensuring that it takes place).

- 14.5 The assessment process must be capable of taking into account pre-existing conditions (e.g. someone who is already intellectually handicapped may have behavioural changes as a result of ABI that are identified by their carers).
- 14.6 The assessment process must be able to distinguish between the symptoms of ABI and mental health issues (e.g. depression)—whether they were pre-existing or have arisen as a consequence of living with ABI.
- 14.7 The assessment should take into account the possibility that the person with ABI may not be cooperating with the assessor—and that the carer’s opinion regarding this should be taken seriously.
- 14.8 The assessment should be more comprehensive or holistic. It should not focus merely on medical issues or one particular support need (e.g. accommodation), but whole of life issues (e.g. relationships with family members).
- 14.9 There should be a greater awareness about the causes (e.g. stroke, concussion) and impact (e.g. social skills) of brain injury and the need for a proper assessment.
- 14.10 In cases of brain injury that do not involve an accident or trauma (involving hospitalisation), an assessment must still take place.
- 14.11 Currently there is no automatic ‘follow-up’ from an assessment—i.e. in terms of ensuring that care and support needs are put in place. This typically tends to be driven by a carer, even when the person is in the Brain Injury Unit. The assessment process (and the provision of whatever support needs are thereby identified) should be instigated and driven by the NDIS, not the client.
- 14.12 The assessment process should be undertaken either by the same person or information should be passed on to any additional assessors—a process that should be overseen by a case manager.
- 14.13 The motivation of the assessment should not be to meet the interests of an organisation or disability service, but rather the interests and needs of the client (e.g. where the assessment is designed to evaluate whether a young person can be placed in a aged care facility).
- 14.14 The assessment must be able to take into account the hidden impact of brain injury (e.g. loss of initiative).
- 14.15 The assessment process should take into account the fact that needs change over time—and so there should be re-assessments.
- 14.16 There should be greater consistency across and communication between medical practitioners and health systems.
- 14.17 The assessment should include not merely the identification of ‘basic survival’ support needs, but also what a person needs to enhance their quality of life and to reach their ‘life aspirations’.

- 14.18 The assessment process should be managed by the NDIS over the time of the person's needs—which includes the transition from hospital and ongoing assessments.
- 14.19 There should be a national database that includes a person's documentation that—with the consent of the client—is made accessible to both (a) the client and (b) those involved in the assessment and care of the person with ABI (so that information is not 'lost' and does not have to be constantly repeated). It will need to be possible for state-based services to access this national database. (The consent of clients should be one-off, not continually required.)
- 14.20 The eligibility criteria must be transparent to people *before* they take the assessment.
- 14.21 If people are assessed as not meeting the criteria for NDIS-funding then should then be given information about how to access other sources of funding or assistance.
- 14.22 The assessment of whether a person is entitled to NDIS-funded support should not be linked to their income—e.g. if a person undergoes rehab and begins to earn an income that should not automatically result in the loss of their NDIS-funding (i.e. where the identified support needs remain).
- 14.23 The NDIS assessment should not be modelled on Centrelink (e.g. losing documentation, being considered 'guilty until proven innocent', patronisation of clients, etc.).

## 15. Paramatta, NSW: 1.30-4.00am, 13 Aug 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Association of NSW	<b>Attendees:</b>	Cathy Bouvy, Derek Brookes, Stephanie Challer, Samantha Frain, Lara Friedman, Wendy Hill, Jane-Maree Hurley, Anthea Karatasoulis, Cheryl Lynn, Kathy Prasad, Anne Reidy, George Samuel, Lindy Williams
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Dr. Derek Brookes		
<b>Notes Taken By:</b>	Dr. Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

15.1 n.a.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

15.2 The assessment process should use a 'toolbox', not one tool only.

15.3 The NSW Lifetime Care's eligibility criteria (score of 5 on FIM) and its assessment tool (FIM) is inadequate for people with ABI. For example, the tool is unable to capture changing support needs, and an accurate diagnosis.

15.4 The toolbox should cover behavioural issues, neuropsychological issues, OT, personal care, the overall functionality of a person (e.g. covering communication, social skills, day-to-day functioning, stage of life, age-related issues, gender, cultural diversity).

15.5 The assessment should identify viable pathways to treatment.

15.6 Eligibility should not be based on the outcome of one tool only, but a composite score taking into account the full range of tools used.

15.7 The delivery of assessments should be transparent and accountable, so that, e.g. the outcomes are not distorted by the 'incentive' to reduce the number of people who can enter the system or have access to the kind and level of supports that they need (cf. the privatisation of assessments in the UK, currently contracted out to ATOS).

15.8 The assessment should specify not only the number of hours of care required but also the level of skill needed in the carer.

- 15.9 Both (a) those who are making decisions about whether or not to approve the kind and level of support needs identified in the assessment (b) and the assessors must be trained and have substantial experience in the disability sector.
- 15.10 There needs to be thought given now about the number of case managers (LACs) that will be needed, and how best to ensure that they have the qualities, values and training required (e.g. capable of using a person-centred approach).
- 15.11 There should be measureable outcomes that case-managers are required to achieve, so as to ensure quality, accountability and transparency.
- 15.12 There should be (a) an easy, clear and transparent appeals process, as well as (b) an advocate or case management service to appeal on behalf of people who feel they have not been properly assessed.
- 15.13 The 'circle of support' model will need to take account of (a) the limited availability and costs of health professionals; (b) the challenges that some families may present (e.g. lack of insight, different goals to the client, unrealistic expectations, etc.)
- 15.14 Case management must be available for those clients who cannot (or do not want to) advocate for themselves. This should either be (a) one central person or (b) a framework in which the case management is quickly and comprehensively 'passed on' to other staff (i.e. information about the client is handed on or is centrally accessible).
- 15.15 The cost of case management or brokerage should not be drawn from (i.e. reduce the amount available for) their care needs, but should instead be factored into the total package at the assessment stage.
- 15.16 The person with a disability should be able to choose their own case manager and have the option to transfer to another one, rather than have them allocated.
- 15.17 There should be an explicit distinction made between (a) the actual support needs as identified in an assessment and (b) those needs that can be NDIS-funded—i.e. without the former being simply reduced to the latter. In other words, the system must be able to identify the extent to which a person's support needs are NOT being met by the NDIS by referring to the assessment.
- 15.18 The assessment should provide links to mainstream services that are able to meet those support needs that cannot be met by the NDIS.
- 15.19 Don't model it on the NSW Lifetime Care System (e.g. In 'The Panel System' a lot of services are excluded because they will not agree to, say, the pricing structure set out by the System).
- 15.20 The NIIS assessment of catastrophic injuries must take into account the support needs that arise due to non-catastrophic injuries (e.g. when a person in a MVA has a spinal injury with fractures, the NIIS should provide funding for both types of injuries.)

- 15.21 The assessment should be able to identify mental health issues that arise as a consequence of ABI (e.g. depression), and ensure that there are linkages between the NDIS and mainstream mental health services (i.e. there should be a 'no closed door' policy).
- 15.22 The system needs to be flexible to meet people's needs (e.g. in a rural environment, it might be more cost effective to employ a friend or neighbour to meet their support needs; recognising that some kinds of assistance do not require specialist training; allowing people with a disability to identify the likely risks to themselves).
- 15.23 With regard to the assessor/circle of support model, the decision-making power should reside with the circle of support with the assessor playing an 'oversight' or 'review' role to ensure the accuracy and fairness of the decisions made. This would better reflect the person-centred philosophy behind the NDIS.
- 15.24 There should a transparent process that specifies (a) when a person who has not met the eligibility criteria can be 're-assessed'; (b) the process that they would need to take to do so; (c) how long it will take for a person's support needs to be re-assessed when their circumstances change (e.g. they've been arrested, they've lost a primary carer, etc.).
- 15.25 The NDIS should take a pro-active, anticipatory approach to re-assessment (e.g. identifying normal or ordinary life-transitions, such as school-leaving or moving home, that are likely to require a re-assessment)—rather than being merely reactive (i.e. waiting until a crisis or a traumatic event occurs).
- 15.26 The assessment should not be distorted (i.e. omitting care needs) because of the need to gain sufficient funds for costly equipment.
- 15.27 The assessment of whether a person needs equipment should not be based upon the extent to which it will reduce their care needs.
- 15.28 The assessment should be able to identify what will ensure that the person has the highest possible quality of life, not what is merely 'adequate'.
- 15.29 The assessment must be able to distinguish between ABI, co-morbidities and other disabilities, so that they will have access to the support that is required to meet the needs that arise from the ABI (e.g. at present, when the person has a spinal injury funding bodies will not fund or are unlikely to even diagnose ABI support needs).

## 16. Dubbo, NSW: 10.30-12.30pm, 17 Aug 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Association of NSW	<b>Attendees:</b>	Derek Brookes, Max Hill, Anthea Karatasoulis, Roslyn Leonard, Narelle Miller, Bev Taylor
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Dr. Derek Brookes		
<b>Notes Taken By:</b>	Dr. Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

16.1 n.a.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

16.2 When assessing the support needs of a person with ABI, the assessor needs to identify what their holistic needs are *apart from or independently of* the support that is currently provided by existing carers. This ensures that when/if the carers (or their circumstances) change, (a) the person with ABI will still be able to access the support needs they require, and (b) will not need to undertake a new re-assessment.

16.3 There should be an expectation that reviews will take place (a) regularly (e.g. annually) and (b) when significant life transitions are taking place (e.g. aging). These reviews should not be dependent upon the initiative of the person with ABI or their carers.

16.4 People are likely to have an inherent fear of losing funding when reviews take place. This should be taken into account, e.g. by reassuring them (not merely in theory, but in practice) that the funding is 'needs-responsive'. In other words, the purpose of the review is not merely to reduce funding but to ensure that a person's needs are accurately and fairly identified and supported. For example, NDIS-funded support could *increase* if and when new needs are identified (e.g. a deterioration in their condition).

16.5 There are cases in which a person with ABI will not have the cognitive skills necessary to initiate requests or engage with medical/support systems and staff. In such cases, the NDIS should actively take steps to identify and then ensure that there is at least

- one person who is able to act and make decisions on their behalf (with the consent of the person with ABI).
- 16.6 This would need to be someone (a) who the person with ABI trusts and can engage with; (b) who has both a good understanding of ABI and how to navigate the system; and (c) who is culturally appropriate for the person with ABI.
- a. There would also need to be some oversight or monitoring to ensure that this person is acting in the best interests of the person with ABI.
  - b. The funding for this person should not come out of the funding that is required to meet their support needs. People needing such a person should not be disadvantaged *just because* they have that need.
- 16.7 The assessment should not compromise a person's attendant care needs due to the expense of equipment, aids or modifications needs (or vice versa).
- 16.8 The assessment should identify supports (e.g. equipment) that will improve a person's quality of life, even if (a) the person with ABI or their family/carers are unaware that these exist, or (b) those supports haven't previously been available for whatever reason—particularly where these supports are essential to meeting a person's long term goals and aspirations.
- 16.9 The assessment should try to identify ways in which the carers can improve their own quality of life (e.g. planning respite, designing return to work or further education strategies, planning a transition to independent living, counselling, providing education about the disability, etc.). In other words, the assessment should include a plan that focuses on how best to meet the needs and life-aspirations of both (a) the person with ABI, and (b) the family/carers.
- 16.10 The assessment should not force either a person with ABI or their carers to choose between (a) obtaining NDIS-funded support and (b) pursuing their life-goals (e.g. employment, education, etc.)—that is, by making the funding dependent upon current income and/or assets.
- 16.11 The assessment should identify:
- a. if/when a person with ABI's challenging behaviour is preventing them from being able to access services (e.g. in a small rural area, a person with ABI may develop such a 'bad reputation' with the few services available, that they refuse to engage with them); and
  - b. strategies that will ensure that they *can* access a service (e.g. (i) providing a higher level of funding as an incentive for services, (ii) linking the person with an advocate who can engage with and educate the services on their behalf, etc.).
- 16.12 It may be more culturally appropriate, in Indigenous communities, to use assessors who do not have a pre-existing relationship with the person with ABI or who are well known in the community (since they don't want to share their 'business' or risk having it 'spread around' the community). However, there should be flexibility, since some people would prefer to talk to someone they know.

- 16.13 The principle of using assessors who do not have a pre-existing relationship with the person with disability should be applied ‘across the board’, given the potential for conflict of interest or unfair advantages (without losing the flexibility needed to allow for special cases).
- 16.14 The cost of travel to access a disability service (or to provide a service) should not be taken out of the funding required to meet a persons support needs. So:
- a. the assessment should identify these travel costs and ensure that they are included in the total funding package; and
  - b. any NDIS regulation of ‘unit costs’ should factor in travel costs for the service provider.
- 16.15 The assessment should identify ‘substitution possibilities’ in the provision of care: for example, if a person with a disability would prefer that a family member attend to certain kinds of needs (e.g. dressing), but that cannot be done unless activities that would otherwise be carried out by the family member are performed (e.g. cleaning), then it should be possible for the NDIS to fund someone to do the latter.
- 16.16 The assessment should be able to accurately and fairly identify when a person is unable—due to their disability—or unwilling to self-manage their funding.
- 16.17 The assessment should take into account the fact that assessment tools are generally context-dependent, which is particularly problematic for people with ABI. For example:
- a. the cognitive/behavioural abilities of people with ABI are likely to be influenced by the fact that a hospital is a structured and controlled environment, and so it is likely that there will be a significant difference between an assessment that takes place in the hospital as compared to the community;
  - b. most tools only capture a person’s condition *at a particular time*, rather than *over time*—however, a person with ABI can improve as a result of rehabilitation, or they may, at some future point, come to be affected by new co-morbidities, drug and alcohol misuse, a secondary ABI, etc..
- 16.18 A neuropsychological assessment will provide a far more detailed and accurate picture of cognitive impairments than more generic tools (e.g. FIM, FAM), and so should be made available and NDIS-funded as an essential part of the assessment for people with ABI.

## 17. Dubbo, NSW: 1.30-4.30pm, 17 Aug 2012

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<b>Meeting Called By:</b>	Brain Injury Australia and Brain Injury Association of NSW	<b>Attendees:</b>	Derek Brookes, Gail Carling, Natalie Coad, Cassie Gardner, Kylie Hacker, Anthea Karatasoulis, Iain Morgan, Andrew Murray, Cecily Murray, Bev Taylor, Isabel Wallace, John Wallace
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

17.1 When the assessment process took into account the views of (a) the family, and (b) other experts who have had a long-term relationship with the person with ABI, this meant that the decisions made were more likely to work in the long term (i.e. because the assessment focused on what the person with ABI and the family wanted to happen, not just what the services or the assessor wanted to happen).

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

17.2 Assessments should be held on a national database (with confidentiality restrictions), so that (i) people with ABI and families do not have to be repeatedly asked for information by medical practitioners, service providers, etc.; and (ii) all those involved in providing a service can have access to—and so can make decisions based upon—the same information.

a. This database should be kept up to date (with the results of re-assessments/reviews), so that obsolete assessments do not prevent people from accessing a service.

b. This database should also be integrated or linked with other relevant databases (e.g. e.Health).

17.3 The assessment process should assist the person with ABI and carers to locate services that will meet the needs that have been identified.

17.4 The person making the assessment must have a good understanding of ABI.

17.5 The assessment should identify needs that exist across a range of contexts, not just home – for example, the supports needed:

- a. to attend and reach their potential at school;
  - b. to access certain physical environments, like the beach;
  - c. to engage in a meaningful occupation; or
  - d. to participate in the mainstream community.
- 17.6 The assessment should not be ‘an end in itself’, but only the start of a process that will link up with service-provision.
- 17.7 GPs should have a good understanding of ABI, since they are likely to be a key person for initiating a request for a NDIS assessment.
- 17.8 The assessment should identify ‘whole of life’, practical, day-to-day issues (e.g. banking, paying bills, purchasing food, cleaning, etc.) that, with the right kind and level of support, will enable a person with ABI to live independently (e.g. ‘drop in support’, ‘supported accommodation’, etc.).
- 17.9 In a public school system, there is only block funding—which is ‘one size fits all’ (what is funded is not matched to the specific needs of the child). In the private system, the school only gets a 1/3 of the funding, and so has to make up the shortfall—which means that the support provided can be, as a consequence, better tailored to the needs of the person with ABI.
- 17.10 The assessment should take into account the ‘ripple affect’ on other members of the family (e.g. siblings, parents) of a person with ABI—that is, by identifying the kind of support they will need to maximise both (a) the quality of the care they are providing, and (b) their own quality of life (noting that the two are inter-dependent).
- 17.11 The assessment must be as objective as possible, and not be so dependent upon the personality, values and qualities of the assessor (e.g. assessments should be independently reviewed). Nevertheless, assessors should be selected on the basis that they have the appropriate values and qualities.
- 17.12 Assessment reviews should (a) take place regularly (e.g. every 6 months), and (b) record any improvements or deteriorations as compared to the previous assessment.
- 17.13 The assessment should identify potential barriers to the person with ABI receiving ‘equal opportunities’ (e.g. access to rental properties, the cost of housing or car modifications, etc.); and how best to remove or avoid these barriers (e.g. linking up with an advocate).
- 17.14 The assessment should cater for those who fall outside the usual pathways (e.g. a person with ABI who is not yet aware of or willing to admit that they need support; their life circumstances are so chaotic that issues other than ‘getting an assessment’ or ‘engaging with the system’ become the priority). For example, consideration should be given to building flexibility into (a) the time frame for completing an assessment tool, or (b) the time of day or place at which the assessment will take place, etc.. People should not be excluded from accessing a NDIS assessment simply because they are unable (for legitimate reasons) to ‘fit in’ with the normal ‘pathways’.

## 18. Teleconference, NSW: 9.30-11.15am, 23 Aug 2012

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<b>Session Called By:</b>	Brain Injury Australia and Brain Injury Association of NSW	<b>Attendees:</b>	Arienne Bourne, Derek Brookes, Dallas Tanner, Bronwyne Chapman, John Roach, Robyn Russell, Vicki Solomon, Greg Williams
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes	<b>Apologies / unable to attend:</b>	Tracye Bush, Alison Porritt, Denis Ginnivan, Steven Hindle, Emily Joseph, Jillian Kirwan-Lee, Cate Millar, Trish Mulham, Helen Tuxworth, Roger Rees

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation teleconference.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

18.1 The Goulbourn Unit has been providing good support to people with ABI in the assessment process (e.g. assessing people's daily living skills, particularly when the person with ABI is unaware of their capacity).

18.2 In Illawarra, during the rehab phase, things are going well.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

18.3 The Goulbourn Unit has not been so useful in providing support to people back in their home environment.

18.4 The assessment needs to be more holistic, i.e. a 'whole of life' assessment rather than merely physical needs (the needs are all so interconnected)

18.5 In Illawarra, we are more worried than anything about being swamped by a bigger organisation that doesn't specialise in people with ABI, particularly given that specialist expertise is limited.

18.6 There should be plans put in place for when a person's main carer is no longer able to care for them.

18.7 There should be more funding made available to provide more appropriate accommodation for young people with ABI (i.e. not nursing homes or hospital wards)

- 18.8 Most clients with ABI would like to be better supported in their own living environment—i.e. having greater independence within or rather than shared accommodation.
- 18.9 For people with ABI that have co-morbidities (e.g. stroke), being referred for services outside the hospital setting is inconsistent and there is no assessment tool for case management to work through with the hospital.
- 18.10 The assessment is not mandatory for someone with ABI. The family are also not assessed for their needs, which is critical given that their life circumstances will have changed so much following the injury.
- 18.11 The assessment must be comprehensive and fair for all people: some people are properly assessed, and others are not at all or only once they are in the community, in which case many of the problems of setting up within the community can be much more difficult (particularly for people with ‘mild’ ABI).
- 18.12 The range of services made available to people with ABI is too prescriptive and not sufficiently comprehensive.
- 18.13 One consequence of providing a comprehensive assessment with proper links to services is that the person with ABI and their families are less likely to experience a ‘second crisis’ (e.g. relationship breakdown, drug and alcohol issues, debt problems, etc.).
- 18.14 People with ABI living in a rural area are likely to receive no rehab, given the lack of specialist expertise available.
- 18.15 The NDIS should not be set up exactly like the NSW Lifetime Care, given the number of problems that currently exist, particularly for people with ABI: For example:
- a. Lifetime Care does not fund support for families who are experiencing, e.g. depression, stress, relationship breakdown.
  - b. Lifetime Care uses the FIM tool, which has categories of concern, in particular psychosocial function (which requires a score a 5 or below to be eligible). The problem here is that because the assessment for lifetime care is done after 2 years, a person might, at this point, be doing quite well because of the external supports they are receiving, but because of this they might not then qualify for life-time care and so lose their case manager and all the external support services. If they were measured 6 months later, the assessment would show that they required support—but because the eligibility time frame is limited to the 2 year assessment, there is no opportunity for re-entry into system. So the assessment needs to be used in a way that takes account of people’s changes over time.
  - c. Mild to moderate injuries are often not eligible for NSW Lifetime Care because of the post traumatic amnesia of 7 days cut off point.
  - d. Under NSW Lifetime care, you can only access an accredited attendant care agency, which means that smaller agencies that do not have the capacity or

resources to become accredited. Yet it is the smaller agencies that are more likely to be able to offer a specialist service to people with ABI.

- e. Lifetime Care's 'community participation' is not funded to provide 'leisure' (under that terminology). However, access to leisure is very important to a person with ABI's psychosocial improvement over time, and so support for this should be funded by the NDIS (e.g. funding transport or attendant care so that they can access leisure activities).
- 18.16 Young males often do not want more rehab after hospital (e.g. because of lack of insight), and many only want rehab after 1-2 years. However, substantial improvements toward independent living can be made even if the rehab is provided many years after the brain injury.
- 18.17 Support services should be age and access appropriate. For example, young people should not be restricted to transport/attendant care on a 9-5 basis—so that they can, e.g. access sporting events on the weekend, socialise with their friends.
- 18.18 People with ABI should be provided with education and assistance with how to access the support services that are available.
- 18.19 People with ABI can be assessed as functioning well across a range of broad areas, and yet there can be small but significant 'gaps' in their capacity to access services and live as independently as possible (e.g. not being able to write an email). The assessment should ensure that these 'gaps' can be identified
- 18.20 The assessment should not be based upon the philosophy that 'people should not expect too much out of life'. It should identify all those aspects that will ensure that people with ABI can reach their life goals and aspirations.
- 18.21 The NDIS assessment must incorporate the support needs of the family, given the crucial role that they play in supporting the person with ABI—this is because the level of independence that is possible for a person with ABI is often far more compromised than other physical disabilities.
- 18.22 There are assessment tools for measuring the support needs of carers, but it is not clear whether these are adequate—insofar as they may not capture the capacity of people who are caring specifically for people with ABI.
- 18.23 Long term ABI-specialist case management would be a way of providing people with ABI and their carers with 'individualised' education, access to services, putting in place long term strategies, etc.. A funding package on its own is not sufficient—it requires this kind of case-management or 'oversight'.
- 18.24 There is a danger, under the NDIS's self-directed funding model, that larger generic services will take over the smaller specialist services.
- 18.25 There needs to be an Indigenous project officer who can create a link between Indigenous people with ABI and services.

- 18.26 There needs to be a culturally appropriate assessment process for Indigenous people with ABI. However, there also needs to be a way of engaging Indigenous people with ABI so that they can 'request' or be encouraged to take part in any assessment process.
- 18.27 There should be a greater awareness in the community of the differences between ABI and congenital disabilities (e.g. ID). There is also a concern that these differences may be overlooked if there is a transition over time toward generic services.
- 18.28 Funding must be based on the assessment of needs rather than merely on diagnosis (degree of injury).
- 18.29 The assessment must be ongoing, given:
- a. the episodic nature of ABI and
  - b. the fact that certain needs emerge over time (e.g. due to improvement, change or circumstances, deterioration, etc.).

## 19. Teleconference, NSW: 1.30-2.30am, 23 Aug 2012

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<b>Session Called By:</b>	Brain Injury Australia and Brain Injury Association of NSW	<b>Attendees:</b>	Derek Brookes, Pankaj Khanna, Colin Murdoch
<b>Type of Meeting:</b>	Consultation		
<b>Facilitator:</b>	Derek Brookes		
<b>Notes Taken By:</b>	Derek Brookes		

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*The following is a record of the responses to the Discussion Questions given by those who attended this consultation meeting.*

### Discussion questions:

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

19.1 N.a.

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

19.2 At the time, the assessment only consisted of MRI because of the cost. Because I had temporal lobe epilepsy, I just happened to stumble upon the right neurologist at the right time - through a series of recommendations. I was just lucky to be a part of a comprehensive epilepsy program at the PWH. The tests were very comprehensive, including freezing the right side of my brain to see if I could do maths and spell etc. - which made me an excellent candidate for an operation. As a result my situation accelerated, and I have been seizure free for the past 10 years. [CM]

19.3 In my journey there are lots of other people with ABI who needed full time care and needed the support of the government and a range of carers and family. That's why I started a counselling service specifically designed for people with epilepsy. It has made me very compassionate, wanting to help people with ABI or whatever else. I'm very keen to get the best outcomes for people with ABI. [CM]

19.4 The impact of ABI is an individual thing—the situation can either remain the same, seem to get better or get drastically worse. I think my condition has become better, but I went for a test recently because I was thinking of getting employment. However, I didn't get past the 2nd level of the test. And yet I came top out of 2500 applicants in an employment test I took 10 years ago. So it is a personal journey for each individual with ABI. [CM]

- 19.5 It is very hard to get a job after a brain injury. Even with a Masters in Computing, prospective employers will not hire me because I have an ABI. [PK]
- 19.6 The anti-discrimination laws are rubbish. It's just that no employer will ever openly admit to discrimination. When the rubber hits the road, employers will sometimes choose against the person just because they have a disability. [CM]
- 19.7 As you get older not only do you have to live with your disability, but if you are not in some type of career or permanent position and you are trying to get employment, you then have the barrier of age as well as the disability. Some companies will only look at candidates in their 20s and 30s. [CM]
- 19.8 Because the MRI did not show any damage to the structure of my brain, I have not been assessed as brain injured—and yet I had severe nausea all day and night (which I don't have now); and short term memory loss (which I still have). I also tire very quickly, and so need to sleep all the time. The insurance paid for the MRI, but nothing after that. I cannot gain employment because of the accident. I've paid for everything myself. I don't know how to prove my memory loss; and I'm worried that as time passes the nausea will arise again. The doctor says that there is 'nothing wrong' with me. [PK]
- 19.9 For me to be re-employed, I would need the assurance that my employer knows that I forget, and that they won't be angry (since it's not my fault). I would also need the employer to get assistance to pay for any insurance increase as a result of hiring me. [PK]
- 19.10 The government, the corporate sector and the whole of society should be transformed so that people with an ABI or any disability could be employed across any sector, e.g. whether in part-time or full-time work. There should be people employed who could provide assistance in the workplace, so that these jobs could be made available. This would not only transform the lives of people with a disability, but also the lives of everyone in society - because they would be giving their time and money to support people with a disability in the workplace. It would change the whole way we look at people and society: they would be saying 'you are a worthwhile person and we will provide you with what you need to be a part of the workplace'. [CM]
- 19.11 The government sector needs to take the initiative, e.g. making laws so that every company has to employ a minimum of 5% people with a disability to make up their workforce. [PK]
- 19.12 Specialist workers would have to be a part of the staff to ensure that people with a disability are properly supported in the workplace. There should also be 'disability support managers' in the workplace (on site or managing a multitude of sites), with a range of staff whose role is to support staff who have disability (just like 'volunteer managers'). [CM]
- 19.13 The NDIS is going to require billions of dollars, not merely 100s of millions. [CM]

- 19.14 People with ABI are some of the most vulnerable members of our society. A society is judged by the way it treats its most vulnerable members. In most cases, we are failing people with ABI miserably. So we are failing as a society. [CM]
- 19.15 The NDIS needs to think in a way that will transform society so that people with a disability are able to be a part of society, making a contribution in the workplace, and being treated with respect and dignity. [CM]
- 19.16 The problem is that people who have never suffered do not understand. [PK]
- 19.17 Politicians and other stakeholders do have someone in the family or in their circle of friends who has an ABI or a disability. Until they are confronted with ideas that will be a culture change for society, they will be prepared to throw a few seeds at ABI and brain injury associations and other disability organisations, without thinking through what can transform society, bring about culture change and make life easier for people with a disability. [CM]

To sum up:

- 19.18 The NDIS assessment should identify the kind and level of support that a person with ABI requires in order to return to some kind of employment—including ‘on site’ support—if that is one of their life-goals or aspirations. [PK & CM]

## 20. Written Submissions

*The following consists of written submissions provided by individuals as a part of this consultation process.*

### **DFS Advocate, Headwest: Brain Injury Association of WA**

- 20.1 “The NDIS needs to ensure that eligibility criteria will not just select the most obviously physically disabled people for the NDIS and fail to ‘see’ cognitive/behaviourally impaired acquired brain injury clients (the hidden disabled).
- 20.2 Including identification of risk factors for poor social determinants of health in the suite of assessment tools for the NDIS/NIIS may reduce the risk of family breakdown, poverty and incarceration.
- 20.3 Agreements between government departments and the not for profit/ community sector would facilitate more streamlined pathways, effective early intervention and coordinated treatment across the health department (hospitals & acute rehabilitation), allied health, HACC, not for profit, community and disability sectors.
- 20.4 Assessment needs to fit ever-changing client goals over the life plan; therefore being ongoing, with opportunities for clients and their families to review progress and modify goals, especially at key points on the life continuum: after hospital discharge, at home, prior to alternatives to employment or employment/ study options or over the key transition points over the life cycle, such as leaving school.
- 20.5 The assessment process must consider a range of resources and expertise; a culturally appropriate suite of tools [should be developed]; and [the assessment should] be regularly monitored and evaluated over the life continuum, with opportunities for a full range of ‘information and community feedback’ from community agencies, clients and families to improve and refine the validity and reliability of the assessment and ensuring the accuracy of the care plans.
- 20.6 Training for assessors and any service providers or advocacy agencies involved in community feedback for the purposes of eligibility for the scheme is essential if the scheme is to be valid and equitable; it cannot be assumed that everyone will have the same understanding of what ‘significant and permanent’ disability means.
- 20.7 There need to be a mandated and recognised pathway for clients and their families to be informed of relevant advocacy agencies at the point of assessment and should an adverse determination for eligibility be received, such clients should be referred to an advocacy agency for a clear, fair and independent appeal pathway.
- 20.8 A clear pathway for return to service is also essential for clients who suffer significant frontal lobe dysfunction and lack of insight who may not initially see a need for any service or initially refuse service.”

— Robyn Fitzgerald, *Executive Summary* from “Discussion notes for the NDIS Development meeting referencing Brain Injury Australia’s NDIS Campaign held at Headwest on 20/7/2012”

## Board members of the Brain Injury Association of Tasmania

What is the current situation as regards the assessment of the support needs of people with ABI in your region? That is:

What is working well? When we engage with those who are designing the NDIS/NIIS, what could we point to as 'best practice' in your region? What should be included in the new scheme?

20.9 "The concept of using the gateways as a first point of contact seems to be delivering some benefits to aid accessibility. Having said that I am concerned about the level of skills and knowledge that the gateway staff are required to have to be truly effective. Since the service has started there has been an increase in the effectiveness, but that has taken time. As the gateway service is provided by contract there is no guarantee of continuity from the end of one contract to the beginning of the next contract. Consequently there is a real danger that once the current contract period expires a new round of tenders may result in a new gateway provider and a potential loss of corporate knowledge and a loss of service improvement gains may result. I appreciate that a change in provider may simply result in current staff changing employers, but I well remember the dislocations that occurred when the employment support service providers were changed a few years ago." [Dario Tomat, email, 26 July 2012]

20.10 "As others have identified, the existence of a gateway service to manage initial enquiries is good. It will be important that the skill base is sufficient to recognise the key issues associated with the varying disabilities, or at least sufficient to recognise the need to seek external consultation as required. Locating this gateway so that it straddles, but is outside, the acute health sector, rehabilitation sector and community sector is also really important so that it does not end up with undue emphasis on any of these, and so that it can have (dare I say) a holistic approach to service identification and delivery. Another aspect I've noticed in Tassie compared to other states is a relative recognition of comorbidities (ABI, mental health, AOD) and the acceptance that we cannot have the luxury of excluding people from services on the basis of this. It will be important to see NDIS supporting cross-sector consultation and collaboration." [Mark Lamont, email, 27 July 2012]

What are your main concerns? What are the key problems that we need to highlight to decision-makers? What needs to change? What should not be 'carried over' into the new scheme?

20.11 "Easy English versions of all literature, assessment forms etc. must be available. These would need simple dialogue, diagrams and photos. Also those making assessments need to be aware of the need for easy to understand verbal dialogue. This would need to cover all necessary languages and cultures. This is not only relevant for the client/patient, but it must be considered that family and supporters of the client may have varying degrees of education and understanding. Emergency hospital staff, G.P.'s etc. require education in looking at symptoms of ABI

in order not to use labels, such as 'just concussion'. Assessments must always consider timing: Stress and wellness of the client as well as the stress and fears of the family." [Leanne Whitney, email, 26 July 2012]

- 20.12 "My key concern is the current inequities in the system - the large divide in funding between those with compensable injuries (who normally have great support) and those with non-compensable injuries who have to rely on 'being in the right place at the right time' on meeting some of their needs due to the vagaries of government funding of service providers. Further, funding alone is not an answer to efficiently servicing the needs of people with a disability. There doesn't seem to be a market signalling method about the need for a service in a particular area, or a service provider may choose not to expand capacity to cater for extra demand. The sector is very reliant on NFP organisations, many of whom are community based. In Tasmania we often have boards that are risk averse or board members are driven by needs of a family member, so rather than adopt a business model for the whole market, they adopt a narrow service focus. This leads to a lack of capacity building and often a lack of focus on more completely servicing the community in which the service is based." [Dario Tomat, email, 26 July 2012]
- 20.13 "I'm hoping that initial screening that might be conducted through a gateway type service [will be] sufficiently sensitive to pick up on ABI concerns—cognitive/behavioural, community integration, post-injury adjustment. The fact that someone with a moderately severe ABI can present on interview as competent needs to be recognised as potentially deceptive, and that assumptions cannot be made regarding adjustment, community integration and service requirements based solely on presentation. Other concerns raised by others (but broader than just assessment concerns)—equity of service—specialist services in Tassie are very restricted—there are no contemporary ABI specialist rehab programs (e.g. transitional community based programs with in-house rehab specialist input, neuropsych, specialist PT, OT, SP services); no specialist behaviour consultancy services. It is one thing for a gateway service to identify service requirements; it is another thing to find service providers that can meet the needs. Tassie is not as well resourced as the larger mainland states in this regard." [Mark Lamont, email, 27 July 2012]

#### **Carer of a teenage son with TBI (non-compensable)**

- 20.14 "There seems to be easy access to short-term supports, with no understanding of longer-term needs. There needs to be a regular schedule of reassessment, rather than waiting for crises.
- 20.15 [My] son has been assessed for funding of supports to go back to work, with the expectation that his supports will one day not be required. Assessment is made that he is walking and talking, so everything is on track. Powers that be don't seem to understand that this is variable: he has good days & bad days. Impact of fatigue in ABI can't be under estimated.
- 20.16 Cognitive care is just as important as feeding/washing, etc. Supervision is as critical as toileting.

20.17 Navigation of the current system is overwhelming. Don't know where to start and then you feel as if you are being sent in a circle. Really important that the scheme have easy pathways."

— Linda Ferguson, phoned in and typed up by BIANSW on 21 August 2012

### Carer of person with ABI

20.18 "CentreLink treatment of Brain Injured applicants:

- a. Our experience has been that psychological instability and the inconclusiveness of 'what has been affected' is not acknowledged in Centrelink 'categories'. Also, the table of decision-making requires one to know what terminology and categories to make a case for. And – whilst the application forms say to provide Dr details for Centrelink to contact, they do NOT contact Dr's. Their practice is not to contact the doctors.
- b. This led (for us) to the most frustrating, exhausting and demoralising application, re-application, and lack of understanding between brain specialist – who saw it as 'obvious' ("this is the worst injury I've ever seen" "you don't survive this kind of injury" "your brain stem was being crushed"). The brain is the most complex organ known to man – if it is damaged, the body goes into fight mode as if it's control centre has been attacked – which it has been!

I was exhausted and myself mentally and emotionally depleted, and there was no help or advice re filling in the huge forms and number of forms. And I had to communicate with someone for whom communication was an overwhelmingly exhausting and confronting activity (listening and speaking – let alone not being able to read).

- c. On top of all this, Centrelink 'got wrong' various requirements like work assessment interviews. Various replies like 'you must go to the assessment' or 'this has been rejected' etc. arrived regularly at home when I was out – read to the injured and traumatised person and then reacted to with additional trauma. All completely unnecessary because Centrelink had forms and processes that were not individualised nor adapted to the case of Brain Injury.
- d. Proving one is 'caring' for someone who is physically OK but psychologically in great trauma, as well as (say) having another condition like aphasia and needing constant reassurance, trauma-counselling/management by family members, translation of documents (i.e. reading them – get the other person's attention, then their concentration, repetition and checking they understand when they can't say what they mean... ! This is re....alllly difficult and tiring. Apart from being available 24-7 in case of panic.... I additionally had to calm and support the rest of the family!

- e. One can do this kind of caring from a distance – Centrelink requires one to be on-site 7 days – whereas some of this work needs one to be away – apart from the need to restore one’s equilibrium so one can continue... and apart from the need to keep working to help support the various needs financially. I gave up my application because I couldn’t face another application and re-application round.
- f. The answer is perhaps for CentreLink to – from the initial application – treat BI as a separate case – not assess through the ‘usual channels’... assessment of applications initially by trained officers who phone specialists and realise that ‘recovery can be over 20 years – and is subtle’. That they ‘believe’ the specialists when they, in their experience and knowledge assess the applicant as disabled or whatever. [We are 4 and a half years’ in and the trauma has only this year retreated, allowing more subtle social awareness and skills and controls to emerge.]

20.19 Services available:

- a. [Services] were all institutionalised. This, to our injured family member was an affront – as many assumptions were made and he was categorised. Whereas all brain injuries and people are different. The institutional manager had no understanding of trauma and individuality. Our injured person is a fighter and can achieve many things if empowered. The institutional experience was depressing and demotivating in the extreme.
- b. ‘Assessment’ – i.e. up-front assessment of the injured person’s ability and disability was going to be costly – but more importantly it was going to be confronting and exhausting. So, we chose not to go down that path. The main thing we needed was hope and a positive path to follow and lots of support and guidance emotionally and information-wise for both the injured person and the family.
- c. I have since read Roger Rees books and approach and feel certain that his individualised approach is a far better way to go.
- d. Although BIA[NSW] does its best to get people together, I have still not found an experienced mentor for us – one that has the authority, knowledge and experience of Dr Rees. Only that kind of stature is likely to draw the trust of a BI’d person, to follow and believe that what they say is important.”

— Chris Lee, submitted by email on 22 August 2012

**Rehabilitation Coordinator, Southern Area Brain Injury Service, Goulburn NSW**

20.20 “In the role I have at Southern Area Brain Injury Service I have found just with the increased demand from the LTCS in the last 4 years on both the public and private sector it’s getting harder and harder to get the clinicians we need to achieve the

clients goals. When you increase funding and access to services you also need to have a plan to increase the clinicians, doctors etc. As you will appreciate in brain injury we need that neurological experience and the few that have it in rural communities are starting to reach capacity if not already there. I hope that the decision makers are looking at this aspect.

- 20.21 An example is between Batemans Bay and the Victorian Border we have 1 private Speech Pathologist and CHC Speechies that are flat out doing the swallow studies etc so are reluctant to take on a client requiring 1-2 sessions every week. That private speechie is in demand by CTP, Workers Comp, LTCSA, DVA and spends a day a week in the public sector. At SABIS we have to compete like the others for the limited services available. Same for Physio in Batemans Bay 2 clinicians have closed their business and the 3rd has said no to our complex cases.”

—Steven Hindle, submitted by email on 22 August 2012

#### **Director at South West Brain Injury Rehabilitation Service, Albury NSW**

- 20.22 People with non-traumatic Brain Injury (e.g. stroke, etc.) are often not considered eligible for cognitive (nonphysical, nonmedical) rehab.. They will move into the ADHC system—and even then they can miss out if the injury is not serious enough (especially when assessors are not trained in ABI, and so tend to look at the issues through the lens of mental health). This should be fixed in the NDIS.
- 20.23 People with ABI in rural areas often remain unassessed because health/community workers are unable to recognise the symptoms of ABI (e.g. conflating them with ID or ‘normal’ challenging behaviour).
- 20.24 In most states, there is no ‘step down care’ rehabilitation for people with ABI once people move away from the city into rural areas. So to ensure that people with ABI in rural areas are eligible ‘in practice’ for NDIS-funding, the NDIS must ensure that the necessary support services are available and accessible in rural areas.

— Denis Ginnivan, phoned in and typed up by Derek Brookes on 21 August 2012

## **Occupational Therapist at Neuroadapt Occupational Therapy Services for Stroke and Brain Injury Rehabilitation, Adelaide SA**

20.25 “[A] neuropsychological assessment has an important role in the needs assessments for people with ABI especially in identifying the organic basis of cognitive and neurobehavioural deficits . . .

[However, it is important to mention] the contribution of occupational therapists as assessors of functional cognition (as well as physical function) – i.e. being able to identify the impact of cognitive limitations on the person's everyday activity and participation experiences through a combination of observation of function in the home, interview data gathered from the person and their family/support team, and through use of specific portable OT assessment tools (eg the AMPS and the Allen’s Cognitive Levels Screening tool) and thus identifying their associated support needs.

Whereas the neuropsychology assessments may be critical for initial establishment of diagnosis/eligibility/support extent, suitably skilled and experienced OTs may have a supplementary role e.g. in the review of functional support needs over time. . . . [T]he contribution to assessing and supporting functional cognition that relevantly experienced OTs can make [should therefore be acknowledged].

I realise that this comment may seem OT-centric especially as it is my own profession, but that is not my intent—I raise it as it seems plausible that more than one professional group who is skilled in the area of functional cognition is going to need to be drawn on to resource the assessment scheme and process for Australians with ABI.”

— Cherie Archer, submitted by email on 11 September 2012.

## C. Productivity Commission's Recommendations (2011)

*The following are those recommendations made by the Productivity Commission<sup>7</sup> that relate to the assessment of care and support needs. The original text of each recommendation has been broken down into discrete points. This makes it possible to identify precisely where the consultation outcomes above correspond (+) or conflict (-) with these recommendations—for example, by using a reference such as “PC: +7.2bii”.*

### Chapter 7 Assessing care and support needs (pp. 69-71)

#### RECOMMENDATION 7.1

The assessment process should:

- a) work within the framework of the International Classification of Functioning, Disability and Health (ICF);
- b) identify the supports required to address an individual's reasonable and necessary care and support needs;
- c) identify an individual's care and support supports across a broad range of life activities;
- d) take account of an individual's aspirations and the outcomes they want to achieve.

#### RECOMMENDATION 7.2

The assessment process should

- a) be a valuable intervention in its own right, rather than just an entry point to supports . . .
- b) draw on multiple sources of information, including:
  - i. information provided by the individual with a disability, including their aspirations and requirements for supports
  - ii. information provided by an individual's circle of support, including family members, carers and direct support professionals
  - iii. information on the current support provided both formally and informally
  - iv. current medical information on the person with a disability
- c) assess the nature, frequency and intensity of an individual's support needs.
- d) be person-centred and
- e) forward looking and

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<sup>7</sup> Productivity Commission, *Inquiry Report – Disability Care and Support*, No. 54 (Australian Government, July 2011).

- f) consider the supports that would cost-effectively promote people's social and economic participation, rather than only respond to what an individual cannot do
- g) determine what supports outside the NDIS people should be referred to, including referrals to Job Services Australia providers
- h) consider what reasonably and willingly could be provided by unpaid family carers and the community ('natural supports')
- i) translate the reasonable needs determined by the assessment process into a person's individualised support package funded by the NDIS, after taking account of natural supports
- j) provide efficiently collected data for program planning, high level reporting, monitoring and judging the efficacy of interventions.

#### **RECOMMENDATION 7.3**

The assessment tools should be:

- a) valid and reliable,
- b) relatively easy to administer and
- c) exhibit low susceptibility to gaming . . .
- d) employed nationally to
  - i. ensure equitable access to nationally funded support services (and
  - ii. allow portability of funding across state and territory borders when people move).

#### **RECOMMENDATION 7.4**

Assessments should be undertaken by [assessors]:

- a) [who are] trained
- b) [who have been] engaged by the NDIA
- c) [who do] not have a longstanding connection to the person . . . [so as to] promote independent outcomes.
- d) [whose performance is] continually monitor[ed] and evaluate[d] . . .
  - i. to ensure comparability of outcomes and
  - ii. to avoid 'bracket creep'.

**RECOMMENDATION 7.5**

The NDIA should

- a) periodically reassess people's need for funded support,
- b) with a focus on key transition points in their lives.

**RECOMMENDATION 7.6**

Where an informal carer provides a substantial share of the care package, they should:

- a) receive their own assessment if they wish.
- b) This should seek to identify their views on
  - i. the sustainability of arrangements and
  - ii. the ways in which the NDIS should support their role, including through the initiatives recommended in recommendation 15.3.

**RECOMMENDATION 7.7**

- a) The consultation with the family as part of the assessment process should also explore the need for:
  - i. assistance with long-term planning, particularly for adults with cognitive impairments living at home with elderly parents
  - ii. family/sibling counselling where there are high levels of carer stress.
- b) Responses to family needs should be tiered, with
  - i. referrals to local support groups for those with less significant needs, and
  - ii. access to NDIS-funded specialist assistance where the needs were high.

**RECOMMENDATION 7.8**

The NDIS should establish

- a) a coherent package of tools (a 'toolbox'),
- b) which assessors would employ across a range of disabilities and
- c) support needs (including

- i. planning and active support,
- ii. attendant care,
- iii. aids and equipment, and
- iv. home modifications).

**RECOMMENDATION 7.9**

- a) The assessment tools should be subject to
  - i. ongoing monitoring, as well as
  - ii. a regular cycle of evaluation against best practices, including the ICF framework, and, if necessary, recalibration.
- b) The scheme should have systematic internal mechanisms to ensure that anomalies can be analysed and addressed.

**RECOMMENDATION 7.10**

The NDIS should

- a) use the best available tools in its initial implementation phase,
- b) with the ongoing development of best-practice tools.