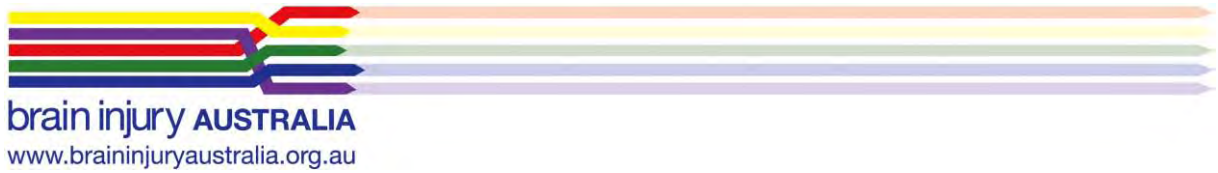

National NDIS Consultation Report

February - March 2013

An analysis and record of the views of key stakeholders across Australia on the "National Disability Insurance Scheme Rules Consultation Paper"

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Contents

Executive Summary

This report provides a set of recommendations in response to the government's "National Disability Insurance Scheme Rules Consultation Paper" ('Consultation Paper'), released on 1st February 2013. The aim of this response is to ensure that the NDIS takes into account the needs of people living with an acquired brain injury (ABI), together with their families and carers. These recommendations are based upon the outcomes of a 3-week national consultation conducted by Brain Injury Australia and its member organisations. This process involved 235 consultees and 18 consultation sessions held in every state and the ACT (including both urban and rural locations). A complete record of these outcomes and a list of the consultees can be found in the appendices.

Every topic in the Consultation Paper was relevant, in some way, to the care and support needs of people with ABI. Hence, this consultation has resulted in a set of responses to every question posed in the Paper. However, a smaller range of topics were considered to be of greatest relevance to this constituency: that is, Disability Requirements, Early Intervention Requirements, Reasonable and Necessary Support, Management of Plans, and Supporting Decision-Making. For this reason, the consultation sessions tended to focus on these topics.[1]

The following is an illustrative sample of the recommendations that emerged from the Consultation sessions:

- Use ABI experts to assess the effectiveness of early intervention in individual cases.
- Justify what supports are 'reasonable and necessary' on a case-by-case basis.
- Ensure that knowledge of specialist services is widely disseminated and available in different locations, including regional and rural areas and that all people with ABI can be referred to and access those services equitably.
- Assess the scope of a person with ABI's capacity to make decisions in their best interests on a regular basis.
- Hold both regular assessments and a mandatory review of the nominee arrangement.

Finally, consultees were asked what supports they felt would be 'reasonable and necessary' for people with ABI and their carers and why. Their responses, in general terms, included: respite for carers, social and relationship support, specialist healthcare, aids and equipment, access to mainstream services, transport funding, psychological support, focused cognitive support (e.g. for decision-making), specialist ABI training (e.g. for carers, nominees, support workers, Agency staff), and support for independent living (see Sections 16-20).

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

[1] Aside from 'Disability Requirements', which was comprehensively addressed in Brain Injury Australia's previous national consultation on eligibility and assessments (June-September 2012).

1. Introduction

The National Disability Insurance Scheme (NDIS) 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). However, 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, in 2012 Brain Injury Australia and its member organisations 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. Our first step was to conduct a national consultation that focused on eligibility and assessment. Over a period of 4 months, we asked a range of key stakeholders across Australia *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.* The outcomes of this consultation were forwarded to relevant decision-makers, and the response was uniformly positive. The Office of Jenny Macklin, for example, sent Brain Injury Australia a letter that included the following comment:

> "The report highlights important issues regarding assessment of eligibility and support requirements of people living with an acquired brain injury and support for their carers. I applaud your commitment to ensuring your national consultation process has captured as many key stakeholders as possible. The information contained in this comprehensive report will be taken into account in the design of an NDIS." (19 Nov, 2012)

The present report is a result of Brain Injury Australia's second NDIS national consultation. In late January 2013, Brain Injury Australia was informed that a "Consultation Paper" on the NDIS Rules would soon be released to the public. Anticipating that the Rules would be of critical importance, we proceeded to arrange a 3-week national consultation with Brain Injury Australia's member organisations. There were 19 consultation sessions in total, starting on 4th of February 2013, and concluding on the 22nd. A total of 235 people attended the sessions, which included 34 people with an ABI and at least 28 family members and/or carers of people with ABI.

Once again, it is hoped that the list of recommendations in this report—together with the recommendations contained in the previous report—will be taken into account by decision-makers as they seek to design a National Disability Insurance Scheme 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 of 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.[2]

[2] 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: that is, Brain Injury Association of NSW, Synapse (Brain Injury Association of QLD), Brain Injury Network of SA Inc., Brain Injury Association of Tasmania, BrainLink Services (Victoria), Victorian Coalition of ABI Service Providers (VCASP), National Brain Injury Foundation (ACT), and Headwest (Brain Injury Association of WA).

Each regions held at least two sessions: one for people with ABI, their families and carers; and the other for professionals who work with and support people with ABI — 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 development process, Brain Injury Australia's NDIS campaign, and an overview of how the NDIS is likely to operate (based on the NDIS Bill and other publically available documents).

2. The facilitator would then introduce the basic contents of the Consultation Paper, followed by a selected range of questions from an 'easy English' version of the Consultation Paper. The facilitator would then type up individual and group responses to the questions. 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. The consultation record was then emailed to all the attendees immediately after the session, again inviting them to amend or add to the record if they wished. Attendees were also sent a list of the questions from the Consultation Paper that were not covered in the session, so that they could, if they wished, send in written responses to these questions. Any written submissions of this nature have been presented together in section 19. Written responses that supplemented the questions covered *within* the session have been placed at the end of that session's record.

Many of the points that were 'voiced' in the consultation sessions were typed up virtually 'word for word' by the facilitator. However, no individual names were attached to any single point nor were quotation marks used. This approach was taken partly to preserve anonymity, but also because many of the points arose out of a discussion, and so 'single person attributions' would have been incalculable or in any case unwarranted. 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. Any revised introduced at this stage are indicated by the reference 'ATD' ('Amendment to Draft').

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:

- providing one line summaries of each recommendation;
- reducing the inevitable duplication;
- re-organising the record into distinct topics;
- adding context to aid understanding (e.g. filling out acronyms); and
- re-framing contributions into positive recommendations (i.e. what the Agency should be doing, rather than what isn't being done at the moment).

The recommendations presented here are mostly based upon the consultees responses to questions that were posed in the ('easy English' version of the) Consultation Paper. These questions have now been rephrased as subheadings (in bold purple font), so as to provide a context for particular sets of recommendations.

The final section in this report ('E. Identifying Reasonable and Necessary Supports') is slightly different from the others, and so has been placed in a separate section. It contains responses to a question that was not (explicitly) in the Consultation Paper: that is, *What kind of supports are 'reasonable and necessary' for people with ABI, and why?*

This question was designed to elicit two things: **first**, the kind of *supports* that people with ABI (and those who care for and work with them) regard as being 'reasonable and necessary' for them; and **second**, the kind of *reasons* that they give for thinking that a particular support is reasonable and necessary.

It is hoped that these two sets of responses will not only illustrate what the Agency can expect to find when the NDIS begins to assess the support needs of people with ABI; but also a method which will enable the Agency to make fair and accurate decisions about whether a support is reasonable and necessary for people with ABI (see 'Recommended Method' in section 16 below).

Finally, these recommendations represent a range of views offered by individuals and organisations who voluntarily participated in the consultation sessions and provided feedback on the draft report. As such, the recommendations here do not reflect all the views of all participants on each of the topics covered, nor should it be assumed that every participating individual or organisation would agree with every position put forward.

A. DIFFERENT FUNCTIONS OF THE NDIS

1. Connecting people to other systems

To make sure that people who are not eligible for NDIS funding can obtain the support they need from other systems[3] the Agency will need to do the following:

RECOMMENDATION 1.1 — Ensure that education can recognise ABI in children and support them as needed.

Where the Agency identifies a potential systemic barrier in other systems, it should ensure the matter is raised with the relevant government department and/or a disability peak body that may be able to work to address the issue through education, awareness-raising, or capacity building (e.g. children with ABI in the mainstream education system can access the educational supports that they require, such as Integration Aides within the school who are appropriately skilled and knowledgeable). [20.359, ATD]

RECOMMENDATION 1.2 — Ensure that both Agency staff and providers receive training and awareness of ABI.

The Agency must ensure that its staff are trained in the nature and sequelae of ABI and the requisite support needs. This will help (a) to ensure that behaviours and changes in functionality are less likely to be misdiagnosed or mislabelled, and (b) to prevent secondary symptoms, such as depression. Awareness training should be promoted both within the Agency, and where possible in other systems (particularly health, Centrelink and education) and community providers of support. Such training and awareness raising can be achieved through mentoring with suitably skilled ABI specialists from within the ABI sector. [20.15, 20.18, ATD]

RECOMMENDATION 1.3 — Identify currently available supports in other systems within each jurisdiction.

The Agency must collect comprehensive and up to date information about what services in other systems are currently available to support people with a disability — across Federal and State jurisdictions, as well as maintain its knowledge of specialised disability information and referral services and advocacy services that can directly assist people to find the most suitable information for them. This will ensure that (a) the Agency is better able to fulfil its function as an accurate source of information about other systems; and (b) people are more likely to receive a person-centred information service and to be able to access services that are appropriate and available. [1.1, 1.3, 20.5, ATD]

RECOMMENDATION 1.4 — Require governments to provide data on organisations they directly fund.

The Commonwealth and other state departments should be required to provide data to the Agency on those organisations that are directly funded by them. For example, the Agency should draw upon the comprehensive list held by FaHCSIA on the services that are funded by the government, service directories in primary care partnerships, electronic referral services, and so on. [1.5, 5.3, 7.3]

[3] 'Other systems' includes mainstream and community services that will not be funded by the NDIS (e.g. health, child protection, family support, housing, education, employment, housing, transport, justice, etc.).

RECOMMENDATION 1.5 — Collect information about other systems independently.

The Agency should not *assume* that there is adequate support for people with disability in other systems (e.g. education). Nor should it rely *entirely* upon the information that other systems provide to the Agency. Instead, it should go out and independently collect in-depth information about the direct experience of people with disabilities in dealing with other systems, including barriers to social participation. This will ensure that the information provided by the Agency is more likely to be accurate and comprehensive in scope. [1.2, 5.2, 7.9, ATD]

RECOMMENDATION 1.6 — Collect information about other systems regularly.

As the NDIS emerges, it is likely that there will be rapid changes in the types and availability of service providers, including those in other systems. Hence, to ensure that the information it provides to people is up to date, the Agency should remain up to date with how other systems are accommodating the needs of people with a disability, and with greater frequency in the early phases of the NDIS implementation. [1.4, 5.2, 5.8, ATD]

RECOMMENDATION 1.7 — Ensure that the information provided is clear and easy to understand.

Ensure all information formally provided by the Agency is clear, accessible for people with different disabilities, and available in easy English format. [20.16, ATD]

RECOMMENDATION 1.8 — Recognise the existence and value of other information and referral services.

The Agency will (and should) not be the only source of information or referrals for ineligible persons. A range of mainstream services and disability peaks, information services and other NGOs will continue to play this role (i.e. of providing information and making referrals, following through, providing oversight, etc.). Indeed, many of these organisations may be better placed to play this kind of role — for instance, where they are disability-specific. The Agency should recognise that it is part of an existing network. It should value, support and fund the work that will continue to be played by these organisations. [5.10, 7.11, ATD]

RECOMMENDATION 1.9 — Support people as they transition from one system to another.

The Agency should recognise that helping people to 'connect with other systems' entails helping people to 'transition to other systems'. This includes people with complex needs or who are in certain institutional contexts (e.g. rehab, the prison system, hospitals, etc.). In such cases, people are likely to need active support to enable them to access appropriate services. [7.5]

RECOMMENDATION 1.10 — Ensure that Agency staff have disability-specific knowledge.

Agency staff must have a good understanding of both (a) specific disabilities and (b) specific information and referral services who can assist people needing information in a specific disability area. This will ensure that people are able to access useful information effectively. [1.7, ATD]

RECOMMENDATION 1.11 — Use the Agency's position to ensure that people get the support they need.

The Agency should, wherever possible, work with other systems to support a person's right and capacity to access the support they need. [4.6, ATD]

RECOMMENDATION 1.12 — Establish referral protocols with a network of services in other systems.

The Agency needs to establish pro-active relationships with services in other systems (e.g. housing, rehab.), but also formal agreements that underpin these relationships, to ensure people with a disability have the best possible opportunity to participate in society without systemic barriers. [5.6, 7.1, 20.10, ATD]

RECOMMENDATION 1.13 — Ensure that the information and referral service is non-discriminatory.

The Agency should build in regulations to ensure that its systems do not discriminate against any person (e.g. it should be a 'no-fault' system). [7.6]

RECOMMENDATION 1.14 — Establish a complaints process for people who use the information and referral service.

The Agency should ensure that there is an independent body to which people can take their complaints or grievances about the Agency's information and referral service, so that these can be effectively resolved. [5.13]

RECOMMENDATION 1.15 — If a person is deemed ineligible, tell them the reasons for this decision.

The Agency should always explain to a person why they are not eligible for NDIS-funded support, and put this in writing to the person. [1.8, 7.10, 20.1, ATD]

RECOMMENDATION 1.16 — Establish an appeals process for people who are deemed ineligible.

The Agency should ensure that there is an appeals process available to people who are assessed as being ineligible for NDIS-funding, and also provide them with a list of independent disability advocacy services that the person may contact to access assistance with their appeal. [5.9, 7.4, ATD]

RECOMMENDATION 1.17 — Ensure people deemed ineligible are not thereafter excluded from re-assessments.

If a person is assessed as ineligible, then they should not necessarily be excluded from making future requests of the Agency to be assessed. This is particularly important for people with ABI, who may lack the impetus or divergent thinking to engage with the scheme. They need to be presented with choices about what is now available to them, rather than a blank 'no'. [5.14]

RECOMMENDATION 1.18 — Ensure that respite options are available for family/carers of ineligible persons.

The Agency would need to ensure that substantial respite options are available to ensure the quality of life for family and carers — even for those who are not eligible for NDIS funding. [7.13]

2. Funding Community-Based Supports

To make sure that community based supports which are funded by the Agency will assist people with disability to realise their potential and participate in all areas of life, the Agency will need to do the following:

RECOMMENDATION 2.1 — Only fund community-based supports that meet Agency criteria for suitability.

The Agency should only fund supports provided by community-based organisations (government or NGOs) that meet key criteria for suitability, as predetermined by the Agency. Essential criteria would include:

(a) meeting the minimum National Disability Standards;

(b) suitable qualifications and accreditation relevant to the services provided;

(c) a police check for dealing with vulnerable people;

(d) evidence of experience in providing age suitable services;

(e) a system of regular reviews;

(f) a pathway of suitable supports, covering (i) immediate and projected needs (e.g. over a 5 year period), and (ii) those needs that community based supports are unable to meet (e.g. a pathway for referring clients to high level care[4]);

(g) the capacity to support education, vocational, recreational, housing, therapy, medical and/or respite needs (both emergency and planned). [1.9, 20.25, 20.27, 20.32, ATD]

RECOMMENDATION 2.2 — Provide trigger questions to help participants think about their goals and aspirations.

When a participant is developing their statement of goals and aspirations, the Agency (or relevant support persons) should ensure that there are some trigger questions to assist them in thinking through what is it they want out of life and give them enough preparation time. Otherwise, in any review, the Agency will not have an adequate benchmark against which to assess whether the community based supports that it funds are assisting participants to realise their goals and aspirations. [20.36, ATD]

RECOMMENDATION 2.3 — Ask participants using the organisation whether it is helping them to achieve their goals.

Participants in the NDIS should be invited to participate in regular (a) participant surveys and (b) face-to-face reviews (with their families/carers if they choose and at a place of their choosing, such as their own residence). These surveys and reviews should check to see whether — or the extent to which — participants are achieving their goals and aspirations *as a result* of accessing specific support(s). Providers of these supports should have a 'right of reply' in a separate review, which could be supplemented by an impartial reviewer. [1.11, 1.12, 20.32, 20.33, 20.34, 20.35, ATD]

[4] "High level care is for people who need 24-hour nursing care. This may be because they are physically unable to move around and care for themselves, or because they have a severe dementia-type illness or other behavioural problems. Residents in high care must receive additional care and services as required." "Types of care and services", Australian Government: Department of Health and Aging. <http://tinyurl.com/d77fqbc>

RECOMMENDATION 2.4 — Ensure that reviewers are person-centred and disability-specific.

The Agency should ensure that any review of a participant's experience of receiving community based supports is conducted by someone who:

(a) has worked with people with ABI;

(b) has knowledge of the participant's history;

(c) does not have preconceived ideas (i.e. someone who thinks they know 'what's best' for a person without actually respecting their wishes, or someone who takes a very textbook approach and put everyone with ABI in the same basket);

(d) who realises the participant's potential for the future; and

(e) has an open understanding of the importance of trying new things. [20.37, 20.39, ATD]

RECOMMENDATION 2.5 — Ensure that an advocate is available to speak on behalf of the person with a disability.

The Agency should ensure that the person with a disability has access to an independent advocate who can assist the person to voice their perspective on the organisation, with a view to their best interest. [1.13, ATD]

RECOMMENDATION 2.6 — Require the organisation to provide data on KPI and outcomes for each participant.

The Agency should ensure that the organisation provides — on a regular basis — data on key performance indicators and outcomes achieved for each participant, including their rate of participation in the supports provided. [1.12, 20.32, 20.33, ATD]

RECOMMENDATION 2.7 — Provide funding that is small, local, immediate, discretionary and goal-directed.

To enable participants to access community based supports effectively and efficiently, the Agency should ensure that they can access funding that is small, immediately available, discretionary, and directed toward meeting their aspirations. This might include temporary funding for the provision of informal care and support (i.e. family members, friends, etc.). [4.7, 4.8, ATD]

RECOMMENDATION 2.8 — Engage broader community and mainstream agencies to be more responsive.

If the Agency wants to stimulate the community to make sure that community-based supports are available to people with a disability (whether eligible or not), then the Agency would need to be working with the broader community and mainstream agencies at a systemic level to get them more engaged to be responsive to the needs of people with a disability. [4.9]

RECOMMENDATION 2.9 — Inform people with a disability and carers about available community based supports.

The Agency should clearly promote and communicate the supports available for people with a disability and their carers. In doing so it should use all available means and technologies available, including the print media, television, an interactive website, SMS text messages (e.g. similar to Natural Disasters declarations), all health sector agencies, and hard copy brochures mailed out to all Australian homes. [20.29, 20.30, 20.31]

B. BECOMING A PARTICIPANT

3. Age Requirements

The kind of information that the Agency will need in order to make sure that people meet the age requirements is as follows:

RECOMMENDATION 3.1 — Establish criteria by which to determine whether the age requirement has been met.

There should be a mandatory set of criteria by which the Agency can decide that someone meets the age requirement. [1.14, 20.47, 20.49, 20.50]

RECOMMENDATION 3.2 — Determine age by reference to existing formal records, but allow for exceptions.

A person's age should be determined by reference to formal records, not mere self-description; but people should not be required to produce formal records if their age can be checked by the Agency against existing government data. Where records are not available (e.g. for refugees or indigenous persons in remote locations), then the Agency should attempt to determine age using the same process as the Red Cross or Medicare. If this is not possible, then self-description should be allowed. Otherwise, the Agency will have to investigate someone's age medically, which would be financially prohibitive. [1.16, 20.48]

RECOMMENDATION 3.3 — Identify a person's age to determine which funding pathway is most suitable for them.

The Age Requirement should not be used merely to exclude people. If there has to be an age-related 'cut off point' for NDIS funding, it should only be on the basis that there is a more age-suited funding pathway for that person. [20.41, 20.52]

RECOMMENDATION 3.4 — Ensure that anyone who initiates a 'request for access' before age 65 is not excluded.

Currently, the NDIS Bill states that the 'request for access' to become a participant in the NDIS must occur before the person turns 65 (or whatever the upper age limit will be for a particular launch site). However, the Bill's wording does not appear to rule out a situation in which (a) someone applies for access to NDIS before they reach the upper age limit, but (b) are then excluded because they pass this limit whilst waiting for NDIS to respond. Hence, the Rules should explicitly state that *a person will meet the age requirement if they formally initiate a 'request for access' prior to reaching the relevant upper age limit.* [20.51]

4. Residence Requirements

To sort out who will count as a 'resident' in a launch site, the Agency should do the following:

RECOMMENDATION 4.1 — Define a 'resident' in terms of their location, not period of time within a location.

To avoid a 'slippery slope' of *geographical* expansion, the Agency should strictly maintain the borders of the launch sites. But it should be flexible with the period of time a person has lived within those boundaries. In fact, the Agency should ensure that there is scope for new people to be able to enter the sites and be transitioned into the scheme in a sustainable manner. The reasons for this view are as follows:

(a) it is unlikely that someone who needs the additional funding that can be provided by the NDIS could afford to move and/or would want to uproot their family;

(b) the NDIS is still too uncertain for people to want to move (although they may wait to see how it goes, and then decide to move);

(c) people with ABI are more transient and may well move in order to be eligible — in which case they should be allowed to stay. [1.17, 1.18]

RECOMMENDATION 4.2 — Ensure that participant support needs take priority over residential requirements.

The residential requirements must be sufficiently flexible to allow a participant to move from one area of residence to another when this is warranted by their medical and social situations — for example, where (a) their underlying medical condition creates social or housing instability, or where (b) their condition is deteriorating and specialist support is only available elsewhere (e.g. both situations can occur for people with moderate to severe cognitive problems and mental health issues).

RECOMMENDATION 4.3 — Ensure that homeless persons can qualify for NDIS-funding.

A person of no fixed address should be deemed to be a resident of a defined area if that person utilises any services provided by the Federal Government, State or Territory Government, Local Government or Community organisation and/or resides in the area for the purposes of employment. [20.56]

RECOMMENDATION 4.4 — Extend the 6-week grace period to allow participants to receive medical treatment.

By way of clarifying the conditions under which the grace period for residing outside Australia can be extended beyond 6 weeks, the Rules should state that *a resident will not lose their resident status for a defined area if the person is moved to a temporary location for the purposes of receiving medical treatment.* [20.56]

To resolve other 'boundary issues' (between launch and non-launch locations), the Agency should do the following:

RECOMMENDATION 4.5 — Clarify the respective funding-responsibilities of the NDIS and other systems.

The role and funding of different service agencies must be clearly delineated – especially the boundary line between supports that will funded by the NDIS and those that will be funded by State and Federal government agencies. In particular, the Rules need to clarify (a) whether the NDIS will provide funded support where other systems that *should* be but are *not* providing an adequate kind or level of support, (b) and if so, how it will do so in a sustainable way, given that other systems are likely to exploit any such arrangement by 'dumping' their responsibilities onto the NDIS. [20.61, 20.62, 20.63]

RECOMMENDATION 4.6 — Prevent false residence claims by establishing evidential requirements.

To prevent people from using family or friends to make false claims of residence, the rules need to state the evidential requirements for establishing residence in a defined area. For example, this evidence could consist of rates notices, rent payments, utilities charges, DHS correspondence and records. The body of evidence could be accumulated in much the same way as the points system for passport applicants. (This must not exclude a genuinely homeless person from qualifying as a resident.) [20.65, ATD]

RECOMMENDATION 4.7 — Ensure that there is a national rollout plan that is effectively communicated.

Clearly state that this is an initial launch and the intent is that once the bugs have been ironed out it will be available everywhere around Australia. [20.66]

RECOMMENDATION 4.8 — Ensure that people who relocate can still access the NDIS when it is rolled out.

If a participant moves out of a launch site permanently and so is no longer eligible for that reason alone, then it should be possible and easy for them to access NDIS-funding when it is introduced into their area. [20.68]

RECOMMENDATION 4.9 — Address cultural and language barriers that participants may face.

The Agency should address cultural and language barriers that arise between participants and Agency staff or professionals involved in providing them with support. [20.69]

5. Continuity of Support

To sort out whether a person can still get the kind of support they were getting before the NDIS started up, the Agency will need to do the following:

RECOMMENDATION 5.1 — Continue any pre-NDIS support, regardless of how long or when it was received.

If a person has been getting any kind of support prior to the NDIS, and the need for that support is still there, they should be eligible for the same or better kind of support — regardless of *when* they were receiving the support, *the kind of program* that delivered this support, or *how long* they had been receiving this support. The reasons for this view are as follows:

(a) Some supports (e.g. rehab) are only periodic, not continuous — it depends on a person's needs, which can fluctuate, sometimes with lengthy intervening periods. Hence, if the Rules stipulated that a support must have been used *continuously over a specified time period* (e.g. 'for 12 months prior to the introduction of the NDIS'), this would unfairly exclude many people who need periodic support.

(b) Continuity of support is designed to ensure that people with a disability — who would not be eligible for NDIS funding — are not disadvantaged when the NDIS is introduced in their area. If that is the case, then continuing a person's support should be determined by evidence of (i) continued need and (ii) positive outcomes. For example, suppose that prior to the NDIS, a person has only been using a minimal disability service or an alternative therapy (such as acupuncture to manage pain or weight loss). If there is sufficient evidence that their need for this support is ongoing and the support has led to positive outcomes, then they should still get this support under an NDIS. [1.19, 1.20, 1.21, 20.70, 20.71, 20.72, 20.75]

RECOMMENDATION 5.2 — Ensure that private care keep service agreements during a client's transition to the NDIS.

If a person is currently using a private care agency, but wishes to transition to NDIS funding, then — to preserve continuity of support — the Agency should require that (a) during that person's transition to NDIS, the private care agency must continue providing supports to the client, as per their initial service plan; and that (b) any funds forwarded to the private care agency by the client that were not used to fulfil its service agreement must be returned to the client. Otherwise, it is likely that clients will be 'dumped'. [20.69a, 20.69b, 20.69c]

RECOMMENDATION 5.3 — Communicate any eligibility criteria for continued support to all relevant persons.

Any eligibility criteria for continued support under the NDIS should be clearly and effectively communicated by the Agency to all those who currently receiving disability support in the relevant jurisdiction (e.g. the time period or duration that a person must have been using a support, the kind of programs they can no longer access once they are in the NDIS, and those they can continue to access if they choose, etc.). [20.69d, 20.8, ATD]

RECOMMENDATION 5.4 — Require eligible programs to help their clients' transition to the NDIS.

Any eligible program that is likely to lose some or all of their funding due to the introduction of NDIS must give their clients (a) sufficient notice of the date by which the program (or their supports) will end, as well as (b) assistance in any transition they plan to make to the NDIS (e.g. providing clients with their 'start up date', so that they can quickly and easily see how long they have been receiving support, etc.). [20.69d]

6. Disability Requirements

In September 2012, Brain Injury Australia and its member organisations published a *National NDIS Consultation Report* on eligibility and assessment (tinyurl.com/b6s6d92). This report contains a comprehensive set of recommendations how best to ensure that people with ABI receive an accurate and fair assessment of their impairments, functionality capacity and social and economic participation. Hence, in addition to the recommendations below the Agency should take this Report into account as it develops Rules on how disability impairments should be assessed and by whom.

To decide whether a person's impairments are (or are likely to be) permanent, the Agency should do the following:

RECOMMENDATION 6.1 — Provide support even where not every aspect of a person's impairment is permanent.

The impairments of a person with ABI may be assessed as permanent in some aspects and not in others. For instance, a rehab specialist may determine that a person has the potential to walk again, but may not get a job again because of their cognitive impairments (such as loss of organisational skills). So the Disability Requirement should not require that *every* aspect of a person's impairments is permanent. [1.22, 1.24]

RECOMMENDATION 6.2 — Provide immediate support where needed, even if prior to a diagnosis of permanence.

It is difficult to determine whether — or the extent to which — damage to the brain is permanent until 2-3 years down the track. And specialists can disagree on whether a disability is (or is likely to be) permanent: no one can say whether a person will definitely get back the use or part use of an arm. So support should be available for those who need immediate help — whether or not the damage has been determined to be permanent (as in the Bill's Early Intervention Requirement, which allows that if early intervention access and practice is done well, then the opportunities for reduction of permanent impact will be increased). [1.23, 1.24, 20.81, 20.82]

RECOMMENDATION 6.3 — Ensure that the eligibility criteria recognise specific areas of cognitive impairment.

It is critical that the criteria for impairment should not be the same as that used by Centrelink, which doesn't take into account particular areas of cognitive impairment. The criteria need to be more sensitive to specific areas of cognitive impairment (e.g. organisational skills, planning, etc.). [1.25, ATD]

RECOMMENDATION 6.4 — Ensure that the definition of 'permanence' allows for variability over time.

The requirement of 'permanence' should not exclude impairments (like ABI) that exhibit variations in intensity, deterioration or improvement over time. [2.3, 20.83]

RECOMMENDATION 6.5 — Ensure the assessment is carried out by a team of disability-specific experts.

The assessment of 'permanence' must be made by a clinical team, consisting of qualified personnel with experience in providing services for the disability in question (only a team experienced in the field can make the judgement of permanency, one individual – however qualified, cannot make this call.) [2.1, 2.2, 20.77c, 20.86, ATD]

RECOMMENDATION 6.6 — Take into account that impairments cannot be deemed 'permanent' by diagnosis alone.

The Rules should take into account the fact that WHO redefined 'impairment' as pathology – and did not point to impairment or pathology as being permanent [ICD-10]. Medical science has not advanced far enough to establish which impairments will be permanent *by diagnosis alone* (i.e. prior to treatment). Any impairment left unattended will be permanent: for example, RSI involving the hand can become permanent if not addressed early, and there are many medical examples of minor problems becoming permanent, such as chronic pain. [20.77]

RECOMMENDATION 6.7 — Ensure that permanence is not defined or assessed in terms of what is 'visible'.

The assessment of a person with ABI should take into account the fact that many impacts of an ABI may not always be visibly evident, but may remain permanent in nature (e.g. memory retention, social skills, etc.). [20.84]

RECOMMENDATION 6.8 — In assessing an ABI's permanence consider its severity, recency and recovery potential.

In considering whether an acquired brain injury is permanent, aspects to consider are:

(a) severity of the injury;

(b) how recently the injury occurred;

(c) the extent to which the person with ABI has had prior access to rehabilitation; and

(d) whether they have reached their neurological and functional potential over a likely early recovery period. [20.85]

To decide whether a person's impairments are having a severe impact on their lives — that is, by substantially reducing their (a) functional and psychosocial capacity and/or (b) social and economic participation — the Agency will need to do the following:

RECOMMENDATION 6.9 — Ensure that the definition of 'severity' does not limit support to high end care.

The NDIS should be able to provide a wide range of levels of care, from minimal episodic support to high-end intensive support. In that case, the definition of 'severity' doesn't need to be just limited to the 'high-end'. [1.28]

RECOMMENDATION 6.10 — Ensure that 'severity' is not defined so as to exclude persons who improve over time.

A person should not be considered ineligible when their condition improves (i.e. it is no longer as 'severe' as it was at first). [1.29]

RECOMMENDATION 6.11 — Assess reduction in functionality using criteria from specialist rehabilitation team(s).

The criteria used by the Agency for measuring the severity of impact must be drawn from a qualified team with experience in each specialised field of rehabilitation — cognitive, physical and mental, paediatrics, adults and aged care. [20.88, ATD]

RECOMMENDATION 6.12 — Measure severity of impact in multiple diverse contexts over time.

Severity of impact should be measured by evidence of whether an individual can safely and effectively meet their social and functional needs and personal goals in 'real life' situations, mapped against current skills or opportunities. This will require that more time be spent with the person to actually assess how various parts of their lives are impacted. This is not something that can be judged in an hour, or over the phone, or even in one day, or in the one place. Assessments should accommodate the person's capacity and preferences, and could be done over multiple visits and in multiple different locations involving many different daily activities and types of evidence-gathering methods (i.e. formal assessments, observations and self-reporting). [13.6, 13.7, 20.96, 20.97, ATD]

RECOMMENDATION 6.13 — Accompany advances in functionality with ongoing assessments for safety and skill.

As supports may allow the person to do more, and they realize that they could expand their goals, then ongoing periodic assessment for safety, skill development, and changing aspirations would be needed. [20.98, ATD]

With respect to whether people can provide the Agency with existing assessments that show they meet the disability requirements, the Rules need to say the following:

RECOMMENDATION 6.14 — Accept existing assessments if they show a person meets the disability requirements.

The Rules should say that if a prospective participant has existing assessments demonstrating that they have the relevant impairment(s) and/or a substantial reduction in their functionality or social/economic participation, then these assessments should be accepted by the Agency as evidence that they meet the disability requirements. [2.8, 20.105, 20.107, 20.109]

RECOMMENDATION 6.15 — Ensure that assessment criteria and methodology are clear and accessible.

To ensure that people are clear about the kind of assessments they will need to provide or obtain in order to meet the NDIS disability requirements, the Rules should specify — in a transparent and accessible way — the assessment criteria and methodology. This should include how the Agency will determine (a) whether a person already has the information or medical assessments that it requires, and (b) whether these assessments are specific to the person's disability and sufficiently current or valid. [1.30, 1.32, 1.33, 1.34, 2.9, 20.100]

RECOMMENDATION 6.16 — Ensure that prior functional assessments cover complex lifestyles and co-morbidities.

Before relying entirely upon existing functional assessments, the Agency should ensure that these assessments are capable of demonstrating the functional impact of the disability *in the context of a complex lifestyle and/or concurrent health issues* (such as mental health, alcohol and drug issues, and other co-morbidities). If this is not the case, then the Agency should ensure that the individual undertakes the necessary additional functional assessments so that a more accurate picture can be brought to bear on the planning process [20.109, 20.110, ATD]

RECOMMENDATION 6.17 — Ensure that the Agency pays for any assessments that it requires.

If someone does not have the assessments required by the Agency, then they should be required to undertake these — and this should be funded by the Agency. [1.31, 20.104]

RECOMMENDATION 6.18 — Require assessments to be in writing, undertaken by teams nominated by the Agency.

If the Agency requires that a person undertake an assessment, these must be provided in writing by teams nominated and recognised by the Agency as having representative expertise to judge the validity of earlier reports in the current time. [20.99, 20.109]

To make sure that the Agency's decision is based on an assessment of what a person can do or aspires to do, rather than a diagnosis, the Rules will need to say the following:

RECOMMENDATION 6.19 — Make severity of impact sufficient for eligibility.

The Rules should say that: where a diagnosis has not been (or cannot be) obtained, but it is clear from a functional assessment that the person has impairments which are having a 'severe impact' on their life, then they should be eligible. [1.35]

RECOMMENDATION 6.20 — Ensure that goal setting takes account of, but is not dictated by the diagnosis.

For people with ABI, their diagnosis significantly impacts on what aspirations are realistic or possible (e.g. it may be highly unlikely that a person will ever be able to drive due to their brain injury). But the science is inexact: a diagnosis of any particular kind of ABI cannot be taken as predictive of what a person can do. Hence, while the diagnosis must be taken into account (so that people are not 'set up to fail'), people with ABI should be supported to reach their current goals and aspirations. Some will never be independent, but could be in a better situation if given the right support and attention. People should never be told: "this is it" and given a level of acceptance. In other words, goal setting must be within a realistic framework, whilst not preventing (e.g. de-motivating) people from trying to move beyond current expectations. [2.10, 2.11, 20.117, 20.118, 20.120]

RECOMMENDATION 6.21 — Use interdisciplinary approaches to assess the functionality-diagnosis relationship.

The Agency must recognise that assessing the relationship between diagnosis and functionality is an 'art', and must involve an inter-disciplinary perspective. [2.12]

RECOMMENDATION 6.22 — Base the decision on a participant's abilities, participation difficulties and goals.

The Agency's decision should be based upon an assessment of the participant's ability, their current 'problems' or 'participation difficulties' and their goals for short term and long term. In cases where there is a mismatch between ability and aspiration, an interim plan needs to be made, with the participant's aspiration documented as a 'future direction'. (This is the kind of approach that would be used by a team familiar with assessing short and long-term rehabilitation needs). [20.114]

RECOMMENDATION 6.23 — Take into account the life and aspirations of a person with ABI prior to their injury.

The Agency must ensure that pre-injury goals lifestyles and social attributes of people with ABI are taken into account. [20.122, ATD]

RECOMMENDATION 6.24 — Use goal planning techniques with people who have an ABI.

The Agency must recognise the need to use goal-planning techniques and a high level of specialist ABI knowledge with people who have an ABI, given that they may:

(a) have difficulty with generating ideas, planning and/or memory;

(b) lack experience in setting goals or considering what they aspire to in life;

(c) have experienced significant or subtle changes in their identity or character;

(d) still be learning what is possible for them after their brain injury;

(e) regularly change their goals or aspirations. [20.123, 20.124, 20.125]

7. Early Intervention Requirements

To decide whether early intervention is likely: (a) to reduce a person's future need for supports, (b) to slow down or even stop someone from losing the ability to get around, communicate or take care of themselves, (c) to help families and other carers support them over the long term, the Agency will need to do the following:

RECOMMENDATION 7.1 — Ensure that the early intervention requirements also apply to permanent disabilities.

People with a permanent disability will also benefit from early intervention. So the Agency should ensure that, at an operational level, the 'early intervention requirements' are understood as determining eligibility for the use of early interventions, *regardless of whether or not the disability is — or is likely to be — permanent.*[5] [5.26]

RECOMMENDATION 7.3 — Ensure people with ABI are referred for an NDIS assessment upon discharge from rehab.

Many people with ABI will not be aware that they are eligible for NDIS support after discharge from rehabilitation. So, the Rules should mandate that they are recommended to or referred by Health to the NDIS for an assessment upon discharge from rehabilitation. [1.37]

RECOMMENDATION 7.4 — Stop health from making early discharges because 'the NDIS pays for early intervention'.

The Agency should ensure that Health does not discharge patients (esp. people with ABI) who would otherwise have been provided with rehabilitation on the assumption that the NDIS will pay for 'early intervention'. To make this happen,

(a) the Rules should require that Health *complete* whatever they would ordinarily have done before patients are discharged;

[5] This recommendation was made before the NDIS Bill was amended to include the permanence of an impairment as a requirement for early intervention (25(1)(a)(i)-(ii).

(b) the Agency should assess whether or not this has happened before it 'takes on' the person, and they should be returned to Health if it has not (this will provide a safety net for those who have been incorrectly managed or discharged too early). [1.36]

RECOMMENDATION 7.5 — Use ABI experts to assess the effectiveness of an early intervention in individual cases.

The Agency should have the capacity to identify and engage ABI experts who can evaluate the effectiveness and availability of a particular early intervention treatment for individuals within their functional contexts. The Agency should recognise and respect the decisions and diagnoses of these experts, and the body of research underpinning this expertise — rather than attempt to make decisions for which they do not have the relevant expertise. [1.38, 2.14, 2.15, 3.2, 3.6, 5.15, 5.16, 5.17, 5.21, 5.22, 20.130, 20.132, 20.135, 20.137, 20.138, 20.139]

RECOMMENDATION 7.6 — Ensure that early interventions are not *merely* assessed by providers who may benefit.

If a service provider makes the assessment that an early intervention that it can deliver would be beneficial to a participant, then the Agency should ensure that this assessment is confirmed by an independent qualified assessor before allowing the participant to purchase that intervention from the provider in question. [3.3, ATD]

RECOMMENDATION 7.7 — Ensure that funding for early intervention is provided on a no-fault basis.

People with ABI should not be excluded from early intervention treatment (rehabilitation) on the grounds of prior drug and alcohol use. [1.39]

RECOMMENDATION 7.8 — Support research into early intervention treatments.

The Agency should support research into early intervention treatments. [2.16]

RECOMMENDATION 7.9 — Monitor the use of early intervention and adjust use/funding based on outcomes.

The Agency should ensure the use of early intervention is monitored and adjust the use/funding based on outcomes. This should include ensuring that both service providers and an independent assessment team conduct a periodic review of the intervention at set dates. [2.17, 3.5, ATD]

RECOMMENDATION 7.10 — Take into account the individual/family's level of engagement in early intervention.

The individual (and/or the family) should take responsibility to (a) engage in the early intervention effectively, and (b) to continue the treatment over the appropriate time span (e.g. rehab. can take 2 years). The Agency's assessment of the effectiveness of a treatment and its continued funding of the treatment for a particular individual (and/or the family) must take this into account. For example, where an individual (and/or the family) has not engaged effectively in a treatment:

(a) there should be provision for follow-up (by a certain time period) by the Agency to see if the situation has changed;

(b) the Agency must take into account whether (or the extent to which) a provider of supports is using a person-centred approach to engage people (e.g. if a service is not offering sufficient choice and control, then this may be the reason why the person is resisting engagement) — for instance, rather than forcing a person to

engage in rehab from day one, a provider might offer a 3 day 'trial' in which a person can explore the rehab service and talk to other patients, without any pressure to continue. [2.18, 2.19, ATD]

RECOMMENDATION 7.11 — Recognise that if improving self-care makes family support more sustainable.

A person's capacity to self-care is the most difficult aspect of personal care. So if an early intervention can improve this capacity, that will in itself make the family/carer support more sustainable. [2.20]

RECOMMENDATION 7.12 — Recognise that reducing need for 'outside care' makes family support more sustainable.

If an early intervention can result in less 'outside care' coming into the house (given its intrusiveness), this is likely to make the family's/carer's support more sustainable. [2.22]

RECOMMENDATION 7.13 — Do not exclude early interventions that only result in small improvements over time.

Incremental improvement is better than none at all, and can be enormously rewarding for individuals and their families. And everyone's journey is unique (for example, not everyone will be able walk in 6 months). So an early intervention should not be assessed merely on its capacity to result in large-scale and/or rapid improvements. [2.21, 20.129, ATD]

RECOMMENDATION 7.14 — Ensure that people likely to benefit from an early intervention can be referred asap.

There should be a range of recognised 'flags' or symptoms that can ensure that people who may benefit from specific types of early intervention treatments or programs can be readily identified and referred to the appropriate program as early as possible. For example, a person's level of social and functional impairment should inform the decision about whether early intervention is likely to achieve the benefits listed. [5.18, 5.28]

RECOMMENDATION 7.15 — Ensure that decision-makers understand benefits of ABI-specific early interventions.

The Agency should make sure that those who make decisions about whether an early intervention for a person with ABI should be funded have undertaken ABI-specific training — and that this training enables them to understand the benefits of early intervention for people with ABI. [5.19]

RECOMMENDATION 7.16 — Apply 'early intervention' to children, before/after diagnosis and soon after trauma.

The Agency should ensure that there is clarity and standards around the use of the term 'early intervention' in the context of NDIS funded support: for example, that the term includes (a) working with children, (b) treatment that occurs before and/or after a diagnosis, and (b) intervening soon after a trauma. [5.20, 5.29]

RECOMMENDATION 7.17 — Address the inequity of remote locations having restricted access to early intervention.

The Agency should seek to address the fact that there will be individuals — particularly in remote locations — who are unable to access early intervention programs. [5.23]

RECOMMENDATION 7.18 — Recognise the existence of established pathways to early intervention.

The Agency should recognise well-established pathways to early intervention that exist already, rather than attempting to re-invent or 'take over' the process. [5.24]

RECOMMENDATION 7.19 — Publish a list of acceptable preventative and therapeutic early interventions.

In the same way as Private Health Insurance companies, the Agency should maintain and publish a list of acceptable preventative and therapeutic measures. [20.126]

RECOMMENDATION 7.20 — Perform risk analysis and evaluate net benefits of early intervention.

To decide whether early intervention is likely to reduce a person's future need for supports, the Agency needs to: perform risk analysis to ascertain the impacts of either proceeding or not proceeding with the early intervention; and verify that there is evidence to suggest that the net effect of the intervention will be positive rather than negative. [20.126]

RECOMMENDATION 7.21 — Ensure that early interventions are sustainable, given family/carer circumstances.

To decide whether early intervention is likely to help families and other carers support a person over the long term, the Agency needs to assess the family/carer(s)' needs as part of the process, so as to ensure that the intervention is sustainable. For example: suppose a child requires therapy for one hour a day, 7 days a week, during working hours; but the child's primary carer is a single parent in the workforce. In such a case, the Agency will need to fund creative solutions: for instance, the therapist could be funded to travel to school to do the therapy and enable the parent to learn the techniques for the weekend; or a support worker or taxi could be booked to help transport the child to and from the therapist. [20.128]

RECOMMENDATION 7.22 — Recognise that early intervention can improve skills or help compensate for lost skills.

The Agency should take into account the fact that early intervention can either increase a person's skill levels or increase their capacity to compensate effectively for lost skills. [20.132]

RECOMMENDATION 7.23 — Ensure that any early intervention includes a properly funded follow-up plan.

Even where early intervention has significantly reduced the need for support, many people with ABI will always need some form of support in place or at least very regular reviews to pick up on any underlying issues that could cause a regression long before too much progress is lost. Hence, the Agency should ensure that any early intervention includes a funded plan that specifies who will take responsibility for providing ongoing follow-up support. This includes a strategy for when support workers 'burn out' and discontinue. [20.131, 20.139, 20.143]

RECOMMENDATION 7.24 — Recognise that structured early intervention helps people with ABI to retain capacities.

The Agency should recognise that if a person with ABI has significantly reduced initiation, then, without early intervention to impose a structured environment and programming (routines), they may deteriorate due to inability to retain capacities. [20.133]

RECOMMENDATION 7.25 — Recognise that early intervention offers family/carers info on ABI, recovery and respite.

The Agency should recognise that any early intervention for people with ABI can offer the family/carers an opportunity for them to receive education about ABI, expectations for recovery, and the need to ensure that respite is part of the long-term routine. [20.134]

In order to decide whether using a new kind of early intervention will offer the best outcome for a person with a disability while also making sure that money isn't wasted, the Agency need to do the following:

RECOMMENDATION 7.26 — Ensure that the provider meets quality standards and can deliver a service as claimed.

The Agency should ensure that the provider (a) has met the standard range of quality assurances, (b) is transparent about whether they can deliver the service that they claim — which includes putting procedures in place to deal with providers who fall short of their claims. [1.40, 3.7, 3.9]

RECOMMENDATION 7.27 — Check to see whether the person with a disability is persisting with the intervention.

One indication that a new kind of early intervention is effective will be that the person with a disability has chosen to keep going with that intervention. [1.40]

RECOMMENDATION 7.28 — Ensure that the person with ABI understands their obligations re the intervention.

Set up a contract with the person with ABI, whereby their obligations are clearly stated (i.e. attendance to a program, participation in intervention, etc.)

RECOMMENDATION 7.29 — Conduct a cost-benefit analysis of new kinds of early interventions.

Any new early intervention should be submitted to an evidence-based cost-benefit analysis that is, an assessment as to (a) whether or not the intervention is likely to result in a positive outcome in terms of that person's capacity to do — and/or to be motivated to do — what is required to reach their own measurable goals within their current functional contexts, and (b) whether or not this outcome could be achieved in a more cost efficient way. [2.23, 3.8, 20.140, 20.141, 20.145, 20.145, 20.146, 20.147, 20.148, 20.149, 20.150]

RECOMMENDATION 7.30 — Fund the research and development of new interventions.

Rather than merely monitoring outcomes, the Agency should fund the research and development of new interventions. This might include (a) the provision of clear guidelines on how participants can apply for and attend pilot early intervention programs, (b) clearly defined goals — measured against the 'baseline results' of other tested interventions — that must be achieved by a certain date for the intervention to be deployed nationally. These goals might include a decrease in support hours over a particular timeframe, a decrease in behaviours of concern (and therefore the need for crisis intervention), and a decrease in the cost of an individual's support package. [3.10, 4.10, 20.152, 20.153]

To work out when there is enough evidence to be reasonably confident that an early intervention is likely to result in the benefits listed above, the Agency will need to do the following:

RECOMMENDATION 7.31 — Check the status of the intervention with Medicare and private health insurance.

The Agency should check the status of the therapy with Private Health Insurance companies or the Departments of Health and Ageing and Human Services (Medicare) [20.157]

RECOMMENDATION 7.32 — Trial the intervention and test its effectiveness.

The Agency should initially fund the intervention as a trial and then examine the evidence (from assessments, observations and self-reports) as to whether it is likely to be successful. Any such pilot must be large enough to ensure that the results can be duplicated across enough situations and people. [20.155, 20.156, 20.162, 20.163, 20.166]

RECOMMENDATION 7.33 — Ask the participant how effective a new intervention has been for them.

The Agency should take into account the person's own perspective on how successful the intervention has been, in terms of meeting their goals. [1.42a]

RECOMMENDATION 7.34 — Ensure there is no evidence that a new intervention is NOT likely to be effective.

Evidence in favour of using a new intervention should include: the fact that there is no evidence that it is NOT likely to result in positive benefits for the individual in question. [1.42b]

RECOMMENDATION 7.35 — Recognise that for ABI the effectiveness of an intervention depends on recovery stage.

The Agency should recognise that the outcomes of an intervention for people with ABI will change as they progress through the different stages of neurological impairment and recovery/coping. [20.166]

RECOMMENDATION 7.36 — Check for its impact on a person's mental health, support network, and debt levels.

Evidence in favour an early intervention should include the extent to which it is having a positive impact on areas such as:

(a) a person's continued good mental health;

(b) sufficient support from family and friends;

(c) how family relationships are coping;

(d) how they are managing their level of debt. [20.158, 20.159, ATD]

C. PARTICIPANTS' PLANS

8. Reasonable and necessary support

To work out which supports are (and are not) reasonable and necessary, the Agency will need to do the following:

RECOMMENDATION 8.1 — Justify what supports are reasonable and necessary on an individual, case-by-case basis.

The Agency must justify what supports are reasonable and necessary for each individual on a case-by-case basis. In other words, it is better not to define with too much precision what kind of supports satisfy these criteria, so that each individual can be assessed on their own. [1.43, 5.31]

RECOMMENDATION 8.2 — Ensure that NDIS does not fund supports that are available elsewhere.

The Agency has to be clear about what else is available in that community – i.e. that the NDIS is not replacing what a person would ordinarily access. [1.44]

RECOMMENDATION 8.3 — Ensure that both Agency and participant agree on supports, within budgetary limits.

Both the Agency and the individual would need to agree on what is reasonable and necessary — taking account of budgetary limitations (e.g. identifying a list of possible supports from which the person can then choose). [1.45]

RECOMMENDATION 8.4 — Ensure that supports are determined by how a participant prioritises their goals.

An individual's capacity to perform an activity on their own does not always mean that support for that activity shouldn't be provided. For example, they might feel that the time or energy it would take to perform that activity themselves would prevent them from engaging in other activities that would enable them to achieve goals that are more important to them (e.g. staying in education or employment). So in cases such as this, if an individual decides that they need support for a particular activity — even if they *could* do it themselves — then that support should be available to them. [1.46]

RECOMMENDATION 8.5 — Ensure that 'fundamental needs' are supported first, then extend to 'aspirational' goals.

The supports should begin with providing for fundamental needs (ensuring that a person can be showered, dressed, and fed), and then extend the support to other more 'aspirational' goals. For example, a person should not be able to exchange funds that are allocated in their plan to support fundamental needs (showering) so that they can meet the more 'aspirational' goals (going to a footy match). However, 'fundamental needs' should not be pre-defined, but take into account cultural appropriateness (e.g. Indigenous persons may feel that 'social connection' is a fundamental need). [2.26, 2.27]

RECOMMENDATION 8.6 — Ensure that supports are consistent with the Bill and the UN Convention.

The supports must be consistent with the principles and objects in the NDIS Bill and the UN Convention on the Rights of Persons with Disabilities. [5.32]

RECOMMENDATION 8.7 — Ensure that people who are 'caught between systems' are properly supported.

The Agency will need to ensure that people are not 'caught in limbo' between systems. For example, how will crisis situations be funded? Will crisis management be built into each support plan? And how will disagreements about which agency/system is responsible for providing a reasonable and necessary support be resolved quickly and without impacting negatively on the care of the person with a disability? [5.33]

RECOMMENDATION 8.8 — Ensure that the generic conditions for support allow disability-specific exceptions.

The generic conditions for reasonable and necessary support (as outlined in the Bill) should allow for the fact that some disabilities will be unlikely to meet one or more of these conditions (e.g. improving social participation for degenerative conditions). Put another way, the generic conditions should be understood as sufficient, rather than necessary (e.g. '*if* a support improves social participation, then it is reasonable and necessary' – rather than: 'a support is reasonable and necessary *only if* it improves social participation'). Again, it would be better if supports were required to be 'reasonable *and/or* necessary', given that some supports might be reasonable without being strictly 'necessary' (at least where this term is defined as 'necessary *for survival*'). [5.34, 5.35]

RECOMMENDATION 8.9 — Recognise that if a support improves mental health, this can impact on physical health.

In determining whether a support is reasonable and necessary in relation to a physical impairment, the Agency should recognise that if a support improves one's mental well being, this can have a significant positive impact on one's physical well-being. For example, hobbies — particularly for people with ABI — can result in significant health benefits. [5.37, 5.39]

RECOMMENDATION 8.10 —Fund reasonable and necessary supports that can only be accessed overseas.

If a participant's support satisfies all the conditions for reasonable and necessary, but can only be accessed outside Australia, then the Agency should enable the participant to access this support with NDIS funding. [5.38]

RECOMMENDATION 8.11 — Recognise the recommendations of government-funded organisations re supports.

The Agency should ensure that employees of government-funded organisations are able to make recommendations about a participant's need to purchase specific supports. For example, if a physiotherapist works with a brain injury service at a public hospital, their recommendations regarding a participant's need for therapeutic equipment (such as walking frames or modified trikes) should be recognised by the Agency for the purpose of funding. (Note: this kind of recognition is not currently permitted by 'Better Start' in NSW). [20.269]

To make sure that the supports it decides to fund are reasonable and necessary, the Agency will need to do the following:

RECOMMENDATION 8.12 — Take advice from those in the best position to judge what a participant needs.

The Agency needs to take advice from and negotiate with people who are in the best position to judge whether the supports really are meeting the participant's needs, including the participant themselves. [12.30, 19.13]

RECOMMENDATION 8.13 — Promote a culture in the industry that empowers the independence of people with ABI.

The Agency should help to change the culture of the disability industry so that it is more likely to empower the person with ABI to become more independent, rather than support staff putting as a priority the protection of their own jobs/hours (taking into account the fact that some people with ABI will prefer or have previously been encouraged to remain dependent, and some families may not want to change current arrangements). [12.31]

RECOMMENDATION 8.14 — Ensure that there are sufficient numbers of support staff with knowledge of ABI.

The Agency should ensure that there are an appropriate number of support staff in any local area who are properly educated about ABI so that they do not, e.g. misunderstand certain behaviours (e.g. a few workers are trained, but they don't end up being the support worker for a person with ABI). [12.32]

RECOMMENDATION 8.15 — Ensure that the right supports are provided when and as needed.

The Agency needs to be responsive to change, conducting quick reviews, so as to ensure that the right supports are provided when and as needed. [12.33]

RECOMMENDATION 8.16 — Establish preventative health measures.

The Agency needs to put in place preventative health measures rather than waiting for a person with disability to develop problems. This will be far more cost-effective and be far more likely to maintain a person's quality of life and independence. [12.34]

RECOMMENDATION 8.17 — Ensure that the person managing the funds is able to purchase supports as needed.

The Agency needs to have (a) a good assessment process and (b) ongoing accountability in place to ensure that the person who is in control of the funds has the appropriate ability to allocate and manage the funds. [12.35]

RECOMMENDATION 8.18 — Ensure that families have access to a consistent support person who knows the system.

Families need a consistent support person (e.g. the Plan Management Provider) who knows the system and the services available. [12.36]

RECOMMENDATION 8.19 — Enable people with ABI and their families to find out about evidence-based therapies.

The Agency should ensure that people with ABI and their families have the most up to date information they need to access to evidence-based therapies. [12.28, 12.29, 12.37]

RECOMMENDATION 8.20 — Don't assume that if people with ABI don't need care, then won't need support.

There is a difference between *support* (i.e. helping people to access services without doing it for them, facilitating independence, etc.) and *care* (i.e. non-paid, hands on, active, helping people to shower, brush teeth, etc.). The Agency should not assume that if people with ABI don't need care (because they can cook, shower, etc.) then they don't need support (e.g. with planning, organising, regaining independence, reconnecting with the community, etc.). [14.8]

RECOMMENDATION 8.21 — Review the support plan early and on a regular basis.

The support plan will need to be reviewed on an early and regular basis, and may require further bedding down or changing. There must be an opportunity to re-direct the program of support without going through a lot of red tape (e.g. changing a program of hydrotherapy to another type of therapy depending on the responses of the participant or its effectiveness). [19.11]

RECOMMENDATION 8.22 — Ensure that the kind and level of supports are equitable in different locations.

In terms of what is reasonable and necessary, there should be broad equity across different locations (e.g. a person in a rural location should have access to the same level of personal care as someone in an urban location if their needs are identical). In other words, expectations about what is reasonable and necessary should not be limited to or determined by what is currently available in any location. [19.14, 19.16, ATD]

RECOMMENDATION 8.23 — Take account of cultural differences.

The Agency should ensure that its decisions about what is 'reasonable and necessary' take into account the fact that people from different cultures may hold different views. [19.15]

RECOMMENDATION 8.24 — Engage in long-term capacity building for ABI-specific services and expertise.

The Agency needs to take account of the lack of (i) general disability services that understand and/or are sensitive to the needs of people with ABI and (ii) ABI-specific expertise available in (a) remote and rural communities, and (b) for people with ABI in general. In other words, the current capacity to provide support for people with ABI will be extremely limited in those areas or for those individuals, and so the Agency — working in partnership with state governments — must also be engaged in (i.e. by funding or supporting) a long-term and sustainable capacity-building program in order to address this issue. [7.16, ATD]

RECOMMENDATION 8.25 — Help to create system-wide ABI-specific protocols, shared responsibility, best practice.

The Agency should have an ongoing developmental responsibility for ensuring that there are system-wide (a) ABI-specific protocols, (b) shared responsibility and (c) best practice for clients with multiple and complex needs who 'sit across' systems (e.g. education, drug and alcohol, mental health, aged care, etc.). (See for example Multiple and Complex Needs Initiative, VIC and SA). [7.17, ATD]

9. Management of Plans

To work out whether it would be an unreasonable risk to a person if they managed (some of all) of their own funding, the Agency will need to do the following:

RECOMMENDATION 9.1 — Identify whether the participant is likely to be exploited due to their access to funds.

The Agency should make sure that the participant will not be seen as a 'target' for financial exploitation because they now have access to funding. [1.48]

RECOMMENDATION 9.2 — Identify whether the participant is vulnerable to undue influence.

The Agency should make sure that, if a participant chooses to manage their own funding, they will not be made vulnerable to undue influence, pressure or manipulation by those around them (e.g. is there conflict in the person's family or informal network about how a plan should be managed?). [6.3, 6.8]

RECOMMENDATION 9.3 — Monitor and review the delivery of supports identified in the participant's plan.

To ascertain whether a participant's self-management of their funds is an unreasonable risk, the Agency should ensure that the delivery and payment of the supports identified in their plan is well monitored and reviewed. Evidence of unreasonable risk would be that (a) they are purchasing services that are not related to their support plan, (b) they are making a lot of purchases in a short period of time, in a way that is inconsistent with their support plan, or (c) they are not making the purchases that were specified in their support plan. [1.49, 8.4, 19.19, 20.210]

RECOMMENDATION 9.4 — Assess the person with ABI's capacity to make decisions in their best interests.

For participants with ABI, there should be appropriate specialist tests by relevantly qualified people (e.g. neuropsychologists and/or OTs) that regularly assess their current capacity to make decisions for themselves that meet their needs or are in the best interests of their welfare. Specifically, this assessment should:

(a) identify whether:
- the participant is cognitively incapable of self-management;
- they have a severe drug and/or alcohol addiction;
- they do not have enough life experience to be able to manage money;
- the person has a history of making impulsive inappropriate decisions;
- their goals are unrealistic;
- their cognitive limitations will make it too hard for them to pay bills on time or meet deadlines (e.g. for some people with ABI, time can seem to pass very quickly or very slowly, or they may have memory loss, or lack of insight into their cognitive limitations or organisation issues);

(b) evaluate the sustainability, duration of or changes to that capacity;

(c) be included in any review process;

(d) take into account the views of all stakeholders involved in the person's life (e.g. parents, carers, spouse, children, guardians or trustees);

(e) be periodic and face-to-face, given that people with ABI can 'present' as able to do more than they can in reality, especially if the assessment happens to be conducted on a 'good day' or on the phone or internet;

(f) be informed by other measures of stability in the person's life (e.g. history of financial stability, family relationships, etc.). [5.40, 5.43, 6.1, 6.2, 6.4, 8.1, 8.2, 8.6, 8.7, 8.8, 8.9, 8.10, 8.11, 10.4, 10.5, 19.19, 19.21, 20.193, 20.194, 20.198, 20.199, 20.201, 20.203, 20.207, 20.208, 20.209, 20.222]

RECOMMENDATION 9.5 — Examine the participant's history for evidence of financial mismanagement.

The Agency should look at the participant's history and determine how they have managed their finances previously (e.g. have they been unable to manage their own daily expenses — e.g. going shopping with their own money and paying bills, are they in a substantial amount of debt, have they been bankrupt, do they have a relevant criminal conviction, do they have a severe gambling addiction, to what extent has the Public Trust, or Office of AG been involved in managing their finances?). [1.47, 5.44, 6.7, 10.5, 19.18, 20.204, 20.206]

RECOMMENDATION 9.6 — Recognise state legislation with respect to the role of public trustees.

The NDIS Bill (as national legislation) and/or the Rules need to be cognisant of state legislation with respect to public trustees. [5.41]

RECOMMENDATION 9.7 — Do not assume that a person under guardianship or a public trustee is too 'at risk'.

If a person is currently under guardianship or a public trustee they should not be *automatically* considered too 'at risk' to self-manage. There may still be decisions that a person can make in relation to managing their support plan. In other words, there should be evidence that this kind of assistance or guidance is needed and wanted (especially given that some guardians prefer to maintain strict control over decision-making, rather than allowing participants to make decisions even when they have the capacity to do so.) Hence, there should still be a review undertaken by the Agency and independent of the usual guardianship or public trustee processes of assessment. [5.44, 8.5]

RECOMMENDATION 9.8 — Focus more on building participant's capacity for choice, instead of risk aversion.

The Agency needs to be careful that it does not focus too much on risk aversion, rather than building the capacity of individuals to choose for themselves. For example, if someone does not *currently* have the skills to manage their own funding, but they have the potential to do so, then the Agency should provide them with training or an 'enabling infrastructure' so that they can manage their own funding. [5.42, 6.9, 19.20, 20.199]

RECOMMENDATION 9.9 — Set up a short-term trial to determine whether the participant is capable.

If a person with ABI feels that they can manage and would like to try, then there could be a trial period (e.g. 3 months) — perhaps starting with lower value supports. If they can show that they have all the receipts for what they've purchased, then this will show that they can manage their funding — in which case expand the range of supports they can control. But if the money is spent but hasn't been used on the service they said they needed (and they don't have the receipts), then the Agency should not simply take away control *completely*. Rather, it should respond in the first instance by engaging in a caring and sensitive negotiation as to what kind of assistance the person needs in order to manage (some or all) of their plan. [10.2, 10.3, 20.195, 20.196, 20.200, 20.202]

RECOMMENDATION 9.10 — Do not assume that the capacity to make decisions is 'all or nothing'.

The Agency should not assume that a person is incapable of making ANY kind of decision. They may be capable of making good decisions in some areas and not in others. So they may need assistance in some areas, but not in others. For example, a person with ABI

could be involved in deciding what they need and who they want it from, but not the process of purchasing supports (paying bills). [1.80, 6.5, 8.3, 20.211, 20.217, 20.219]

Things in a participant's plan that must not be managed by *any* participant:

RECOMMENDATION 9.11 — Ensure that mandatory services cannot be cancelled or changed by the participant.

For reasons of safety, the participant should not be able to cancel or change services that are mandatory for them (even if they don't want them). [1.50]

RECOMMENDATION 9.12 — Ensure that participant do not self-manage medical procedures or 'miracle cures'.

The participant should not be permitted to self-manage the selection or purchase of:

(a) medical procedures at any stage in their life, especially any that have the potential to lead to further disability;

(b) services or costly equipment that purport to 'cure' or make 'miraculous changes ' to clients physical /mental status. [20.212, 20.213, 20.214]

RECOMMENDATION 9.13 — Don't allow participant to self-manage reviews if they are unable to identify the need.

If a participant is not able to assess whether a review is required or there is evidence that they are likely to avoid reviews (e.g. because they do not like their routine to be changed), then they should not be given the responsibility for deciding when a review should occur. [6.10, 20.220]

10. Reviewing a Support Plan

The kind of changes that a person can make to their support arrangements without needing to have a review of their plan:

RECOMMENDATION 10.1 — Allow participants to change service provider, as long as quality and choice are upheld.

Participants should be able to make changes to their provider of supports without a formal review of their plan, so long as:

(a) the new provider meets relevant quality assurance standards or they are registered by the Agency;

(b) the participant has not been pressured or manipulated by the new provider into switching to them;

(c) the participant can produce evidence (in writing) that there has been a discussion and an agreement made with their advocate and family;

(d) the Agency is notified of the change. [1.51, 20.223, 20.225, 20.229, ATD]

RECOMMENDATION 10.2 — Allow participants to change the delivery of a support if it meets broad goals in plan.

They can change how or when a support is delivered so long as it meets the broad goals of the support plan. [1.52]

RECOMMENDATION 10.3 — Allow participants to change provider or support when it is uncompetitive or available.

The Agency should allow a participant to change to a new provider or support when this is made necessary by the unavailability of the old provider or support. Specifically, they should be allowed to:

(a) purchase alternative equipment (that fills the same functions at the same price or less) when the previous equipment is made obsolete or removed from the market;

(b) change the goods supplier when the person can get a better deal or the supplier ceases to trade. [20.226]

RECOMMENDATION 10.4 — Allow as much liberty to change as is reasonable, safe and consistent with their goals.

Changes to the support plan of people with ABI will be inevitable: it is a constant trial and error. So participants should be able to add things to their plan without unreasonable bureaucracy getting in way and slowing down or stopping it, so long as (a) doing so is consistent with the broad goals set out in their plan, and (b) there is a safe-guard of a minimum amount or kind(s) of support (e.g. hours of personal care) that they would have to keep regardless, and (c) ongoing regular assessments that they are coping and are not at risk of a crisis or regression. [20.231, 20.232, 20.233, 20.234]

The kind of circumstances that can trigger an automatic review of a person's plan:

RECOMMENDATION 10.5 — Hold a review if a participant applies for services exceeding the agreed plan or budget.

The Agency should initiate a review when a participant makes an application for goods or services that will either exceed the budget or the amount of supports as specified in the current support plan. [20.236, 20.237]

RECOMMENDATION 10.6 — Hold a review if a participant notifies the Agency of a change in circumstances.

The Agency should initiate a review when a participant notifies them that there has been a change in circumstances that will significantly affect the support plan. [20.238]

D. OTHER MATTERS

11. Information Sharing

It would reasonable for the Agency to share a person's private information with a Commonwealth or state or territory authority in the following circumstances:

RECOMMENDATION 11.1 — Share a person's information if it is for auditing or research and de-identified.

The Agency may share a participant's private information with a Commonwealth or state or territory authority if the information is de-identified and used for auditing purposes or on pilot programs for research outcomes (i.e. gender, age, locality by postcode). [20.241, 20.247, 20.249]

RECOMMENDATION 11.2 — Share a person's information if it doesn't exclude them from services unnecessarily.

Any private information that the Agency shares with a Commonwealth or state or territory authority must not be used to exclude the participant unreasonably from the provision of supports. [20.242, ATD]

RECOMMENDATION 11.3 — Share a person's information if it is required by legislation.

The Agency may share a participant's private information with a Commonwealth or state or territory authority if doing so is required by legislation. [20.240, 20.248]

RECOMMENDATION 11.4 — Share a person's information only with the informed consent of the participant.

The Agency may share a participant's private information with a Commonwealth or state or territory authority only if they have explicit and informed consent from the participant. [20.250, ATD]

RECOMMENDATION 11.5 — Share a person's information only if it meets conditions for sharing Medicare records.

The Agency may share a participant's private information with a Commonwealth or state or territory authority only if the conditions that apply to the sharing of a person's Medicare records also apply (see The Health Act (1953) Section 130, The Heath Insurance Act (1973) Section 135, The Privacy Act (1988)). [20.243, 20.245]

RECOMMENDATION 11.6 — Share a person's information if they request additional funding from that government.

The Agency may share a participant's private information with a Commonwealth or state or territory authority if the participant is requesting some type of additional funding from either the Commonwealth or a state or territory authority, and provides their informed consent. [20.246, ATD]

To make sure that people with a disability can get the support that they need, while respecting their privacy at all times, the Agency will need to do the following:

RECOMMENDATION 11.7 —Only disclosing information relevant to a participant's support.

The Agency should only disclose necessary information that is relevant to their support. [20.251]

RECOMMENDATION 11.8 — Do not share information if a participant considers it to be irrelevant to their support.

Respect the participant's right to withhold certain information that they believe is not relevant to their support. [20.252]

RECOMMENDATION 11.9 — Maintain participant records in a secure place, with a workable security plan.

The Agency must maintain client records in a secure environment and have a workable security plan in accordance with the Defence Signals Directorate Information Security Manual. [20.254]

RECOMMENDATION 11.10 — Only allow access by police-checked individuals, and only on a 'need-to-know' basis.

The Agency should ensure a person's information is not available to all and sundry as this can make people very vulnerable. Hence, everyone who has access to this information should be police checked and audits/controls put in place to ensure that staff are not accessing files they do not need to see. [20.251]

RECOMMENDATION 11.11 — Where possible, de-identify information before sharing it.

Wherever possible, and consistent with ensuring that the supports a person needs are provided, any information that is shared should be de-identified. [20.251]

RECOMMENDATION 11.12 — Share a person's information if they request additional funding from that government.

To get their support package, a participant will need to share some private information. But the extent and the use of this information should be limited to the specific purpose of enabling the Agency to (a) make the right decisions and (b) develop a support plan that can effectively meet the person's goals. These limitations to privacy would need to be clearly explained to the participant and their consent obtained *before* the information is shared. [20.257, 20.258, 20.259]

12. Registered providers of support

To decide whether it will register (or de-register) a provider, the Agency will need to do the following:

RECOMMENDATION 12.1 — Use existing state endorsements for disability support providers.

If it can be assumed that each State/Territory has a robust and reliable quality assurance system, the Agency should utilise existing State/Territory endorsements for disability support providers, rather than requiring that each organisation 're-apply' for approval with the Agency. [2.31, ATD]

RECOMMENDATION 12.2 — Ensure the provider is a legal entity and accredited by a system relevant to the service.

To be registered with the Agency, a provider of support should be a legal entity and have accreditation relevant to the service that it provides (e.g. attendant care). However, it is important that the actual accreditation not be listed (e.g. ACIMMS, ISO. etc.) as there are many kinds and service providers will have different accreditations. It would be better to require that a provider be accredited against a system that is approved by and relevant to the industry or service area (e.g., for attendant care this system would be 'JAS ANZ'). The Agency could then be assured that the service provider was liable for all legal and quality requirements, without needing to engage in a substantial quality management process. [20.273]

RECOMMENDATION 12.3 — Allow providers to remedy a breach, with de-registration used only as a last resort.

The Agency should provide a clear, concise and succinct policy on (a) what would constitute a breach of registration guidelines, (b) how many breaches would need to occur before de-registration, and (c) the steps that a provider can take to avoid de-registration (e.g. correcting the fault, making amends, and so on.) [2.32, 20.267, 20.268]

RECOMMENDATION 12.4 — De-register providers that fail to meet service standards and agreements.

A provider should be de-registered if:

(a) they are not compliant with relevant quality standards (e.g. Disability Service Standards);

(b) they do not fulfill their service requirements;

(c) criminal charges are made against the provider or head of the provider;

(d) they mismanage funds;

(e) there is a list of reportable items that the Agency requires them to report within a defined time-period on penalty of de-registration, and the provider does not comply. [2.32, 20.260, 20.265, 20.272, 20.274]

RECOMMENDATION 12.5 — Ensure that feedback about the provider is collected from all relevant consumers.

In determining whether a provider should be de-registered (e.g. because it has failed to meet the relevant standards and agreements), the Agency should obtain the views of the participants, their families and their carers. [20.271, 20.287]

RECOMMENDATION 12.6 — Only register providers with appropriately qualified staff and internal/external reviews.

To be registered a service provider must show that:

(a) they have the appropriately qualified staff to do what has been claimed;

(b) they provide up-skilling and ongoing training to their staff;

(c) in complex care cases, the relevant staff have been trained to take on clients' particular needs — physical and mental;

(d) they have a pathway that ensures that appropriately qualified personal (in house or external) will review each client's needs at least once a year;

(e) there are in-house reviews at set intervals;

(f) there is a pathway for external reviews, preferably by professionals from an assessment centre recognised by the Agency. [20.264]

To make sure providers don't have to go through a lot of red tape, while also making sure that services are delivered to the highest standard, the Agency will need to do the following:

RECOMMENDATION 12.7 — Make regular audits unannounced and targeted, rather than scheduled and 'blanket'.

The Agency should ensure an audit/inspection process is used that is regular, but unannounced and directly targeted to what they want to find out, rather than scheduled, 'blanket' audits. [2.33, 20.276, 20.287, ATD]

RECOMMENDATION 12.8 — Do not use 'red tape processes' to extend a service that a participant wishes to keep.

If a participant is happy with their existing service, they should be able to remain without needing to go through 'red tape processes' (e.g. submitting forms to re-apply for or extend service provision). [2.34, 2.35]

RECOMMENDATION 12.9 — Do not use 'red tape processes' to extend a service that a participant wishes to keep.

To reduce red tape:

(a) when funding is approved, the participant or their advocate should liaise directly with the Plan Management Provider or the Agency if they are managing the plan (e.g. via a case manager/coordinator from the Agency);

(b) medical personnel and assessing team members should highlight issues, needs, change in status, and unmet needs for the individual participant — and communicate this directly to the Plan Management Provider or Agency;

(c) carers and participants should be able to request a review if changes in mobility, self -care and/or self- management become evident;

(d) if there is controversy or disagreement, participants and carers should be allowed to get a second opinion and submit this to the Plan Management Provider or Agency directly. [20.279, ATD]

RECOMMENDATION 12.10 — Employ Systems Efficient Consultant, consult the sector, use web for data-submission.

To reduce red tape, the Agency should:

(a) employ a Systems Efficiency Consultant, to develop a system that the Agency and all service providers can use;

(b) consult with the sector;

(c) give service providers the ability to submit their data over the internet via a web browser on an internally supported application, maintain and publish publicly the meta data for the input required and provide user guidelines for data submission [20.281, 20.282, 20.283, 20.284, 20.285, ATD]

RECOMMENDATION 12.11 — Ensure that participants can employ friends/family to support them without red tape.

People with ABI require services from someone familiar and they need to feel comfortable with them. So the Agency should make it possible for a participant to hire the services of a friend or (extended) family member, without any red tape. [20.287]

If the Agency is managing a person's support plan and makes a referral to a provider of supports, then the Agency will need to do the following:[6]

RECOMMENDATION 12.12 — Proactively ensure that referrals have been effective.

If the Agency refers a participant to a provider of supports, then it needs to take active steps to ensure that they have been connected to the relevant service and received the supports they required (e.g. by going back to the person to check or requiring a written response from the service). This is particularly important for people with cognitive impairments. If, for instance, they have language, speech or physical difficulties, these can prevent them from following up on the referral themselves (e.g. filling out paperwork, communicating with service staff, etc.). [4.2, 5.5, 5.11, 5.12, 7.8, 20.3, 20.11, 20.14, 20.20, 20.22, ATD]

RECOMMENDATION 12.13 — Establish a pathway for people rejected by services to which they were referred.

The Agency should ensure that it has a pathway for responding to the needs of people who are rejected by services to which it referred them. [20.4, ATD]

RECOMMENDATION 12.14 — Ensure that after a person has been referred, they can return for additional assistance.

The Agency needs to ensure that people who have been referred can come back at any point for further assistance. This might include speaking to staff about issues that have arisen as a result of the referral or a request for advocacy, and so on. [5.11]

RECOMMENDATION 12.15 — If the Agency cannot follow-up on a person's referral, connect them to advocacy.

If the Agency is unable to follow-up on a referral it has made for a person, then it should ensure that the person is connected to an independent advocacy agency that can contact for assistance. [4.3, 5.11, ATD]

RECOMMENDATION 12.16 — Refer a person to a service provider that is most likely to meet their needs.

The referral process must be carefully coordinated, so that the person is connected to the most suitable provider for their needs. This is to avoid situations in which, for instance, a person receives calls from numerous service providers, requiring them to undertake multiple eligibility assessments. [4.4, 5.4, 7.2, 20.10, 20.17, 20.27]

RECOMMENDATION 12.17 — Provide short-term funding where more effective than a long-term referral.

There should be some capacity for discretionary funding — for instance, when a simple and immediate response by the NDIS would be more effective than a longer-term referral. [7.15]

[6] This topic was not explicitly raised in the Consultation Paper. However, the set of recommendations here (which originated from Section 1 'Connecting with other systems') seemed more appropriate as responses to a situation in which the Agency — when managing the funding for supports — is referring participants to providers of support, rather than non-participants to other (non-NDIS funded) systems.

RECOMMENDATION 12.18 — Ensure that referrals do not take longer than is reasonable or necessary.

The time it takes for a referral process to be finalised must be reasonable, taking into account a person's life circumstances and the personal cost of waiting. [4.5]

RECOMMENDATION 12.19 — Engage a support person to assist in referring a person with ABI, where necessary.

Where a person with ABI is not able to make decisions or follow through on a referral for themselves, the Agency must ensure that the most appropriate support person (as established by the initial assessment process) is provided with all the necessary information relating to any referral the Agency makes (e.g. contact details of providers, etc.). Otherwise the person with ABI is likely to 'fall through the cracks'. (This kind of support must be specialist and ongoing, given the time it takes to build trust and identify the impact of cognitive deficits.) [7.12, 20.18, 20.20, ATD]

To make sure that people with disability are exercising choice and control over the supports they are getting, the Agency will need to collect the following kind of information from registered providers of supports:

RECOMMENDATION 12.20 — Assess systems or mechanisms that best indicate the participant's degree of choice.

It is impossible to measure the extent to which any individual is exercising choice and control. There are too many decisions in any day. Hence, , the Agency should focus on the systems or mechanisms that a provider has in place: for example:

(a) policies and procedures (e.g. Is the client the centre of how they deliver a service?);

(b) the 'exit' procedures (e.g. is there a client 'get out' clause? How easy is it for a client to suspend that service if they no longer wish to use it? Do they have the choice to suspend that service?)

(c) hiring suitably skilled staff with relevant values;

(d) training staff in person-centred approaches;

(e) communication systems (e.g. are the 'in-take documents' client-centred? Are they in/available in an accessible format?);

(f) face-to-face interviews with staff (e.g. the Agency should come out to a provider and ask the staff: 'How do you ensure that your clients are exercising choice?');

(g) evaluation and review systems (e.g. providers should be required to send the Agency written reviews and feedback or evaluations of the service provided, and this should match the details submitted in their funding agreement). [2.36, 2.37, 20.288, 20.289, 20.298]

RECOMMENDATION 12.21 — Ensure that the Agency contacts participants directly about the service used.

It is possible that providers of supports will submit current care plans to the Agency with things on them that the service has not actually done. So the Agency will need to speak with the participants directly to find out what the provider has done, and what the person did for themselves. The Agency will also need a way of measuring any gap between (a) what a participant wanted from the service and (b) how they feel the process actually went for them. [20.299, ATD]

13. Children

What kind of person can act on behalf of a child if they are not a parent:

RECOMMENDATION 13.1 — Only a legal guardian can act on behalf of a child if they are not a parent.

A person can act on behalf of a child only if they are a legally mandated guardian. [3.11, 20.304, 20.309, 20.312, 20.313]

RECOMMENDATION 13.2 — A person can act on behalf of a child only if vetted by child protection/DCS and police.

A person can act on behalf of a child only if (a) they have been vetted by child protection and/or deemed to be suitable by the department of child safety and (b) a police check has been carried out to ensure that the individual concerned is fit to carry out this role. [3.13, 20.310, 20.313]

RECOMMENDATION 13.3 —Persons can act on a child's behalf only if they have appropriate values and attributes.

A person can act on behalf of a child only if they have values and personal attributes that are conducive to ensuring the wellbeing of the child (e.g. they are compassionate and empathetic, not manipulative; they have a good understanding about financial matters, but have no vested interest). [4.11, 20.311]

RECOMMENDATION 13.4 — Persons representing a child need to understand and uphold their medico-legal duties.

A person can act on behalf of a child only if they fully understand and are able to uphold the medico-legal aspects of their duties—which includes the principles of confidentiality, their own rights as a representative, and the rights of the child/adolescent. [20.316]

RECOMMENDATION 13.5 —Persons can act on a child's behalf only if they have an ongoing, positive relationship.

If a person is not a child's parent, then they can act on behalf of that child only if they have an ongoing, positive relationship with the child — which the child affirms, where appropriate. [4.12]

RECOMMENDATION 13.6 — Do not automatically ask child protection agencies to act on behalf of a child.

If a child's parent(s) are unable to act on their behalf, the Agency should not automatically give child protection agencies this role. [3.14]

RECOMMENDATION 13.7 — Make available an independent advocate to protect the interests of the child.

If a person other than the child's parent is acting on the child's behalf, it would be appropriate for the Agency to assign an independent children's advocate to protect the interests of the child. [3.15, ATD]

RECOMMENDATION 13.8 — Create fall-back positions to manage the child's plan, such as a 'circle of support'.

If no one is appropriate to act on the child's behalf, there should be a fall back position so that decisions in relation to the child's needs can be made. For example: there could

be a 'circle of support' around the child, rather than an individual, that commits itself to ensuring that the child's plan is managed affectively. [4.13, ATD]

To decide when a child under the age of 18 is able (or not able) to make decisions about their supports, the Agency will need to do the following:

RECOMMENDATION 13.9 — Conduct an appropriate assessment of the child's capacity to make decisions.

The Agency should ensure that there is a comprehensive assessment of the child's capacity to make decisions about their supports. This assessment should:

(a) draw on appropriately skilled professionals and specialists (treating teams);

(b) take account of the child's developmental stage, self-awareness, cognitive limitations, significant psychiatric conditions, the level of risk, the nature of the decision, and so on;

(c) include the views of stakeholders (teachers, care-givers, parents/legal guardian);

(d) refrain from an 'all or nothing' determination, instead indicating the range of decisions about which the child should be given the opportunity to decide for themselves;

(e) use, where appropriate, the Gillick Competence Test (UK-based frame work for assessing children's whether a child is able to consent to his or her own medical treatment, without the need for parental permission or knowledge). [1.80, 3.17, 4.14, 20.317, 20.319, 20.322, 20.323, 20.324, 20.326, 20.327, 20.328, ATD]

RECOMMENDATION 13.10 — Allow a child to be involved in the decision-making, but not ultimately responsible.

A child should be involved in making decisions to whatever extent possible, for instance, by the legal guardian/parent taking their wishes into account. But they should not take ultimate responsibility for decisions. [3.18, 3.19, 3.26, 3.27, 20.325, 20.341]

RECOMMENDATION 13.11 — Respect a child's decision if it's in their best interest, informed and not harmful.

While a child with an ABI may have cognitive limitations, if (a) the child wants something that is clearly in their best interests, (b) it is clear that they understand the likely consequences (risks/benefits), and (c) there is no evidence that the outcome would be harmful to the child (e.g. having a negative impact on their development or quality of life), and (d) their decision is informed and supported by their family/carers, then their decision should be respected. [4.15, 20.317, 20.324, ATD]

To ensure that a child or young person under the age of 18 is involved in decisions about the support they receive, the following kind of additional supports should be given to (a) that child or young person and to (b) their parent or guardian:

RECOMMENDATION 13.12 — Provide or refer parents/carers to training or guidance on helping children to decide.

The Agency should ensure that training, guidance, mentoring, or counselling on the most effective ways of enabling children to become involved making decisions about

their support is available and refer parents and carers to that training etc. (e.g. preparing children for independence begins at a very early age — 4 years old; how to prioritise a child's best interests over what the parent's wants and needs) [3.20, 3.23, 4.16, 4.17, 20.318, 20.333, ATD]

RECOMMENDATION 13.13 — Create a culture that promotes independent decision-making by children.

There should be a culture within the NDIS that explicitly promotes and fosters the independent decision-making — and this should include building the capacity of children with a disability to make their own decisions about supports. [3.22]

RECOMMENDATION 13.14 — Provide necessary aids/devices to assist children with communication difficulties.

To ensure that children are able to participate in decision-making, the Agency should provide children who have communication difficulties with communication aids or devices. [20.337]

RECOMMENDATION 13.15 — Ensure that information is tailored to and accessible for children.

To ensure that children can make informed choices, the Agency should provide them with information that is:

(a) tailored to their age and cognitive level;

(b) accessible and easy to understand;

(c) multimodal; and

(d) relevant to different cultures. [20.329, 20.338]

RECOMMENDATION 13.16 — Monitor the extent to which a child is making their own decisions.

The Agency should monitor (a) the extent to which a child is making (or is given the opportunity to make) their own decisions about their supports; and also (b) the extent to which any person acting on behalf of a child is taking the needs of the child into consideration. This might include providing an independent third party to record the participation or non-participation of the child in key decision-making processes. [3.21, 20.310, 20.332]

RECOMMENDATION 13.17 — Refer to independent response team for concerns re the decision-making of children.

The Agency should ensure that it refers to an existing independent child complaints/crisis response team or department to address situations in which there was evidence that the capacity of a child to make their own decisions about supports was being unjustifiably over-ridden, unacknowledged or under-developed. [3.24, ATD]

To reflect the fact that as children and young people with a disability get older, they may want to have more say in what they do, and the care and support they receive, the Agency will need to do the following:

RECOMMENDATION 13.18 — Set up a education package to help children move across to adult disability services.

There should be a 'transition education package' that helps children to move from paediatric to adult disability services, so that they have realistic expectations and an understanding of how best to use their new capacity to make choices as an adult. [3.28]

To ensure that a child is most likely to be able to express their views about the support that they receive, the Agency will need to do the following:

RECOMMENDATION 13.19 — Use audio/video technology, communication devices or goal-setting tools.

To help a child express or communicate their views about the kind of supports they want, the Agency could use:

(a) communication aids/devices;

(b) technology (audio/video);

(c) goal setting tools appropriate for young people (e.g. diagrams or pictures) [3.25, 20.360, 20.361]

RECOMMENDATION 13.20 — Ensure that children are given the information they need.

Ensure that children are given sufficient information about their options to enable them to have (and so express) an informed view about their supports — for instance, they should be made aware of what support services are available to them. [20.358, 20.362]

14. Supporting decision-making

To decide what kind of person should (or should not) be appointed as a nominee, the Agency will need to do the following:

RECOMMENDATION 14.1 — Use a nomination process that takes into account the views of the participant.

The Agency should ensure that the process of selecting a nominee takes into account the wishes of the participant. For example:

(a) the participant could be asked who they would like to be the nominee and why (e.g. questions put to the participant might include: "How well do you know this person? How long have you known them?")

(b) the Agency could set up two separate appointments: one with the participant and those who know them well and are actively involved in supporting them (like their doctor or relevant family members); and the other with the potential nominee — and then, on the basis of these meetings, assess whether the participant — as compared to the nominee's wishes — genuinely wants that person as their nominee. [8.12, 10.6, 20.364c, 20.372]

RECOMMENDATION 14.2 — Investigate prior family disputes if the prospective nominee is a family member.

If the nominee being considered is a family member, then the Agency should ensure an investigation of prior family disputes — in particular, where there has been a fight over money or assets – is undertaken. [1.53, ATD]

RECOMMENDATION 14.3 — Use a similar process to the appointment of guardians by the OPA.

The Agency should use a process for selecting nominees that is similar to that used by the Office of the Public Advocate to appoint guardians. (For example, the outcomes of the Office of SA Public Advocates supported decision-making project trial could be used to inform the criteria for selecting nominees.) Indeed, a person who is a legal guardian should be considered as a possible nominee — unless, for instance, those involved wish the nominee arrangement to be less formal. [1.54, 6.20, 6.25, 19.25, 20.366, 20.367]

RECOMMENDATION 14.4 — Investigate the nominee's past for financial mismanagement, criminality or liabilities.

The Agency should look into the history of the nominee to see if there is evidence of past financial mismanagement or criminality (e.g. prior charges of fraud), personal or professional liabilities, or a current legal proceeding against them (e.g. a violence order). [1.55, 6.17, 8.18, 10.8, 10.9, 20.364b, 20.377]

RECOMMENDATION 14.5 — Assess whether they will be able to act as a nominee over the long term.

In evaluating a person's suitability as a nominee, the Agency should try to ensure that they can play this role over the long term. This is because (a) other professionals in the person's life can be very temporary; and (b) participants are unlikely to want a series of people going through their finances and personal details. [1.56, 8.15]

RECOMMENDATION 14.6 — Ensure that the nominee is well known to the participant.

A nominee should be someone who is well known to the participant, in the sense of having a strong, long-term and stable link to them. [1.57]

RECOMMENDATION 14.7 — Ensure that the nominee is empathetic and focused on the participant's needs.

There should be evidence that the nominee has empathy, and that they are concerned with the needs of the person rather than their own ego. Put another way, they should be capable of putting themselves in the shoes of the participant, rather than imposing their own views on them. [6.18, 8.17, 8.19, 19.24]

RECOMMENDATION 14.8 — Ensure that the nominee is compassionate and non-judgmental about the ABI.

A nominee needs to be compassionate and nonjudgmental — particularly about how the person got their ABI. [8.19, ATD]

RECOMMENDATION 14.9 — Ensure that the nominee has the patience to listen to the participant.

The nominee should have the patience to listen to the participant — especially a person with ABI — so that they can find out what they want, rather than just assuming they think they know. [8.14]

RECOMMENDATION 14.10 — Ensure that the nominee is independent, not directly benefiting from their role.

The nominee should be independent, in the sense that they are not benefiting directly from this role (e.g. financially). They should be genuinely motivated to do the right thing by the person, not for what they can get out of it. The Agency should therefore ensure that there is no conflict of interest between the nominee and what they will be doing (e.g. where a family member has ties with the care agency providing a service and so is motivated by their own interests when they buy this service). [6.19, 6.23, 8.16, 10.10, 20.364c, 20.365b]

RECOMMENDATION 14.11 — The nominee must be reliable, having time, training and decision-making abilities.

The Agency should ensure that there is sufficient evidence that the nominee is reliable — that is, the nominee must be an adult, they must show that they will have the time to follow through with their commitments, they are well trained to perform their duties, and they have proven abilities as a decision-maker. This evidence gathering might include an interview with the nominee and referee reports [6.18, 8.18, 8.19, 10.8, 20.364b, 20.367, 10.369, 20.374]

RECOMMENDATION 14.12 — Ensure that the nominee's mental health will not prevent rational decision-making.

The nominee should not have an obvious emotional, cognitive or psychiatric impairment that would prevent them from making rational decisions. [6.22, 8.18, 20.375]

RECOMMENDATION 14.13 — The nominee must know the participant well, but be able to make objective decisions.

The nominee should have a strong enough relationship with the participant to know about their personality and what they might actually want. But it is also important that they are not so emotionally involved that they are unable to make objective decisions. For example, family members can sometimes be overly focused on their own needs and worries, rather than the best interests of the person. [1.58, 6.24, 8.13, 19.23, 20.375]

RECOMMENDATION 14.14 — A trial period to test the compatibility of the nominee and participant may be helpful.

The nominee should be compatible with the participant — so there should perhaps be a 'trial period' to see whether it works for both people. This should include an assessment of how comfortable the participant is around the nominee, and the extent to which the participant displays trust towards the nominee. [8.17, 20.378]

RECOMMENDATION 14.15 — The nominee must be willing to be audited and their role assessed by the Agency.

The nominee must be willing to be audited, and assessed for their professionalism and financial competence by the Agency. [8.22]

RECOMMENDATION 14.16 — If a participant can't decide on a nominee, a 'circle of support' should be established.

If the participant cannot make a decision about who should be the nominee for themselves, then there should be a group of people (a 'circle of support') that can make sure that the nominee is the right person and monitor the arrangement to make sure that their needs are met. Then the responsibility is not left entirely on one person. This circle of support could be made up of at least 3 people, and might include:

(a) family member(s) or friend(s) who love and care for the person;

(b) an independent advocate;

(c) providers of supports who the person knows and trusts (e.g. a psychologist, an occupational therapist, a social worker, the doctor of the person, a support worker).

If professionals are invited or expected to participate in the 'circle of support', then the Agency will need to fund their attendance. Non-professionals or carers should also be supported so that they can take part in the 'circle of support' — either financially or in other ways (e.g. providing transport or looking after children while they are there). [10.15, 10.16, 10.17, ATD]

RECOMMENDATION 14.17 — Ensure that nominees of a person with ABI is educated about ABI.

If a nominee is appointed to a participant with ABI, but has insufficient experience or knowledge about ABI, then the Agency should ensure that someone who has a good knowledge of ABI should speak to and educate the nominee about ABI. [10.26]

To show that a nominee understands the participant's wishes, goals and life aspirations, the Agency will need to do the following:

RECOMMENDATION 14.18 — Ensure that the nominee has a direct, healthy relationship with the participant.

The Agency should ensure that the nominee has a direct relationship with or understanding of the person. The Agency should not assume, however, that those who have a direct relationship are automatically able to understand the participant's wishes etc. (e.g. a partner may be overbearing, egoistic, non-empathetic or have problems themselves). [6.26, 6.27, 10.14]

RECOMMENDATION 14.19 — Create a contract between the nominee and participant reflecting goals and duties.

There could be a strictly binding written agreement between the nominee and the person that reflects (a) what the participant wants, their goals and aspirations and (b) what the nominee will do to ensure that these are taken into account. [1.59]

RECOMMENDATION 14.20 — Recognise that a nominee will need to adapt a participant's goals to what is realistic.

The Agency will need to take into account the fact that the nominee may know what the participant wants, but also recognise that some of these goals will need to be redefined or adapted so that they are realistic. For example, the participant might be very keen to get a license so that they can be independent, but the nominee knows that that the participant will not, at this time, be able to get a licence — so the nominee has instead arranged for the person to have access to independent transport. [10.13]

RECOMMENDATION 14.21 — Ensure that a participant using a nominee has access to an independent advocate.

There should be an independent advocate that can protect the interests of the participant who is using a nominee to manage their plan. [1.61]

RECOMMENDATION 14.22 — Monitor the nominee's capacity to prioritise the participant's goals over their own.

The nominee should be able to show that they can separate their own personal feelings from what the participant wants; and be supportive of the participant's support plan, rather than trying to determine what their goals and supports should be. This is particularly important where the nominee is a parent of the participant. This could be demonstrated by:

(a) evidence of regular meetings between the nominee and the participant, which will indicate that they have ongoing opportunities to talk to each other about what the participant wants;

(b) getting the nominee and the participant — on a regular basis — to create two separate lists (or hold two separate interviews) to find out what they each think are the goals and aspirations for the participant — and then compare the two to test for consistency;

(c) evidence that, at planning meetings, the nominee is able to discuss with the participant the pros and cons of a plan and arrive at a genuine consensus;

(d) provide evidence of continued support in a statutory declaration as well as independent references to support this evidence;

(e) a regular monitoring and review process (i.e. if there is evidence that the person has been instrumental in making a participant's goals happen, that would demonstrate that they had an understanding of the participant's wishes). [1.60, 1.62, 1.63, 6.28, 6.31, 10.11, 10.12, 20.379, 20.380, 20.381, 20.382, 20.383, 20.384]

RECOMMENDATION 14.23 — Ensure that the participant genuinely agrees with the nominee's appointment.

If the participant doesn't want someone to be a nominee, then that counts as evidence that this person is not (or is unlikely to be) understanding. Similarly, if there is evidence that the participant has been talked into, pressured or manipulated by a person into agreeing that they will be their nominee, then that demonstrates that this person does not understand the participant's goals, wishes, etc. [6.29, 6.30]

To establish whether the decisions of a nominee are reasonably those the person would have made if they had the capacity to do so, the Agency will need to do the following:

RECOMMENDATION 14.24 — Consult the nominee, the participant's support network, and the participant.

If the participant does not have the capacity to decide for themselves or communicate their decision, then the Agency should assess a nominee's decision by (a) talking separately with both the nominee and the participant's wider support network (family group, friends, etc.); and (b) verifying the decision with the participant to whatever extent possible. [1.64, 10.18, 20.391, 20.392]

RECOMMENDATION 14.25 — Consult with the participant's 'circle of support' about the decisions of the nominee.

If the participant has a 'circle of support' in addition to a nominee, then the circle members could offer an objective view of the person's situation and their responses —

since the nominee may be too close to the person or the situation, and so either cannot see what is happening or they may see it but don't know what to do about it. [10.20]

RECOMMENDATION 14.26 — Ensure that the nominee's decisions reflect the participant's age, gender, culture, etc..

The Agency needs to evaluate whether the nominee's decisions reflect the specific background, age, gender, ethnicity, culture, religion (etc.) of the participant. For example, if the participant is an adult, then the nominee's decisions should reflect the fact that the participant would not ordinarily live at home with their parents; or in a nursing home if they were still a young adult; or if the person's nominee is a family member, the decision should take into account the family's cultural beliefs around money and how money is shared. [1.65, 20.393]

RECOMMENDATION 14.27 — Check for any significant changes in the participant's health, emotions or behaviour.

Following the appointment of a nominee, the Agency should assess whether there has been any significant improvement or deterioration in their physical health, emotions or behaviour (e.g. Are they managing their day to day life as well as they can? Have they gone backwards in their rehabilitation? Has their mood changed? Have they become depressed? Are they resisting food? Are they constantly angry or depressed? Are they 'lashing out'?). This assessment should be carried out by relevantly qualified personnel. [1.66, 10.19, 20.384, 20.386, 20.389, 20.394]

RECOMMENDATION 14.28 — Draw upon person with ABI's 'past life' to determine what they would have decided.

For participants with ABI, they will have had a 'past life'. So this can be taken into account when deciding what the participant 'would have done'. But the nominee will need to have access to or know a great deal about this 'past life' in some way. This could be done by including parents in the decision-making process (if they are not a nominee). [1.67]

To make sure that the nominee arrangements can change, the Agency need to put in place the following:

RECOMMENDATION 14.29 —Hold both regular assessments and a mandatory review of the nominee arrangement.

The Agency should ensure there are both (a) regular assessments (as people with an ABI may not take it upon themselves to ask for it) and (b) a mandatory formal review of the nominee arrangement after a certain amount of time (e.g. an initial review half way through the planned appointment). [1.68, 10.21, 20.398, 20.400]

RECOMMENDATION 14.30 — Allow anyone to request a review if they wish to change the arrangement.

If anyone (including the participant, their 'circle of support' or the nominee) wishes to change the nominee arrangement (e.g. because the nominee is not acting in the best interests of the participant), then they should be able to contact the Agency and request a review of the arrangement. This should be stated clearly in any contract between the participant and nominee. [1.69, 10.22, 20.396, 20.398]

RECOMMENDATION 14.31 — Allow the participant to appeal someone else's request to change the arrangement.

If the participant is dissatisfied with changes that have been requested by someone else (e.g. by the Agency or the nominee), then they should have access to an appeals process. [20.397]

RECOMMENDATION 14.32 — Respond appropriately to requests to change a nominee made by a person with ABI.

The Agency would need to take into account the fact that a participant with ABI can be impulsive, and so may request a change of nominee on the spur of the moment. So

(a) there has to be some evidence that the request has been thought through and can be justified or explained by the participant;

(b) there should also be a 'cooling off' period, and if they still feel the same way, then the request can go through;

(c) if there is a 'circle of support' they should be consulted. [10.23]

RECOMMENDATION 14.33 — Where the care requires it, consider using a disability-specific professional nominee.

The Agency should consider the use of a disability-specific 'professional nominee service', for (a) those who do not want a family member, friend or carer to play the role of a nominee and (b) where there are no suitable plan management providers available. [10.25]

RECOMMENDATION 14.34 — Ensure that a review is held if the nominee is unable to continue their duties.

If the sustainability of the nominee is in question (e.g. they are sick or are planning to move away), then a review should automatically be called. [1.70]

RECOMMENDATION 14.35 — Ensure that nominees can be discharged if proven to be ineffective.

The Agency must be allowed to discharge nominees who have proven to be ineffective in carrying out their duties. [20.395]

Nominees need to support a participant's decision-making personally and give appropriate weight to their views. Other things nominees will need to do include the following:

RECOMMENDATION 14.36 — Even if a nominee is not managing the funds they should be able to monitor spending.

It would be helpful if the nominee had some knowledge of expenditure to safeguard the spending — even if they are not managing the funding (i.e. because this is being done by the participant, the Agency or a Plan Management Provider). [1.71]

RECOMMENDATION 14.37 — The nominee should be able to assess any risk of abuse or neglect to the participant.

The nominee could assess if there are any unnecessary risks (abuse and neglect) in the participant's life (e.g. from care providers, friends, etc.). [1.72]

RECOMMENDATION 14.38 — Nominees need to ensure that the participant's plan is implemented effectively.

A nominee needs to ensure that (a) the support needs identified in their plan are matched by the funding allocated by the Agency and support services available, that (b) the participant is getting the services for which they were funded, (c) that they are meeting their goals and outcomes, and (d) spending their money how they need to. [20.401, 20.402, 20.406, 20.407, 20.408]

RECOMMENDATION 14.39 — The nominee's duties should not limit the participant's choice and control.

The nominee should not be given too much to do, otherwise that will dilute the extent to which the participant has control and choice. [1.73]

RECOMMENDATION 14.40 — Nominee reviews should set reasonable goals for them, linked to the support plan.

Reviews of a nominee's role should set goals for them that are reasonable to expect them to achieve, linked to the support plan. [1.76]

RECOMMENDATION 14.41 — Nominees should receive training on how best to carry out their responsibilities.

Nominees will need to be trained with respect to the rights, responsibilities and obligations in their role as plan or correspondence nominee. [20.405]

Whether the appointment of nominees should be for a fixed period or reviewed on a regular basis to make sure the person with disability was satisfied with their nominee:

RECOMMENDATION 14.42 — Regular reviews would enable nominees to continue without being re-appointed.

If someone is working well as a nominee, then regular reviews would enable them to continue without the hassle of a re-appointment. [1.74]

RECOMMENDATION 14.43 — Review are less likely to be regular if the appointment of nominees is fixed.

If the appointment of nominees is for a fixed period, then reviews of the arrangement are less likely to occur regularly. [1.75]

RECOMMENDATION 14.44 — Regular reviews will ensure that nominee's role is being progressively monitored.

Nominee arrangements should be reviewed on a regular pre-planned basis, so that it is possible to monitor the effectiveness of their role on a progressive basis: for example, making sure that the plans have been put in place, the goals have been met, the services put in place, the participant's views are being respected, and so on. These reviews should involve a specifically designed process and tool for assessors to pick up on any, initially hidden, issues. [6.32b, 6.32c, 10.14, 20.409, 20.410, 20.412, 20.413, 20.414, 20.415]

RECOMMENDATION 14.45 — Regular reviews will allow the nominee to amend or opt out of the arrangement.

The nominee might want to change their minds about the arrangement without leaving the participant in the lurch (nominees should have the choice to opt out). [6.32d]

To make sure that the nominee arrangements continue to build the decision-making capacity of people with a disability, the Agency will need to do the following:

RECOMMENDATION 14.46 — Ensure that nominees always involve the participant in any decision-making.

The Agency should ensure that the nominee does not by-pass the participant at any stage in the decision-making process (e.g. by not informing them of reviews). [1.77, 14.23, 20.421]

RECOMMENDATION 14.47 — Request evidence of regular contact between the nominee and participant.

To assess whether the nominee is building the participant's decision-making capacity, the Agency would need to request evidence of regular contact between the nominee and the participant. [1.78]

RECOMMENDATION 14.48 — Ensure that expectations about a participant's decision-making capacity are realistic.

The Agency must ensure that any expectations of the extent to which a person's decision-making capacity can 'improve' is both individualised and realistic. [1.79]

RECOMMENDATION 14.49 — Ensure that a person's capacity to make decisions is not assessed as 'all or nothing'.

Decision-making capacity should be assessed in a very specific, fine-tuned way. For example, someone can be capable of choosing their food, but not whether they should purchase a house. There shouldn't be a 'blanket' assessment that a participant does not have the capacity to decide for themselves *in any respect*. [1.80, 19.22]

RECOMMENDATION 14.50 — Encourage the nominee to 'let go' of their control, even just for trial periods.

The Agency should encourage and remind nominee to 'let go' of areas over which they have previously had control — even just for trial periods to see how the participant goes (but these trials should be ongoing, even when it doesn't work first time so as to allow for the possibility of future improvements). [10.27]

RECOMMENDATION 14.51 — When reviewing a support plan, identify any increase in decision-making capacity.

The review of a person's support plan should identify whether the person's decision-making capacity has increased since the last review. Any assessment tool used for this purpose should be developed by appropriately qualified people. [10.28, 20.423, 20.424]

RECOMMENDATION 14.52 — To be re-appointed nominees must show they have tried to increase this capacity.

For the nominee to be reappointed, they would need to show what steps they have taken to ensure that the participant's decision-making capacity has increased. This could be done by:

(a) the participant writing down (perhaps using a tick-box survey) or explaining what they can now do, and the nominee doing the same, and then comparing the two versions;

(b) the nominee showing that they have attended a course which aims to teach them how to increase their decision-making capacity. [10.29]

RECOMMENDATION 14.53 — Produce and distribute educational material on increasing choice and control.

The Agency could ensure and/or support the production, publishing and distribution of educational material that helps people gain the confidence to take control of their own lives. [20.419, ATD]

RECOMMENDATION 14.54 — Dialogue with providers about maximising participant ownership over services.

The Agency should not leave this task entirely up to the nominee, but should (a) continue or commence dialogue with services providers to ensure that the participants have as much ownership of their support, wherever possible; and (b) build a therapy plan that will enable the participant to increase their decision-making skills and capacity. [20.418, 20.422, ATD]

16. Compensation

How compensation payments for care and support should be treated in working out how much care and support should be provided by the NDIS:

RECOMMENDATION 15.1 — Base preclusion period calculations on what's left after paying Health or Centrelink.

If any preclusion period is calculated it should be based upon the dollar figure after they have paid back any outstanding amounts from any Health departments or Centrelink. [1.81]

RECOMMENDATION 15.2 — Require a full disclosure of any compensation payout to a participant.

If a participant receives (or has been in receipt of) a compensation pay out, they should be required to make a full disclosure of the pay out, including the terms of the pay out. [20.426]

RECOMMENDATION 15.3 — Conduct a support needs assessment to identify how much NDIS funding is needed.

If a participant's compensation payout is (or is likely to be) insufficient to meet their support needs, then the Agency should ensure that an assessment by a qualified assessment team is conducted to establish how much additional support will need to be provided by the NDIS. [20.427, ATD]

RECOMMENDATION 15.4 — Clarify what will happen if the compensation purchased a home that is now unsuitable.

The Rules need to clarify what will happen if (a) participants received a payout and purchased necessary supports, but (b) their circumstances have changed to such a degree that these supports are no longer adequate. For instance, the compensation may

have been spent on modifications to a family home, but their impairments have deteriorated or changed to such a degree that the home no longer meets their needs. [20.433, 20.428]

RECOMMENDATION 15.5 — If a person's compensation is spent they should not be *thereby* deemed ineligible.

If a participant's payout has run out, they should not be excluded from receiving NDIS funded support by the wording of the Rules. [20.429]

RECOMMENDATION 15.6 — State precedence of distribution, management of difference and indexation issues.

The Rules need to state:

(a) precedence of distribution;

(b) management of the difference (e.g. if the payout through compensation is greater than, equal to or less than what the NDIS package would provide); and

(c) how indexation is to be applied and what happens when indexation causes the difference to change from less to more, more to less and more to equal. [20.431]

E. IDENTIFYING REASONABLE AND NECESSARY SUPPORTS

16. Recommended Method

The Agency will be ultimately responsible for deciding whether any particular support is 'reasonable and necessary', in the sense defined by the NDIS Act and the NDIS Rules. To enable it to make this decision in a fair and accurate manner, it is recommended that the Agency use the following approach — particularly for people with ABI:

First, in deciding whether a support counts as 'reasonable and necessary', the Agency must listen carefully to the perspective of that person who may (or may not) be receiving this support, as well as the views of those who care for and work with them — including specialist assessors and practitioners. These are the experts. They have first-hand experience and a substantial understanding of what happens (or is likely to happen) when this person receives or does not receive this particular support.

Second, the reasons why a particular support might be reasonable and necessary for a person with ABI are likely to be hidden from surface view by the unique and complex relationship between that person's impairments and their life context or history. So it is crucial that decision-makers in the Agency not only ask participants (and those who care and support them) *what kind of supports* they think are reasonable and necessary, but also *why* they have come to hold this view. This additional step will significantly enhance the Agency's ability to determine whether or not a requested support satisfies the criteria for being 'reasonable and necessary', as provided in Section 34 of the NDIS Act.

To illustrate this 2-step method, the following section presents a compilation of 'case studies' and 'examples', as recorded during this national consultation. Each case study or example consists of two parts:

Support: Those support(s) that consultee/s has identified as being reasonable and necessary, either for themselves ('case studies') or for people with an ABI in general ('examples').

Reason: Why consultee/s thought these supports were reasonable and necessary.

It is hoped that this compilation will also serve as a vivid illustration of the kind of supports that are taken to be 'reasonable and necessary' by people with an ABI and those who care and work with them.

17. Case Studies — by people with ABI

What kind of supports are 'reasonable and necessary' for people with ABI, and why?

CASE STUDY 17.1 — Transport

Support: I need cab fares – to go to pay bills, to go to employment, etc..

Reason: Catching a bus is too hard. [11.1]

CASE STUDY 17.2 — Focused cognitive support

Support: I need assistance to access community (e.g. shopping, getting to the metro).

Reason: I need assistance to direct me when I am shopping – e.g. to make sure that I am able to choose from amongst a variety of products. [11.3]

CASE STUDY 17.3 — Social participation support

Support: I need assistance to have a productive social life and be able to contribute to community.

Reason: I can get there on my own but I have lost the motivation to get out and do things socially. I become too tired, and feel that I have to explain certain problems or mistakes I am making — and this takes away from my enjoyment. [11.4]

CASE STUDY 17.4 — Independent Living

Support: Day-to-day support for living, a home to live in, with toilet and shower facilities.

Reason: These are necessary and reasonable all the time, every day due to my physical constraints. [11.7]

CASE STUDY 17.5 — Independent Living

Support: I need support with caring for myself, going shopping, etc.

Reason: I don't want to impose on my family or be a burden on them — they have family of their own, or are living somewhere else, or the support that they can provide is too limited. [11.8]

CASE STUDY 17.6 — Transport

Support: I need to access community services (like Headway).

Reason: The cost of funding my own transport is adding to my financial burden, given that I am buying a house and caring for my daughter; and I need to access this service because it is helping me to rehabilitate myself. [11.9]

CASE STUDY 17.7 — Social participation support

Support: I need support to go sailing.

Reason: I couldn't sail if I didn't have this support (because I don't have balance anymore). And sailing is my life: I have a group of friends who also sail who have stuck with me and so this is part of my social life. And my family are not close, and have not taken an interest in helping me. [11.10]

CASE STUDY 17.8 — Focused cognitive support and specialist healthcare

Support: When I got my head injury, all the friends that I had couldn't cope seeing a different me — someone who had changed 180 degrees, to a completely different person. They would stick by me for a while, but it was too hard to do this over time — and so they disappeared. At the moment, my mother looks after me. She is around 70 years old. I am also living in a nursing home. I have problems handling money, but my mother has organised a 'book-keeping' system which helps me to manage my money carefully. In terms of additional support, I need hydrotherapy and the gym.

Reason: I need this to keep me active and for my physical rehabilitation. If this doesn't happen, I can experience severe pain in my neck and shoulders. This is an indirect result of my injury. And it is likely to get worse as I get older. But I don't have the funds to pay for this. [11.11]

CASE STUDY 17.9 — Accommodation

Support: I live in my own home, and rent the front property out to Headway. I receive 20 hours of support, and my mum plays an active role in helping to pay bills, etc.. But I do my own shopping, and I live fairly independently.

Reason: There was a big cost-benefit in moving out of a residential facility into my own home, but I couldn't have done this without funded support. And I am now far more independent than I used to be. [11.13]

CASE STUDY 17.10 — Social and economic participation support

Support: First, I have needed a 'life-style support person' to go back to education — someone who was suitably (i.e. academically) qualified to be able to support me (e.g. who knew enough about the topic). Second, I don't have support to help me with difficult family members — e.g. when they have a mental illness themselves or they don't understand the results of ABI, or they do understand the impact of ABI and use it to their advantage. Third, I am aiming to use my degree to start up a business that can help other people with a disability (i.e. a paraplegic employment service to produce niche furniture). But I have no experience in starting a business from scratch. And business planning is not one of my interests. I want to focus on the creative side, not the paperwork.

Reason: With regard to the support I need to start up a business, this is because I want a role. I want to feel like I am achieving something in life. I need to (and I have a right to) have a purpose and to feel valued in life. Getting support

and funding from the NDIS to help me start up and run this kind of 'social enterprise' would bring these benefits — as well as increase my social network. With regard to difficult family members, it is devastating to me that I do not have better relationships and support to deal with them. [11.14]

CASE STUDY 17.11 — Independent living and transport

Support: Normally, I am fine. But first, there are episodes when I experience the impact of my ABI, and need personal care 24/7 during these times (e.g. being showered, taken to the toilet, brushing my teeth). Second, during these episodes I cannot drive, and taking a bus from where I live is impossible. So I need to catch cabs. However, the system doesn't recognise the episodic nature of my ABI – so they will take away my licence for 6-12 months because I can't drive during these episodes, but I can't get cab vouchers because I will be getting my licence in 6-12 months time (even though my condition is permanent). So I have to pay taxis myself, which is $30 a day.

Reason: The system needs to recognise that my condition is permanent, but episodic — and it needs to provide funded support for basic every day living, because my parents are now too old and physically incapable of caring for me; and I need funding for taxis during these episodes (and afterwards), because I cannot afford to pay for taxis. And without transport I will be unable to get out into the community, get to work and access support services — and so I will become even more isolated, introverted and I will become far less independent. [11.15]

CASE STUDY 17.12 — Social participation support

Support: I needed the 'leaders for tomorrow' program.

Reason: It was consistent with my aspirations, it was intellectually stimulating, and it enhanced my participation in all the boards and committees that I sit on. [12.27]

CASE STUDY 17.13 — Focused cognitive support

Support: I need support with managing money and paying bills.

Reason: If I don't pay it on time I accrue costs, and I can't manage it on my own. [13.1]

CASE STUDY 17.14 — Focused cognitive support

Support: I would like support to build my capacity to enable me to manage more and more of my money and other administrative tasks.

Reason: This will help me (a) to find out what my capabilities are, (b) to develop and expand the range of my skills and abilities, and (c) to push the industry to develop more creative, innovation solutions. [13.2]

CASE STUDY 17.15 — Focused cognitive support

Support: I'd like to have support to enable me to go back to school or TAFE.

Reason: Due to issues with organisation skills and memory loss, I am scared that I won't be able to cope with (a) learning in the classroom, (b) getting the assignments in on time, and so on. If I don't cope I will go into meltdown, and everything will come to a stop. [13.3]

CASE STUDY 17.16 — Focused cognitive support

Support: I need funded specialist support with returning to driving.

Reason: I will need a driving school instructor who has experience with working with someone with ABI. [13.4]

CASE STUDY 17.17 — Specialist heathcare

Support: I need support to fund a physio in the community who can give me continuous help and practice in walking.

Reason: Being in a wheelchair I have the capacity to walk, but I only get 6 weeks of physio a year. But with an ABI you need continuous repetition to help you undertake a task. [13.12]

CASE STUDY 17.18 — Social participation support

Support: People with ABI need support to reduce their social isolation — like groups or 'buddies' that can motivate you and take you to mainstream activities (e.g. learning how to surf, going for a coffee or to the movies, or shopping).

Reason: This is because a lot of people don't understand ABI. For example, they think that because I can talk and communicate, I am fine. (Some even deny that I have a brain injury). More broadly, social isolation can contribute to mental health issues and substance misuse — including the abuse of medication; and mainstream supports are often not suitable (e.g. hours are not flexible, lifeline has no idea about brain injury, etc.). [13.13]

18. Case Studies — by carers of people with ABI

CASE STUDY 18.1 — Transport, social support, focused cognitive support and independent living

Support: My son needs support to live a normal life —to get back into the workforce, transport training to his workplace, assistance with public transport, social activities, independent living support (which uses a personal assistant).

Reason: Due to the ABI, he has short term memory loss, and so cannot plan ahead or for himself, he has no initiative so needs prompting, he needs to repeat things over and over again to learn things, and he has seizures, he gets too tired to do anything in the afternoons, he also suffers from depression and loneliness, lack of motivation and initiative, and lack of concentration. [17.1]

CASE STUDY 18.2 — Transport, social support, focused cognitive support and independent living

Support: I need carers to be able to take my son out to do things.

Reasons: He has an intellectual impairment and so is vulnerable and needs assistance with doing things. [17.2]

CASE STUDY 18.3 — Respite, specialist healthcare, social support, focused cognitive support and independent living

Supports: My wife and I look after our son. But, due to his ABI, his behaviour is such that my wife can't look after him for more than 2 to 5 hours at a time because he can become too aggressive. So at the moment we need enough support in the home, community based access, sufficient respite for us as carers, and emergency care when this is not covered by mainstream services. In the long term, we want to have fully supported 24/7 care (i.e. in a facility which is age appropriate, where all his needs are met, where he has full access to the community and his own child, where he has as much independence and control over his life as possible).

Reasons: We need these immediate supports in order to keep him at home and out of nursing home. We need the long-term supports so that, as we age, we can know that he will be fully cared for. [17.3]

CASE STUDY 18.4 — Respite, social support, psychological support, focused cognitive support and independent living

Supports: (1) Our son still has seizures, so he needs to be with a carer to go on public transport or to the shops. And he needs (carers to help him with tending to the plants, and to be with him when he is using high-speed tools during sculpture. In the long-term, he would need to have support at the home, visits every day, help with transport to shopping, and someone to meet with.

(2) We need more respite as carers.

(3) He needs psychiatric help that is local, specifically for people with ABI, and with someone who does not make judgments about a person on the basis of how the ABI was caused. As a family member and carer, I have needed psychological and psychiatric support over the years to meet our emotional needs.

Reasons: (1) He needs these supports to be able to go on outings (e.g. to the shops); and to have someone teach him what to do and to help him remember the steps, and for social support.

(2) A holiday from our son would be very beneficial because we are with him 24/7.

(3) He has short-term memory loss and depression can be a problem at times. Psychological and psychiatric support is very expensive, and so should be funded. [17.4]

CASE STUDY 18.5 – Respite, social support, specialist healthcare, transport, flexibility, psychological support, focused cognitive support, specialist ABI training and expertise, information, and independent living

Supports:

(1) In the first 2 years since my son's brain injury, intensive therapy is very important. So more funding should be available during that initial stage.

(2) After hospital, we needed ABI specific support (like speech therapy) offered at home or school (rather than the hospital) at flexible times.

(3) It would also be useful to have one or two week sabbaticals at the hospital or 3-day camps. Access to these should not be limited to certain age groups.

(4) He needs to be able to access the local brain injury service.

(5) As a carer I need appropriate mental health support.

(6) His needs need to be met over the long term.

(7) We need trained staff who understand brain injury.

(8) We need a repository of appropriate literature about what is available for people with ABI.

(9) Currently school funding for disability support (e.g. one-on-one teacher's aide) is inadequate, so we would hope to get additional funding to supplement what the school provides. We also need innovative and flexible approaches to support (e.g. paying a university student to provide engaging support and assistance).

Reasons:

(1) My son's injury is relatively recent. He will continue to improve, but there is strong evidence that it is more rapid in the early stages.

(2) Support offered at home or school would have made it more accessible – and at flexible times would have allowed it to be suited to the energy levels of my son.

(3) Sabbaticals or camps that are not limited to certain age groups would give my son better access to OT, physiotherapy, a neuropsychologist and speech therapy.

(4) Because we live in a rural area, we must travel to the nearest city to access a brain injury service.

(5) I am still suffering from the trauma of my son's ABI, and I want to maintain my relationship with my son, which is all he has at the moment.

(6) I want to be confident that if I am not there his needs will be met.

(7) The current level of ABI training is insufficient (e.g. they can be extremely negative when it comes to setting goals for my son, minutes during meetings are inaccurate, being referred by a GP to a specialist in a distant location when there is one locally, case managers who don't understand the specific needs of people with ABI).

(8) We need more information about what is available for people with ABI.

(9) He needs a lot more help at school and transitioning to the workforce. [17.5]

CASE STUDY 18.6 — Equipment, independent living, accommodation, focused cognitive support, social participation

Support: My son has both ABI and a physical disability, so we need equipment, mobility options to access everyday life, home and vehicle modifications (so he can own his own car) and technology for augmented communication and access. From a personal support perspective, he needs assistance for personal care, including feeding. We would like him to be supported for post-secondary education and open employment support, and living in his own home with other people of his choosing, and by people who respect and support his own vision for his life.

Reason: These things mean that he can live his life, i.e. enabling him to have a job and income and independence. [17.6]

CASE STUDY 18.7 — Focused cognitive support, equipment, support at school, transition to home

Support: (My daughter (9 yrs old) has ABI, epilepsy, anxiety and oppositional defiant disorder. We are the primary carers, but eventually she will need a carer, ongoing support and guidance, if she will allow this. She gets very tired, she is not reading or writing at the moment. So we need more funding for ongoing speech therapy (for as long as required), and the choice about who to use and where. We want to keep her in school, but that depends on the continuation of disability support funding (i.e. currently she has an aide during class, but not in the playground — which is needed, given her epilepsy). She also needs technology to help her to learn to write. We need help with the transition from hospital to home, to provide guidance and information.

Reason: These supports will enable her to learn to speak, read and write, stay in school, and transition from hospital to home. [17.7]

19. Examples — supports needed by people with ABI

Specialist training and expertise *(e.g. for support workers, medical staff, and the Agency)*

EXAMPLE 19.1 — Specialist training for support workers

Support: Staff who support people with ABI need to be better trained in terms of treating them with dignity and respect, and acknowledging their abilities and intelligence (e.g. they should not use humiliation as a form of behaviour management).

Reason: Every human being has the right to be treated with dignity and respect. [17.8]

EXAMPLE 19.2 — Specialist training for health professionals

Support: The Agency should ensure that all health professionals are educated to encourage people with a disability to exercise or know where to send them.

Reason: This will help to ensure their maintenance of health and well-being. [12.24]

EXAMPLE 19.3 — Specialist training for Agency staff

Support: There should be access to people within the Agency who have specialist knowledge of ABI across the board, rather than someone who has only a generic understanding of disability.

Reason: ABI is a complex condition, and specialist expertise is required if the Agency is to fund or provide more efficient and effective services. [14.26]

EXAMPLE 19.4 — Specialist training for health professionals

Support: GPs should be better educated about ABI.

Reason: This is so that they are able to identify emerging issues for people with ABI and direct them to more specialist expertise and assessments. [14.29]

EXAMPLE 19.5 — Specialist training for support workers

Support: The Agency must not only provide funding for necessary supports, but also ensure that the workforce required to deliver these supports is adequate (i.e. in terms of numbers and relevant skills).

Reason: Otherwise the person with ABI will not have their necessary needs met within a reasonable time period or to a reasonable level of quality. [15.7]

EXAMPLE 19.6 — Specialist training for support workers

Support: Support workers need to be funded for training that relates to the specific care needs of the participant (e.g. an intensive daily physio or behaviour management plan which (a) is unique to the client, and (b) requires specific training for safety and quality purposes).

Reason: This kind of training is not currently funded. [16.14]

EXAMPLE 19.7 — Specialist training for support workers

Support: Currently people who can engage within a group have an advantage over those who need one-on-one support — because the cost of providing the latter is higher than the former (e.g. the cost of extra support workers, travel costs, etc.). But many people with ABI need one-on-one support, so this should be funded.

Reason: This is so that they are not disadvantaged due to the uniqueness of their disability. [18.7]

Consistency over time

EXAMPLE 19.8 — Consistent support workers over time

Support: Where possible and appropriate, there should be consistency in the staff who are working with a person with ABI.

Reason: This is so that relationships are built and maintained between the support staff and the person with ABI. [16.5]

EXAMPLE 19.9 — Consistent case management over time

Support: There should be long term ABI-specific case management for each person with ABI.

Reason: This is to ensure that (a) there is consistency over time, which is critical given (i) the episodic nature of ABI; (ii) pre-existing social, familial, drug and alcohol issues, which are exacerbated post-ABI and which are less likely to be identified without consistent long-term oversight, and (iii) the organisational, memory, problem-solving and other executive functional issues that people with ABI commonly experience. [16.9]

EXAMPLE 19.10 — Consistent case management over time

Support: There should be a greater coordination of care and support for people with ABI over the long term (i.e. case management).

Reason: People with ABI have difficulties negotiating systems themselves and organising supports for a variety of goals, and so need a case manager who understands ABI to assist them (i.e. knowledge of how to case manage alone is not sufficient). [14.25]

EXAMPLE 19.11 — Consistent pathway of support

Support: There should be a consistent pathway of support for any person with ABI post-injury, regardless of the cause and circumstance of their injury. For instance, people who don't go through a brain injury rehab unit or who are not compensable should still have access — under the NDIS — to early intervention therapies (e.g. physio, OT, speech therapy, social work, etc.).

Reason: This is to ensure that (a) there will be better outcomes, and (b) they will be more inclined to participate in terms of doing what is required to achieve their goals, etc. [16.10]

EXAMPLE 19.12 — Consistent availability of support

Support: There should not be pre-determined time-scales or 'cut off' dates connected to particular budget areas (e.g. making respite unavailable for people who have been receiving support to transition out of home for 2 years).

Reason: The funding should be connected to a person's actual needs and life circumstances. [16.12]

Flexibility over time

EXAMPLE 19.13 — Flexible support over time

Support: The supports should be flexible over time (e.g. there should be periodic reviews).

Reason: It is not always possible to decide *now* what will be reasonable and necessary *in 10 years time*. [15.1]

EXAMPLE 19.14 — Flexible support over time

Support: People with ABI may need an increase of services as they progress through life.

Reason: There is evidence that for people who age with a disability, the aging process accelerates. [16.3]

EXAMPLE 19.15 — Flexible support over time

Support: Services should be delivered (a) in a flexible manner, to adjust to changes in their functioning and circumstance (e.g. where there is a transition to independence, due to, say, aging parents), and (b) in a person-centred way.

Reason: This will help to optimise their functionality, i.e. where possible to enable them to return to a pre-injury status; and to bring the quality of care up to the highest possible standard, and to ensure that their dignity as a person is upheld. [18.5]

EXAMPLE 19.16 — Flexible support over time

Support: The kind of supports used should be flexible, rather than too fixed — looking for naturally occurring networks, rather than paid support.

Reason: This will allow for creative, more effective, socially inclusive and cost-beneficial options (e.g. the Agency provides funds to enable the participant to buy a season ticket for a game for a 'suitably qualified' friend, rather than paying a support worker per hour). [12.21]

Social Participation and Relationships

EXAMPLE 19.17 — Relationship support

Support: They need support to access family and friends on a regular basis.

Reason: It is important to them emotionally, and to maintain relationships. [11.2]

EXAMPLE 19.18 — Social participation support

Support: ABI isolates and segregates people from society. They lose existing social networks and find it difficult to establish new networks. This can result in the development of very negative behaviours and patterns of thought — resulting in depression, criminality, drug and alcohol issues. This is because their capacity to make these connections is reduced by, for example, their

cognitive limitations, communication limitations, etc.. So they need supports there to help them maintain and build new relationships — e.g. by having someone who is a 'Coordinator of Social Networks' and/or a 'Circle of Support'.

Reason: The benefits of this include improved mental health, self-confidence, improved ability to make friends, etc.. In other words, funded support should not be limited to physical issues, but include social and emotional support. [11.12]

EXAMPLE 19.19 — Social participation support

Support: Social inclusion supports.

Reason: When paying their bills, there is not much left for those things. [12.2]

EXAMPLE 19.20 — Social participation support

Support: People with ABI need support in social and recreational engagement.

Reason: They need a sense of purpose and engagement with the community (e.g. ABI can prevent people from connecting with their work, their network of friends, and social activities). [13.8]

EXAMPLE 19.21 — Social participation support

Support: Support services will often fund transport to social activities or support during the activity but not the activity itself.

Reason: Without this funding, many people with ABI won't be able to afford these activities, and so will be less likely to be able to achieve their social participation goals (e.g. reducing social isolation, creating friendship networks). [14.17]

EXAMPLE 19.22 — Social participation support

Support: To avoid the pitfalls of other schemes that exist (e.g. Lifetime Care and Support), any goal connected with leisure, pleasure or recreation must not be automatically declined.

Reason: These are the kinds of things that will help people feel worthwhile again, connect them to a social life (i.e. avoiding social isolation), and help them to meet the kind of goals that they had prior to their injury. [15.10]

EXAMPLE 19.23 — Social participation support

Support: Service providers should be required to enable participants to become active members of the community — which includes components for transport, costs of going to community activities, like the gym (rather than focusing merely on medical issues).

Reason: This will increase their social inclusion and quality of life (e.g. depression levels, behavioural issues, etc.). [16.8]

EXAMPLE 19.24 — Social participation support

Support: People with ABI need social supports (e.g. being linked in with their old friends, networks they had pre-injury, and to explore new interests and activities).

Reason: This can have a very positive effect if they can maintain or establish new social networks; with these supports, there can be significant cost-reductions and a limited need for formal service provision, and it helps to avoid social isolation and depression. [18.2]

EXAMPLE 19.25 — Relationship support

Support: People with ABI have significant problems with relationships (e.g. some want a full-blown relationship, others only want a sexual relationship) — so support is required to enable these areas to be explored in a safe and respectful way.

Reason: These are basic human needs that should not be denied to someone just because they have a disability. [18.11]

EXAMPLE 19.26 — Relationship support

Support: People with ABI need support and education (from professionals in the field of sexuality) in finding appropriate outlets or ways to form and manage relationships and sexual intimacy.

Reason: Otherwise they can find themselves in trouble with the law. [13.9]

EXAMPLE 19.27 — Social participation support

Support: Every person with an ABI who does not have the ability to return to employment due to severe physical and/or cognitive disability and/or challenging behaviour related issues must receive adequate funds to facilitate a range of meaningful activities on a daily basis.

Reason: An ongoing lack of regular, meaningful activity and social interaction leads to depression, low self-esteem/self-worth and increased social isolation. [18.13]

EXAMPLE 19.28 — Social participation support

Support: Group therapeutic organisations should be supported (e.g. horse-riding for disabled children and adults).

Reason: This is so that they are able to deliver services in a more cost-effective way. [19.2]

Focused Cognitive Support *(e.g. decision-making, goal-setting, behaviour, memory)*

EXAMPLE 19.29 — Focused cognitive support (handling money)

Support: One of the biggest problems for people with ABI is money handling: they need someone to help them and guide them. For some people, this support could be needed for every day routines of life; for others, it could be just on days or times when they are going out into the community and need to purchase things.

Reason: To make sure that they are as independent as possible. [11.6]

EXAMPLE 19.30 — Focused cognitive support (personal care)

Support: Personal care.

Reason: Some of our clients don't see this as a priority – they choose instead to spend their money on the nice things in life. [12.1]

EXAMPLE 19.31 — Focused cognitive support (administrative tasks)

Support: Recognition within Centerlink that people with ABI don't always understand correspondence, return dates and forms, forgetting appointments, etc..

Reason: Without this recognition (and the support they will need), they are cut off — simply because they don't know how to navigate the system (and are often falsely accused of being resistant or 'non-compliant'). [12.3]

EXAMPLE 19.32 — Focused cognitive support (goal setting)

Support: Support with articulating goals and objectives.

Reason: Without this, they will find it very difficult to articulate what they need and want. [12.9]

EXAMPLE 19.33 — Focused cognitive support (decision-making)

Support: Support and education in making decisions (e.g. utilising a decision-making model, or problem setting approach, within the limits of their abilities, with a suitably trained facilitator).

Reason: This will build and sustain their capacity to make decisions for themselves. [12.10]

EXAMPLE 19.34 — Focused cognitive support (goal setting)

Support: There needs to be future planning.

Reason: The needs are going to constantly change over time. [12.14]

EXAMPLE 19.35 — Focused cognitive support (planning, organising)

Support: People with ABI need access to a multi-disciplinary support team (e.g. neuropsychologist, OT, etc.).

Reason: This is so that they can learn new ways of doing tasks, and strategies to be able to do tasks that they used to do (e.g. planning, organising how to get somewhere). [13.6]

EXAMPLE 19.36 — Focused cognitive support (challenging behaviour)

Support: People with ABI need support in helping them to manage challenging behaviour (e.g. by doing effective functional behaviour assessments, drawing on a multi-disciplinary team).

Reason: Otherwise they can find themselves in trouble with the law, it limits their capacity to engage in community, and it can lead to increased social isolation. [13.10]

EXAMPLE 19.37 — Focused cognitive support (planning, decision-making)

Support: People with ABI need one-on-one support in relation to planning and decision-making.

Reason: People with ABI can be articulate, but planning and decision making issues can stop them from going back to work, making appointments, etc. [14.7]

EXAMPLE 19.37 — Focused cognitive support (goal setting)

Support: People with ABI need support at the stage of creating their support plan.

Reason: They often struggle to identify meaningful and realistic goals (because of lack of self-awareness, neurological impairments, etc.), and so would be significantly disadvantaged without this support. [14.28]

EXAMPLE 19.38 — Focused cognitive support (attendant care)

Support: Some people with ABI will need attendant care (but should not be over supported if they have skills to do it themselves).

Reason: This support is needed (a) to meet their rehabilitation goals, (b) to maintain them in the community (e.g. budgeting, diary management, etc.), (c) to develop skills, (d) to progress over time, meeting new goals to fit their changing life circumstances and personal aspirations, (e) to build their self-esteem (f) to increase their independence, (g) to do so in a way that helps to maintain and improve family relationships (e.g. without intruding on their family environment). [16.1]

EXAMPLE 19.39 — Focused cognitive support (goal setting)

Support: People with ABI and their families need to be provided with education about how to set goals in the context of the NDIS.

Reason: First, they may be used to a very different funding approach (e.g. rationing). Second, they are unlikely to know how the new system works, or what is possible, and so they may develop plans that are not as beneficial or effective as they could be. [16.13]

EXAMPLE 19.40 — Focused cognitive support (decision-making)

Support: People with ABI need a wide group of people available to help them decide what they need, as opposed to just parents or a guardian (e.g. work colleagues, a neighbour, etc.).

Reason: To ensure that a full range of perspectives can be brought to the decision making (e.g. the person will have different needs in different contexts — home, work, education, social activities, etc.). [18.3]

Independent Living

EXAMPLE 19.41 — Independent living (shopping, meals)

Support: People with ABI will need supervision or personal assistance in practical tasks (e.g. going shopping, preparing meals, etc.).

Reason: To meet the objectives of making sure that they have quality of life and can participate in the community. [14.1]

EXAMPLE 19.42 — Independent living

Support: After an assessment, people with ABI need ongoing support to use strategies to cope in everyday life, in work, at home in relationships.

Reason: This will enable them to participate in life far more effectively than they would without this support. [14.3]

EXAMPLE 19.43 — Independent living (household tasks)

Support: People with ABI need support to manage basic household tasks — some of which are 'hidden' or 'not obvious' (e.g. when to eat, that they have to eat, checking the letterbox, opening letters).

Reason: Otherwise they can end up with significant health issues (e.g. becoming underweight or sick from eating 'out of date' food); and there is an increased risk of bills not being paid (e.g. which can result losing their funding or phone connections, or their electricity being cut off). [13.11]

Aids and Equipment

EXAMPLE 19.44 — Equipment (communication)

Support: Equipment (e.g. communication device, like a mobile or an iPad).

Reason: This enables them to access all aspects of social inclusion experiences (e.g. helps them to open their door or blinds). [12.4]

EXAMPLE 19.45 — Equipment (mobility)

Support: Wheelchairs (OT assessed).

Reason: Without these, they have limited access to the community. [12.5]

EXAMPLE 19.46 — Equipment (safety, maintenance)

Support: Access to services that can (a) maintain and adjust equipment, (b) ensure that (it is mandatory that) the participant receives equipment that is safe and appropriate to their needs, and (c) provide training on how to use the equipment, including safety issues.

Reason: This will (a) ensure sustainability of the equipment, (b) prevent any deterioration of their health and well-being (injuries, loss of function), and (c) prevent injury to the person pushing/operating the equipment. [12.7]

EXAMPLE 19.47 — Equipment (mainstream)

Support: Some equipment is 'mainstream' (e.g. iPads), but would be too expensive for most people with a disability.

Reason: Yet they are often a cheaper option than specialist disability equipment (e.g. specialised communication devices), they are universally available, and more socially acceptable. [12.25]

EXAMPLE 19.48 — Equipment (communication, mobility)

Support: People with ABI need aids and equipment (e.g. GPS, iPad, iPhones, hoists, electronic wheelchairs).

Reason: This will help them to access community, to live a more productive life (e.g. going to work, getting to work on time), and to increase their independence. [13.7]

EXAMPLE 19.49 — Equipment (assistive technologies)

Support: There should be funding for assistive technologies (e.g. smart homes that are put up for rent so that they could be shared by people with a disability).

Reason: This would allow people with ABI to live independently and with dignity (e.g. you don't have hands on intrusive care, with support being provided more remotely). [14.13]

EXAMPLE 19.50 — Equipment (mainstream)

Support: People with ABI need support with equipment and aids over and above what government agencies will provide (e.g. aids around cognition and physical aids).

Reason: To allow access and participation and increase independence [14.19]

EXAMPLE 19.51 — Equipment (individualised and flexible)

Support: The Agency should fund aids and equipment that are (a) individualised for the specific needs of a person with ABI, (b) provided at the time that it is needed (not in 2 or 5 years time), and (c) accompanied by the support that they need to use the equipment as their needs change.

Reason: First, this will make sure they have access to the community. Second, their quality of life is less likely to deteriorate while they are waiting for the equipment. Third, if the waiting time is too long, then the situation is likely to have changed to the detriment of their quality of life. Fourth, having access to the right kind of equipment can, for people with ABI, be the difference between life and death — because people with ABI commonly suffer from deep depression and frustration over what they've lost, how they are treated by others and coping with their new reality. [15.9]

EXAMPLE 19.52 — Equipment (age-appropriate)

Support: People with ABI need equipment that is age-appropriate, timely and non-damaging (e.g. wheelchairs, nappies, etc.) and home modifications, especially for children.

Reason: As the child grows the equipment may become damaged and the child will be unable to live without discomfort if the equipment doesn't fit, parents have to find vast sums that they don't have to make home modifications. (Note, it would be cost-effective to have an equipment pool, so that — where appropriate — equipment can be 're-cycled'). [19.1, ATD]

EXAMPLE 19.53 — Equipment (mainstream)

Support: Equipment modifications that are necessary to meeting your goals (e.g. returning to work) and that are not paid by existing schemes, should be covered by the NDIS.

Reason: To ensure that they are able to meet their goals and social and economic participation. [18.4]

EXAMPLE 19.54 — Equipment (adaptive technologies)

Support: The NDIS should provide funding for adaptive technologies (e.g. smart phones to help with organisation, planning, modifying their car to enable them to drive again, Skype for their friends, specially made toothbrush).

Reason: This is so that they can meet their personal, vocational, educational or social goals (e.g. to return to work, school, feeling more included within their community, etc.). [18.10]

EXAMPLE 19.55 — Equipment (communication)

Support: People with ABI need funding for communication devices (e.g. iPads).

Reason: This is so that they can communicate outside of their network (e.g. with shops), and so reduce barriers to social inclusion. [19.3]

Interface with and access to Mainstream Services

EXAMPLE 19.56 — Access to mainstream supports (community groups)

Support: The NDIS should look at encouraging people with ABI to explore other ways of getting support — i.e. not just depending on disability services, but also using mainstream services (e.g. by helping a person to join a knitting group in the community, rather than a knitting group that is only for people with a disability). It should also focus not just on deficits and maintenance, but on what people can do, and the potential they have for increasing their independence and quality of life.

Reason: People with ABI can reduce their dependency on the NDIS (and so their disability funding), as well as helping them to increase their social networks in the community. [11.16]

EXAMPLE 19.57 — Access to mainstream supports (challenging behaviour)

Support: People with ABI who have unique and challenging behaviours need education and support (e.g. through housing or community-based services).

Reason: Otherwise they can be disenfranchised from mainstream services, and it is more likely that mental health services will be used inappropriately. [14.14]

EXAMPLE 19.58 — Interface with mainstream supports (equipment)

Support: Where a support (such as a wheelchair) could be provided by a non-NDIS organisation, but it is not of a suitable quality or doesn't meet the specific needs of a person with ABI, then the NDIS should be required to supply the funds necessary to purchase that support.

Reason: This is so that the person is not disadvantaged simply because mainstream services are not able to provide the necessary support (e.g. where a mainstream service will only provide a one-size-fits-all wheelchair, and this does not fit the person in question). [16.6]

EXAMPLE 19.59 — Interface with mainstream supports (supports)

Support: If a person with ABI has not received necessary support from a mainstream service within a reasonable period of time (at any time after the injury), then the NDIS should step in to provide this kind of support.

Reason: This is to ensure that they receive the support they need. [16.11]

EXAMPLE 19.60 — Access to mainstream supports (recreation)

Support: People with ABI should have supported access to participate in mainstream recreational activities (e.g. art therapy, fitness, living skills programs, etc.), including funding for transport.

Reason: This is so as to increase their social and community connections, to make friends, and re-establish their social network. [19.6]

EXAMPLE 19.61 — Access to mainstream supports (legal and financial)

Support: Access to funded legal services, the full range of financial services, child protection or protection for vulnerable parents and comprehensive management would be important for people with ABI.

Reason: People with ABI might do things that would create legal or financial difficulties (e.g. substantial mobile phone bills, taking part in scams that they don't have the capacity to consent to), and support workers shouldn't be providing advice where they don't have the skills to do so, and because some people with ABI will be quite good at managing their finances, and others will not. [19.9]

Psychological support

EXAMPLE 19.62 — Psychological support (adjustment, insight)

Support: There should be access to longer-term psychological support.

Reason: This is so that people with ABI can adjust to and become better aware of the impact of their brain injury. [14.27]

EXAMPLE 19.63 — Psychological support (grief, relationships)

Support: Counselling relationship and mentoring services.

Reason: This will help with grief, anxiety, relationship breakdown with children, partners and parents. [12.8]

Specialist Healthcare

EXAMPLE 19.64 — Specialist healthcare (botox)

Support: Access to Botox.

Reason: For people who have issues with tight ligaments and limbs. [12.5]

EXAMPLE 19.65 — Specialist healthcare (nutrition)

Support: People with ABI often require expert feeding and feeding equipment (by a dietician).

Reason: This is because (a) they may not tolerate a varied diet, and — if feeding is not done effectively, it will have a considerable impact on their quality of life (e.g. they could experience aspiration, which can lead to infections; and if the client is a child, their consideration about their development is crucial); and (b) nutritional intake is difficult given their feeding difficulties (e.g. swallowing problems). [12.13]

EXAMPLE 19.66 — Specialist healthcare (health checks)

Support: The NDIS should ensure that, where required to support a client effectively, it is mandatory for the health system to provide an integrated health check.

Reason: This will help to ensure the maintenance of their overall health and well being over the long term. [12.15]

EXAMPLE 19.67 — Specialist healthcare (rehab)

Support: Access to rehabilitation in an appropriate setting, proper assessment (i.e. cognitive, functional, psychosocial), and immediate support for both the person with ABI and their family.

Reason: This will have (a) a much better outcome for a person with ABI and (b) be more cost-effective in the long run (e.g. sustainability of family relationships is more likely). [12.19]

EXAMPLE 19.68 — Specialist healthcare (indirect health issues)

Support: People need supports for the indirect consequences of their ABI (e.g. physical pain, deterioration).

Reason: This will have a direct impact on their well being. [12.20]

EXAMPLE 19.69 — Specialist healthcare (consumables)

Support: Delivery of consumables, like peg feeding, suppositories, gloves, catheters, medications, etc..

Reason: These are procedures that cannot be done by someone who isn't credentialed; and it is expensive for RNs or credentialed people to come out and provide this. There are also problems of availability outside normal hours. [12.22]

EXAMPLE 19.70 — Specialist healthcare (substance misuse)

Support: People with ABI need support with managing substance misuse issues.

Reason: Mainstream services that deal with substance misuse don't understand ABI issues; and yet before a person can access ABI supports, they need to be free of using a substance. [13.14]

EXAMPLE 19.71 — Specialist healthcare (family planning)

Support: There needs to be support for family planning.

Reason: People with ABI can believe that someone is in a relationship with them and so children are brought into the picture, but they may not have the skills to parent the children or the relationship may break down — in which case they become financially responsible for the child which creates additional hardships for someone with a disability. This can happen several times as multiple relationships are started and ended with the same results. [13.17]

EXAMPLE 19.72 — Specialist healthcare (mental health)

Support: Currently, people with ABI may not receive support unless they have a dual diagnosis (e.g. of both ABI and a mental health condition). This should not be duplicated under the NDIS.

Reason: Otherwise people with ABI who do not have a dual diagnosis will continue to be disadvantaged. [14.5]

EXAMPLE 19.73 — Specialist healthcare (mental health)

Support: The Agency needs to encourage and promote better access to services that address dual diagnosis.

Reason: There should be no 'wrong door' for people with ABI and a mental health condition [14.31]

EXAMPLE 19.74 — Specialist healthcare (physio, speech therapy)

Support: People with ABI will need ongoing and consistent care and support (physio, speech therapist).

Reason: Whilst improvements in certain areas can be made, other areas will emerge over time and so will also need addressing. [14.9]

EXAMPLE 19.75 — Specialist healthcare (dental, podiatry)

Support: People with ABI need support in order to access other health services (like dental, podiatry, etc.).

Reason: Otherwise these services will be unaffordable for many. [14.10, ATD]

EXAMPLE 19.76 — Specialist healthcare (rehab)

Support: The Agency needs to encourage and promote better access to specialised slow-stream rehab units.

Reason: These services are currently inadequate, and this kind of rehab enables people to return to their community, etc.. [14.30]

EXAMPLE 19.77 — Specialist healthcare (rehab)

Support: People with ABI should not be excluded from rehab because of short-term memory loss (i.e. where the justification is: "they can't learn").

Reason: First, this discriminates against people with a particular type of impairment. Second, people with short-term memory loss *can* learn tasks if they are repeated enough. Third, this kind of 'defeatist' response unnecessarily demotivates both the person with ABI and their family/carers. [15.3]

EXAMPLE 19.78 — Specialist healthcare (OT, physio)

Support: People with ABI need access to and funding for ongoing health maintenance (e.g. OTs, physio, counselling, etc.), rather than having time-limited access.

Reason: This is to maintain and improve their long-term health and well being. [19.5]

Specialist Needs Assessments

EXAMPLE 19.79 — Specialist needs assessments (individualised)

Support: Support needs for people with ABI will need to be individualised and assessed by Agency staff who are trained in ABI.

Reason: This condition is so broad and complicated: it is impossible to categorise cognitive disability in the same way that we do physical disability. So each person with ABI will be different. [12.17]

EXAMPLE 19.80 — Specialist needs assessments (regular reviews)

Support: The Agency needs to ensure that people with ABI have their assessments reviewed on a regular basis (e.g. as part of a yearly health check).

Reason: Their condition will inevitably change over time, and to prevent future health issues. [12.18]

EXAMPLE 19.81 — Specialist needs assessments (neuropsychological)

Support: People with ABI need neuropsychological assessments.

Reason: They need these (a) to determine the strengths and barriers that they need to address in a return to work situation (e.g. learning new information, breaking down tasks) and (b) to educate the employer on how best to support them in the workplace. [14.2]

EXAMPLE 19.82 — Specialist needs assessments (current)

Support: People with long-term ABI (i.e. 15-20 years post ABI) who want to return to work may need to be referred back to an assessment of their support needs.

Reason: They will often have had no proper assessment or community support in the last 10 years, and so will require a more current assessment. [14.4]

EXAMPLE 19.83 — Specialist needs assessments (ongoing)

Support: There should be recognition that supports will be needed some time down the track post-ABI, not only in the immediate aftermath.

Reason: Many issues requiring support only emerge (or are only identified) sometimes several years later. [14.6]

EXAMPLE 19.84 — Specialist needs assessments (multi-disciplinary)

Support: The assessment of what supports are reasonable and necessary for a person should not be entirely dependent upon one individual's perspective (e.g. an Agency staff member who happens to be your assessor on the day), there should instead be a multi-disciplinary approach to this assessment.

Reason: Otherwise the assessment is likely to be flawed and inaccurate. [16.7]

EXAMPLE 19.85 — Specialist needs assessments (individualised)

Support: The assessments of a person with ABI's support needs should be targeted for ABI and individualised for that person, not generic.

Reason: Otherwise the person's needs will not be captured effectively and they will eventually need to be re-assessed. [18.6]

EXAMPLE 19.86 — Specialist needs assessments (objective)

Support: The assessment of a person's support should (a) be done in an objective way, and (b) it is paramount that the retained capacity of the individual who is being assessed is taken into account.

Reason: Otherwise necessary supports may be excluded because (a) of an assessor's subjective perspective or judgements, or because (b) the assessor is not equipped with the skills and knowledge required to identify both the cognitive limitations and the cognitive abilities that have been retained. [19.8]

EXAMPLE 19.87 — Specialist needs assessments (qualified)

Support: People with ABI need to have access to qualified assessments and expert assessors.

Reason: Otherwise their needs won't be adequately identified and the program they use will inevitably be inadequate. Note, sometimes a person's needs are hidden by the way that they are cared for (e.g. a parent fills in support gaps, in a way that is unsustainable); or a program is designed primarily to meet the needs of parents/carers. [19.10]

Transport

EXAMPLE 19.88 — Transport (access)

Support: People with ABI need access to transport.

Reason: Otherwise they won't have access to the services they need. [12.26]

EXAMPLE 19.89 — Transport (funding)

Support: People with ABI need funding for transport (bus or taxi fares).

Reason: This can be the single biggest barrier for people to access support or health services. [14.15]

EXAMPLE 19.90 — Transport (supervision)

Support: People with ABI will need transport (including supervision on public transport).

Reason: This is to help them to live more independently. [16.2]

EXAMPLE 19.91 — Transport (on-off road assessment)

Support: People with ABI who need to get an on-off road assessment to return to drive require a funded OT assessment.

Reason: It is prohibitively expensive, and so excludes many people from returning to work (esp. those who have been tradies). [14.16]

Accommodation

EXAMPLE 19.92 — Accommodation (at-home support)

Support: Some people with ABI need to have funded support to live in their own homes.

Reason: Otherwise they will have to be helped by family members — but often parents are too elderly to look after them; also support will help them to be more independent. [13.5]

EXAMPLE 19.93 — Accommodation (alternative models)

Support: The Agency should consider a range of alternative models of support for people with ABI — especially accommodation, which might include 'cluster housing' (rather than relying entirely upon traditional attendant care or 'living at home with family-as-primary-carer' models)**.**

Reason: This is due to the risks associated with these traditional models (e.g. family burn out, increased dependency, the need for consistent monitoring for high risk clients, clients with challenging behaviour, etc.). [16.4]

EXAMPLE 19.94 — Accommodation (age-appropriate)

Support: People with ABI need suitable age-appropriate accommodation supports (or other options). Currently if they're not supported by their family they are put into residential aged care.

Reason: This can impact on them further (e.g. if they don't recognise that they have an ABI, being in a home with aged people can affect their mental health, leading to depression, suicide, their independence and choice about who they live with is taken away from them). Generally, if they are not accommodated appropriately, it makes them vulnerable to being taken advantage of financially, drugs and alcohol. If they are forced to live with their families, this can put the family at risk of further breakdown due to violence, etc.. [18.1]

Support in Regional, Remote and Rural Areas

EXAMPLE 19.95 — Regional specialist services (availability)

Support: There needs to be sufficient services regionally for people with ABI.

Reason: Otherwise these services can't be accessed by people with ABI in regional areas; and if they re-locate in order to access the services they lose their family networks and can become socially isolated. [13.15]

EXAMPLE 19.96 — Rural and remote specialist services (equitable and timely)

Support: People with ABI — particularly those who live in rural and remote areas — need equitable and timely access to support services.

Reason: Otherwise these services will be unavailable for many. [14.11]

EXAMPLE 19.97 — Rural and remote specialist services (transport)

Support: Many people with ABI need access to and funding for transport — especially in rural and remote areas; and they may not be able to use public transport (e.g. if existing services do not follow a strict routine, or if they need a support person to assist them).

Reason: Otherwise they will not be able to get to services, can't participate in social and economic activities, etc. [18.12]

EXAMPLE 19.98 — Rural and remote specialist services (access)

Support: People with ABI in remote or rural locations need access to appropriate therapies (e.g. OT) that are provided within the home, fully funded (in terms of filling the funding gap left by mainstream health, and that accounts for travel time), and that take into account new technologies.

Reason: First, without this support they will be at a significant disadvantage — particularly if the therapy is not provided within the first 16 months post-injury and ongoing, as needed. Second, therapy in the home is essential for short-term memory loss. Third, mainstream health only funds a limited number of visits, and travel time is charged at the cost of therapy time. [15.2]

EXAMPLE 19.99 — Rural and remote specialist services (flexibility to hire family)

Support: In some cases (e.g. rural areas), there should be sufficient flexibility in the plan to allow a participant can pay family members to provide support — however, there are many risks involved, so there must be adequate standards and regulation applied, particularly for high risk participants.

Reason: This is in order to meet the clients goals and social and economic participation, particularly in areas where there are insufficient numbers of trained professional support workers or culturally appropriate personnel. [18.8]

Support for children and young adults

EXAMPLE 19.100 — Transition to adult services

Support: There needs to be support for children with ABI who are transitioning to adult services.

Reason: The existing approach is inadequate. [13.16]

EXAMPLE 19.101 — Transition to adult services

Support: Support should be provided to people with ABI during their transition from childhood to adulthood (e.g. ongoing information, vocational support, mental health, independent living) rather than leaving the responsibility for this up to the parent.

Reason: First, parents may not have enough information, which can be highly stressful to them. Second, they are now caring for an adult, which can involve more challenging behaviours, Third, it can result in family conflict and relationship breakdown. Fourth, it can perpetuate the person with ABI's dependence on the parent. [14.22]

EXAMPLE 19.102 — Age appropriate placements

Support: Young people with ABI need access to appropriate placement.

Reason: This is to ensure that they have age appropriate social interactions, and because it is more cost effective. [14.12]

EXAMPLE 19.103 — Social and educational support

Support: People with ABI need additional educational and social support (i.e. over and above what is covered by education).

Reason: First, children with ABI fall 'between the cracks' in mainstream education — unless they are profoundly impaired. Second, they are frequently victims of bullying (e.g. due to speech difficulties, physical, cognitive and behavioural issues). Third, adults trying to access TAFE or distance education are not supported (e.g. with planning, the extra time needed to comprehend course content). [14.18]

EXAMPLE 19.104 — Independent decision-making for young adults

Support: There should be someone to advocate for a young adult to ensure that they are supported in making decisions for themselves.

Reason: Otherwise it is likely that the person will have the goals and perspectives of others (e.g. parents) imposed upon them. [14.24]

EXAMPLE 19.105 — Developmentally appropriate support plans for children

Support: When a participant is putting together their support plan, the Agency needs to ensure that they consider not only short-term goals, but also long-term goals— particularly when the participant is a child.

Reason: Due to the developmental issues and changing needs that will arise for children with a disability (e.g. in the transition to adulthood, completely new circumstances will emerge — such as learning how to drive, sexuality, social interaction, relationships, educational and vocational goals, learning to take responsibility for their own life, etc.). [15.8]

20. Examples — supports needed by carers of people with ABI

EXAMPLE 20.1 — Education about ABI

Support: Carers need to be educated about what is realistic for a person with ABI.

Reason: This will enable them to (a) gain a greater understanding of the cognitive limitations and (b) reduce their anxiety. [12.11]

EXAMPLE 20.2 — Focused cognitive support

Support: Carers may also have cognitive limitations, and so need support themselves.

Reason: This will enable them to provide better support (i.e. better decision-making, more realistic expectations) when caring for the person with ABI. [12.12]

EXAMPLE 20.3 — Education about specialist healthcare (nutrition)

Support: Carers need to be educated about nutrition.

Reason: This will enable them to help the participant to prevent chronic disease development and maintain patient safety (e.g. preventing swallow issues). [12.16]

EXAMPLE 20.4 — Education about ABI and self-care, psychological support and respite.

Support: Long-term holistic support for parents, siblings and partners is needed (which can include education about self-care, counselling, etc.).

Reason: First, parents need help with adjusting to their child's condition, and addressing specific issues that arise over time. Second, without this support, relationships break down, parents 'burn out', siblings need to be able to thrive and develop appropriately, and so on. [14.20]

EXAMPLE 20.5 — Education about ABI and specialist healthcare (exercise)

Support: There should be (a) ongoing training for carers to ensure that they can adjust to changing conditions in the person of ABI; and (b) training provided to people with ABI so that they can learn that it is good to move (e.g. this is required because of (i) the high propensity of type 2 diabetes in the population, (ii) a statistically low level of exercise among Tasmanians in general, plus (iii) the impact of disability.

Reason: First, this kind of support will not be available without funding, particularly where the family is not involved or interested in providing it. Second, exercise can significantly enhance the motivation and emotional well being of a person with ABI. Third, without proper supervision, a person with ABI who undertakes exercise may experience injuries (e.g. because a person with ABI used the wrong shoes, they needed amputation, which could have been avoided if a podiatrist had been involved). [12.23]

EXAMPLE 20.6 — Respite

Support: Self-directed, flexible family respite should be funded.

Reason: It can free the family from the carer's role for a while (recognising that this may involve employing someone to support the person with ABI during the respite, rather than the family taking respite without the person with ABI). [14.21]

EXAMPLE 20.7 — Education about ABI and the support that is available.

Support: There should be (a) immediate post-injury support and education made available to people with ABI and their carers, and (b) better public awareness about the availability of this kind of support (e.g. through the hospital or GPs).

Reason: First, the transition to someone who now has a brain injury, and the transition from a 'spouse', 'partner' or a 'significant other' to a 'carer' is immediate and overwhelming (emotionally, physically and intellectually). Second, they do not have the time, energy or knowledge about how to access this kind of support or education. [15.4]

EXAMPLE 20.8 — Respite and information about the support that is available

Support: Carers of people with ABI should be provided with respite (including information about what is available), rather than have to ask for it.

Reason: First, they would not otherwise know what is out there. Second, it may help to avoid the breakdown of important relationships, and/or the abandonment of the person with ABI. [15.5]

EXAMPLE 20.9 — Support with navigating the system

Support: The Agency needs to ensure that carers of people with ABI are not over-burdened with the process of navigating the system.

Reason: Even with additional external funded support for the person with ABI, the stress and energy required of the carer can still be overwhelming. [15.6]

EXAMPLE 20.10 — Psychological support

Support: Grief counselling should be made available to both the person with ABI and their carers, for as long as (and whenever) it is required.

Reason: First, both have suffered immense losses (e.g. the person they used to know, the future they had planned and hoped for, prior relationships with 'significant others', etc.). Second, given that the grieving process is not time-limited, the current mainstream funding for a fixed number of sessions with a counsellor or psychologist is insufficient. Third, the lack of ongoing counselling, as and when needed, is very likely to contribute the deterioration of both the person with ABI and their carers' quality of life and mental health. [15.11]

Appendices

A. List of Consultees

In total, there were 20 consultation sessions and several written submissions, involving a total of 235 consultees—as listed below:

Name	Role and/or Organisation	Session
1. Lee-Anne Brenssell	CEO, Headwest: Brain Injury Association of WA Inc., Psychologist	Perth, WA
2. Lisa Wainwright	ABI First Stop Advocate and In-take Coordinator, Headwest: Brain Injury Association of WA Inc.	Perth, WA
3. Jesse Bruggler	Individual Advocate, Headwest: Brain Injury Association of WA Inc.	Perth, WA
4. Denise Butler	Advocate, Psychologist, Headwest: Brain Injury Association of WA Inc.	Perth, WA
5. Sophii La Cey	Advocate, Headwest: Brain Injury Association of WA Inc.	Perth, WA
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7. Pippa Cebis	Manager Services for Younger People, Business Innovation, Brightwater Care Group (Perth)	Perth, WA
8. Amanda Halfpenny	Rehabilitation Consultant / Social Worker, Lighthouse Health Group	Perth, WA
9. Caroline Watt	Manager Policy and Planning, Nulsen	Perth, WA
10. Anna Gubbay	Department of Paediatric Rehabilitation, Princess Margaret Hospital for Children, Perth	Perth, WA
11. Kate Langdon	Paediatrician, Princess Margaret Hospital	Perth, WA
12. Elspeth Kerr	Community Neurological Nurse, The Neurological Council of WA	Perth, WA
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14. Jonine Collins	Executive Officer, Stroke Foundation	Perth, WA
15. Carol Franklin	Carer, Chair of Carers WA (outgoing), Vice Chair Young People in Nursing Homes Alliance, Advocate with PWD	Perth, WA
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17. Ardis Hood	Consumer representative, lived experience ABI	Perth, WA
18. David Hounsome	Chair, Board of Headwest: Brain Injury Association of WA Inc.	Perth, WA
19. Shew-Lee Lee	Clinical Psychologist, Princess Margaret Hospital for children	Perth, WA
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24. Ivan Lawton	General Manager Specialist Services, Novita Children's Services	Adelaide, SA
25. Frankie Anderson	General Manager Customer Services, Public Trustee, Govt of SA	Adelaide, SA
26. Fiona Macgregor	Project Officer – Adelaide, Indigenous Coordination Centre, FaHCSIA	Adelaide, SA
27. Amanda Quarrell	Caring Choice	Adelaide, SA
28. Phil Saunders	Alzheimer's Australia, SA	Adelaide, SA
29. Danny Carroll	Disability Advocate, Malssa Disability Rights Advocacy Service	Adelaide, SA
30. Alice Graham	Legal Services Commission	Adelaide, SA
31. Pat Coidan	Senior Research & Policy Officer, Exceptional Needs Unit, Department for Communities & Social Inclusion	Adelaide, SA
32. Sue Houston	Homecare Plus	Adelaide, SA
33. Heather Hales	PARAQUAD SA	Adelaide, SA
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35. Peter Rovira	Brain Injury Rehabilitation Service, Australia	Adelaide, SA
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37. Lauren Moulds	Disability SA, Department for Community Social Inclusion	Adelaide, SA
38. Terry Sommerville	Person with ABI	Adelaide, SA
39. Chris Farrand	The Brain Injury Network of SA, Inc.	Adelaide, SA
40. Shaneen Renshaw	The Brain Injury Network of SA, Inc.	Adelaide, SA
41. Marcia Stewart	Carer of a person with ABI	Adelaide, SA
42. Jim Plenderleith	Father and carer of a person with ABI, LLOB Trust Inc	Adelaide, SA
43. Doreen Schulz	Carer of a person with ABI	Adelaide, SA
44. Alan Bevan	Carer of a person with ABI	Adelaide, SA
45. Jeff Leunig	Person with ABI	Adelaide, SA
46. Mary-Anne White	Person with ABI	Adelaide, SA
47. Anne Bunning	Carer of a person with ABI	Adelaide, SA
48. Enrico Grani	Person with ABI	Adelaide, SA
49. Karen Arthur	The Brain Injury Network of SA, Inc.	Adelaide, SA
50. Joanna Goldsworthy	Person with ABI	Adelaide, SA
51. Victoria Zelipski	The Brain Injury Network of SA, Inc.	Adelaide, SA
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56.	**Michael Summers**	ATSA	Melbourne, VIC
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58.	**Bronwyn Harding**	Southern Health	Melbourne, VIC
59.	**Melanie Muir**	Leadership Plus	Melbourne, VIC
60.	**Vanessa Marrama**	Brainlink	Melbourne, VIC
61.	**Tyrell Heathcote**	MS Australia	Melbourne, VIC
62.	**Wayne Pfeiffer**	Epilespy Foundation	Melbourne, VIC
63.	**Tom Worsnop**	Manager - Service Development, Melbourne Citymission	Melbourne, VIC
64.	**Marc Paradin**	Policy Officer, Victorian Coalition ABI Service Providers	Melbourne, VIC
65.	**Kerry Stringer**	Victorian Coalition ABI Service Providers	Melbourne, VIC
66.	**Maureen Mac Phail**	Grampian Region / TASC / BHS	Melbourne, VIC
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68.	**Laura Corda**	Arbias	Melbourne, VIC
69.	**Julie McConnell**	MND Victoria	Melbourne, VIC
70.	**Rodney Harris**	CEO, Motor Neurone Disease Association of Victoria	Melbourne, VIC
71.	**Bronwyn Morkham**	YPINH Nat. Alliance	Melbourne, VIC
72.	**Florence Kingsley-Matthews**	Person with ABI	Melbourne, VIC
73.	**Simon Chong**	Person with ABI	Melbourne, VIC
74.	**Dharmendra Prasad**	Person with ABI	Melbourne, VIC
75.	**Helen Caligiuri**	Person with ABI	Melbourne, VIC
76.	**Debbie Finch**	Carer of a person with ABI	Melbourne, VIC
77.	**Sally Green**	Person with ABI	Melbourne, VIC
78.	**Anj Barker**	Person with ABI	Melbourne, VIC
79.	**Helen Barker**	Carer of a person with ABI	Melbourne, VIC
80.	**Warren Phillips**	Person with ABI	Melbourne, VIC
81.	**Paul Kefford**	Person with ABI	Melbourne, VIC
82.	**Robyn Kefford**	Carer of a person with ABI	Melbourne, VIC
83.	**Ray Freda Cole**	Carer of a person with ABI	Melbourne, VIC
84.	**Lyn Macdonald**	Person with ABI	Melbourne, VIC
85.	**Peta Ferguson**	Person with ABI	Melbourne, VIC
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89.	**Stephanie Campion**	Department of Health and Human Services, Tasmania	Launceston, TAS
90.	**Theraze Deegan**	Department of Health and Human Services, Tasmania	Launceston, TAS
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94.	**Steve Swenson**	Service Provider, Tasmanian Acquired Brain Injury Services	Launceston, TAS
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96.	**Maggie McKenzie**	Physiotherapist, West Tamar Physiotherapy	Launceston, TAS
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98.	**Chris Demeyer**	Baptcare	Launceston, TAS
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101.	**Jamie West**	Eskleigh	Launceston, TAS
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103.	**Leanne Sanderson**	Department of Health and Human Services, Tasmania	Launceston, TAS
104.	**Adrian Caelli**	Department of Health and Human Services, Tasmania	Launceston, TAS
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110.	**Christopher Hill**	Chief Operating Officer, Motor Accidents Insurance Board	Launceston, TAS
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113.	**Kerry Barwick**	Person with ABI	Launceston, TAS
114.	**Ian Roden**	Person with ABI	Launceston, TAS
115.	**Kim Roden**	Carer of person with ABI	Launceston, TAS
116.	**Ashling Buchanan**	Person with ABI	Launceston, TAS
117.	**Sue Linnett**	Carer of person with ABI	Launceston, TAS

118. Anthony Rodman	Person with ABI	Hobart, TAS
119. Lesley Field	Parent/Service Provider	Hobart, TAS
120. Leanne Whitney	ABI Co-ordinator Veranto/Committee Member, Brain Injury Association of Tasmania	Hobart, TAS
121. Leigh Castles	Stanhope Nursing Services/family member	Hobart, TAS
122. Rodney Dale	Person with ABI	Hobart, TAS
123. Sue Hodgson	Family member/ Housing Options Providing Extra Support	Hobart, TAS
124. Julie Smith	Person with ABI	Hobart, TAS
125. Craig E Scott	Person with ABI	Hobart, TAS
126. Diane Lynd	Headway Rebuilding Lives Support Worker	Hobart, TAS
127. Lynn Francis	Headway Rebuilding Lives Support Worker	Hobart, TAS
128. Belinda Payne	Person with ABI	Hobart, TAS
129. Chantal Wright	Headway Rebuilding Lives Support Worker	Hobart, TAS
130. Rebecca Tedeschi	Headway Rebuilding Lives Support Worker	Hobart, TAS
131. Paul Allen	Person with ABI	Hobart, TAS
132. Brett McCallum	Person with ABI	Hobart, TAS
133. Darren Osborn	Headway Rebuilding Lives	Hobart, TAS
134. Nicholas Cooper	Person with ABI	Hobart, TAS
135. Roger Genge	Person with ABI	Hobart, TAS
136. Stuart Maughan	Person with ABI	Hobart, TAS
137. Robert Hillier	Person with ABI	Hobart, TAS
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142. Clive Skilbeck	Neuropsychologist, Neuropsychology Tasmania	Hobart, TAS
143. Tracey Dean	Clinical Psychologist, St. Giles, Tasmania	Hobart, TAS
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148. Connie Digolis	EO, Stroke Foundation Tasmania	Hobart, TAS
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150. Francis Touber	Community Support Co-ordinator, Headway Rebuilding Lives	Hobart, TAS
151. Natalie Rose	Coordinator Client Services, Veranto: Lifestyle Assistance	Hobart, TAS
152. Dan English	Royal Guide Dogs	Hobart, TAS
153. Catlin Saunders	DHHS, Tasmania	Hobart, TAS
154. Kerry Pearce	DHHS, Tasmania	Hobart, TAS
155. Robyn Hamilton-Smith	APM, Tasmania	Hobart, TAS
156. Jennie Gamble	Area Manager, Anglicare, Tasmania	Hobart, TAS
157. Jenny Buckingham	Anglicare, Tasmania	Hobart, TAS
158. Jackie Witt	Support teacher	Hobart, TAS
159. Mary Evans	DHHS, Tasmania	Hobart, TAS
160. Paul Duncombe	TAD, Tasmania	Hobart, TAS
161. Debra Drew	Business Manager, Headway Rebuilding Lives	Hobart, TAS
162. Darren Osborn	CEO, Headway Rebuilding Lives	Hobart, TAS
163. Louise Arnold	Headway Rebuilding Lives	Hobart, TAS
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165. Robyn Montgomery	TAD, Tasmania	Hobart, TAS
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167. Marilyn Ginn	Person with ABI	Brisbane, QLD
168. Maria Hoogstrate	Person with ABI	Brisbane, QLD
169. Donna Sanderson	Person with ABI	Brisbane, QLD
170. Viki Walters	ROBIN Team Leader, Rehabilitation Of Brain Injured Children - Mater Hospital	Brisbane, QLD
171. Dianne Cavanagh	Jacana	Brisbane, QLD
172. Margaret Rae	Rehab Ambulatory Programs Manager, Qld Paediatric Rehabilitation Service, Royal Children's Hospital	Brisbane, QLD
173. Shannon Galletly	Nurse Unit Manager, Brain Injury Unit - PA Hospital	Brisbane, QLD
174. Ron Cousemacker	Clinical Nurse Consultant, Brain Injury Unit, The Princess Alexandra Hospital	Brisbane, QLD
175. Brooke Kooymans	Director/ Case Manager, Rehability ABI Services	Brisbane, QLD
176. Kellie Sheridan	Case Manager/ Social Worker- Rehability ABI Services	Brisbane, QLD
177. Sanjeeta Mackrani	Allied Health Manager, Alzheimers Queensland	Brisbane, QLD
178. Emma Pawley	Mother and Supporter of a person with ABI, Brain Waves	Brisbane, QLD
179. Mark Burns	Out Reach Projects, FSG Australia	Brisbane, QLD
180. Cathy Pilecki	MAIC	Brisbane, QLD
181. Thea Isles	ABI Service Development Manager, Open Minds	Brisbane, QLD
182. Owen Lloyd	Neuropsychology Clinical Leader, Qld Paediatric Rehabilitation Service, Royal Children's	Brisbane, QLD

	Hospital	
183. Ben Turner	Program Co-ordinator STEPS, Acquired Brain Injury Outreach Service	Brisbane, QLD
184. Ray Quinn	Manager, Acquired Brain Injury Outreach Service	Brisbane, QLD
185. Lee Hearn	Partner, Psycare	Brisbane, QLD
186. Janelle Cooper	Rehabilitation Consultant, CRS Australia	Brisbane, QLD
187. Rachel Merton	EO, Brain Injury Association of NSW	Penrith, NSW
188. Bev Taylor	Training and Development Manager, Brain Injury Association of NSW	Penrith, NSW
189. Nicole Lucas	Advocate, Brain Injury Association of NSW	Penrith, NSW
190. Nerida Johnston	Brain Injury Association of NSW	Penrith, NSW
191. Penny Stephen	Carer of Person with ABI	Penrith, NSW
192. Vicki Lovegreen	Person with ABI	Penrith, NSW
193. Ian Lovegreen	Carer of Person with ABI	Penrith, NSW
194. Beverley Williams	Carer of Person with ABI	Penrith, NSW
195. Kaye Weaver	Carer of Person with ABI	Penrith, NSW
196. Julie Satterly	Carer of person with a disability	Penrith, NSW
197. Galia Ayala	ADHC	Penrith, NSW
198. Lionel Verwey	Person with ABI	Penrith, NSW
199. Gillian Woodcock	Carer of Person with ABI	Penrith, NSW
200. Karina Clarke	Premier Care Pty Ltd	Penrith, NSW
201. Kerry Stafford	ABI Services	Penrith, NSW
202. Kate Loxton	Rehab on the Move	Penrith, NSW
203. Fiona Curtis	Manager, Headway ADP	Penrith, NSW
204. Michelle Barrett	Complete Care Team	Penrith, NSW
205. Jennifer Moon	Community Education Coordinator, Guide Dogs NSW/ACT	Penrith, NSW
206. Rita Blundell	Care & Support Services	Penrith, NSW
207. Muriel Dalmasso	General Manager, Nursing Group	Penrith, NSW
208. Marilyn Styles	Brain Injury Association of NSW	Nowra, NSW
209. Tina Chapman		Nowra, NSW
210. Larry Tibbets	Carer of Person with ABI	Nowra, NSW
211. Debbie Whittaker	Carer of Person with ABI	Nowra, NSW
212. Mike Wootten	Carer of Person with ABI	Nowra, NSW
213. Gina Wilson-Burns	Carer of Person with ABI	Nowra, NSW
214. Helen Parker	Carer of Person with ABI	Nowra, NSW
215. Tammy Jones	Carer of Person with ABI	Nowra, NSW
216. Zachary Jones	Person with ABI	Nowra, NSW
217. Naomi Curtledge	Carer of Person with ABI	Nowra, NSW
218. Kathy Griffiths	Greenacres Disability Services	Nowra, NSW
219. Donnella Robinson	Greenacres Disability Services	Nowra, NSW
220. Drew Sullivan	Interchange Shoalhaven	Nowra, NSW
221. Cathryn Arcus	Workskills - The Disability Trust	Nowra, NSW
222. Robyn Russell	Headway Illawarra	Nowra, NSW
223. Margaret Whyman	Headway Illawarra	Nowra, NSW
224. John Dostine	Illawarra COPS	Nowra, NSW
225. Irena Gordon	IBIS	Nowra, NSW
226. Tricia Hoad	Manager, Disability & Outreach Services & Community Development, ACT	Canberra, ACT
227. Adam Bode	ATODA	Canberra, ACT
228. Julie McRoy	Catholic Care	Canberra, ACT
229. Jeanette Budak	National Brain Injury Foundation	Canberra, ACT
230. Peter McCullagh	National Brain Injury Foundation	Canberra, ACT
231. Libby Steeper	Friends of Brain Injured Children	Canberra, ACT
232. Nic Stuart	Board member, National Brain Injury Foundation	Canberra, ACT
233. Nick Rushworth	EO, Brain Injury Australia	Canberra, ACT
234. Bronwyn Thomas	Senior Physiotherapist, Brain Injury Service, Kids Rehab., The Childrens Hospital Westmead, NSW.	Written submission
235. Sean McCandless	Carer of a person with Cerebral Palsy and EDW Support Officer, EDW Transition Taskforce, Medicare Financing & Listing Branch, Canberra ACT	Written submission

B. Record of Consultation Outcomes

1. Perth, WA: 1.30-3.30pm, 4 Feb & 8.30-9.20am, 5 Feb 2013

Meeting Called By:	Brain Injury Australia and Headwest	**Attendees:**	Denise Butler, Jesse Bruggler, Sophii La Cey, Lisa Wainwright
Facilitators:	Lee-Anne Brenssell and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

The Different Functions of the NDIS

Connecting people to other systems

Question: To make sure that a person who is not eligible for NDIS funding can get the support they need from other systems, what will the Agency need to do?

1.1 The Agency must have a clear understanding of what is available in each location.

1.2 The Agency shouldn't just rely on Commonwealth Carelink and the Carer Respite Care Centre (these used to be separate but are now amalgamated): these have been designed as a 'one-stop shop'. They rely on the sectors to keep their information up to date, rather than going out themselves to collect the information. This means they are quite limited in terms of their knowledge of what's available and they aren't up to date (e.g. they refer people to services that are no longer available because their data-base isn't up to date).

1.3 There should be a central register of not for profit organisations, which include agencies to which people who are not eligible can be referred.

1.4 Whatever data-base is used must somehow be kept up to date, particularly given that providers will be rapidly changing as the NDIS emerges.

1.5 The Rules should mandate that the Commonwealth and other state departments provide data on the organisations that are directly funded by them.

1.6 This data should include (a) ratings on performance, (b) what they can deliver, and (c) whether they offer a service for specific disabilities (similar to 'Urban Spoon').

1.7 The Agency must have a good understanding of specific disabilities if it is to be able to recommend services or support effectively.

1.8 The Rules should say what the Agency will do if a person self-identifies as having a disability, but are not eligible for the NDIS — e.g. what will the process be for referring them, and what kind of support will be available to them?

Funding Community-Based Supports

Question: To make sure that community based supports which are funded by the Agency will assist people with disability to realise their potential and participate in all areas of life, what will the Agency need to do?

1.9 These organisations must meet minimum National Disability Standards.

1.10 If a community-based organisation is currently funded by a state or the Commonwealth, then they will at least have proper governance, etc.

1.11 The most person-centred way of doing this would be to check with the person themselves (e.g. a fortnightly/monthly meeting with them) to see if they are achieving their goals (i.e. realising their potential and participating in all areas of life) by using that community-based organisation.

1.12 The review with the person should be separate to checking with the organisation, but the organisation should have a 'right of reply'. This could be supplemented by an impartial reviewer.

1.13 There will also need to be independent advocates who can voice the perspective of the person with a disability, with a view to their best interest.

Becoming a participant

Age Requirements

Question: Do the Rules need to say exactly what kind of information the Agency needs in order to make sure that people meet the age requirements?

1.14 Yes: there needs to be a mandatory set of criteria by which the Agency can decide that someone meets the age requirement. Otherwise, there will be no way of formally excluding people who are attempting to get in by deception.

1.15 The method should not rely upon self-description, but on formal records (e.g. for refugees, the birth date that was determined by the Red Cross).

1.16 For indigenous persons, documents are not always available. Determining age could be done using the same process as, e.g., the Red Cross or Medicare. But there may need to be an exception to the Rules for Indigenous people in (particularly in remote locations) and refugees. Otherwise, the Agency will have to pay to investigate someone's age medically, which would be financially prohibitive.

Residence Requirements

Question: To sort out who will count as a 'resident' in a launch site, do the Rules need to say that a person must: (1) live there on a date or date in a period of time? (2) have lived there for a certain length of time? (3) continue to live there?

1.16 **Argument for** requiring that a person have lived in the launch site for/at a certain time:

a. It would be helpful if there could be a way of distinguishing (a) between people who have moved **just to become eligible** and (b) people who have moved for other reasons.

b. But this is likely to be too difficult. So either (a) there should be a significant period of time in which they have lived in the site prior to the launch site; or (b) they should have been a resident on or before the date when (i) it was announced that there would be a launch site at that location or when (ii) the launch site commences.

1.17 **Argument against** (this was the consensus view of the consultees)**:**

a. It is very unlikely that someone who needs the additional funding that can be provided by the NDIS could (a) afford to move and/or (b) would want to uproot their family in any case.

b. The NDIS is still too uncertain for people to want to move (although they may wait to see how it goes, and then decide to move).

c. People with ABI are more transient and may well move in order to be eligible — in which case they should be allowed to stay.

d. So it is more important that the Agency manage the borders of the sites, rather than the period of time they were a resident (see response to 2.2b below).

e. In fact, the Agency should ensure that there is scope for new people to be able to enter the sites, and be transitioned into the scheme.

Question: What other 'boundary issues' (between launch and non-launch locations) are likely to arise? What could the Rules say to prevent or sort out these issues?

1.18 The geographical boundaries need to be fixed and strictly maintained, otherwise there will be a 'slippery slope' of expansion.

Continuity of Support

Question: To sort out whether a person can still get the kind of support they were getting before the NDIS started up, what do the Rules need to say about: (1) when they were getting this support? (2) the kind of program that was delivering this support? (3) how long they had been getting this support?

1.19 If they have been getting any kind of support (for however long) prior to the NDIS they should be eligible for the same or better kind of support (e.g. some rehab is only periodic, not continuous — it depends on their needs, which can fluctuate). So it would be difficult for the Rules to define a 'time period' criterion.

1.20 It would be better to assess a person's the current needs.

1.21 If a person has been assessed as needing a disability support service, then this should be continued under the NDIS if the need for that support is still there. For example, if a person is only using a minimal service or an alternative therapy (such as acupuncture to manage pain or weight loss) then we would want to see that they can still get this under an NDIS — so long as the positive outcomes can be evidenced.

Disability Requirements

Question: How should the Agency decide whether a person's impairments are (or are likely to be) permanent?

1.22 The impairments of a person with ABI may be assessed as permanent in some aspects and not in others. For instance, a rehab specialist may determine that a person has the potential to walk again, but may not get a job again because of their cognitive impairments (such as loss of organisational skills).

1.23 It is difficult to determine whether or not — or the extent to which — damage to the brain is permanent until 2-3 years down the track.

1.24 For these reasons:

a. support should be available for those who need immediate help — whether or not the damage has been determined to be permanent (as in the Bill's Early Intervention Requirement);

b. the Disability Requirement should not require that *every* aspect of a person's impairments are permanent.

1.25 It is critical that the criteria for impairment should not be the same as that used in Centrelink — which doesn't take into account particular areas of cognitive impairment. The criteria need to be more sensitive to specific areas of cognitive impairment (e.g. organisational skills, planning, etc.).

Question: How should the Agency decide whether a person's impairments are having a severe impact on their lives: that is, by substantially reducing their (a) functional and psychosocial capacity (e.g. to get around, communicate or take care of themselves); and/or (b) social and economic participation

1.26 The problem with 'severity' is that it can be relative to subjective preference or life-style choices.

1.27 Severity should be determined by the loss of functionality (a) compared to the previous situation the person was in, or (b) what could have been reasonably expected for that person prior to the disability.

1.28 The NDIS should be able to provide a wide range of levels of care, from minimal episodic support to high-end intensive support. In that case, the definition of 'severity' doesn't need to be just limited to the 'high-end'.

1.29 A person should not be considered ineligible when their condition improves (i.e. it is no longer as 'severe' as it was at first).

Question: What do the Rules need to say about people being able to provide the Agency with existing assessments that show they meet the disability requirements?

1.30 Rules should specify the assessment criteria in a transparent and accessible way.

1.31 If someone does not have the assessments required by the Agency, then they should be required to undertake these — and this should be funded by the Agency.

1.32 Existing medical/psych. assessments must be within the 'validity period' of the assessment.

1.33 Functional/support needs assessments should be current (within approx. 2 years for a brain injury).

1.34 Any assessment required must be relevant to the disability.

Question: What can the Rules say to make sure that the Agency's decision is based on an assessment of what a person can do or aspires to do, rather than a diagnosis?

1.35 The Rules should say that: where a diagnosis has not been (or cannot be) obtained, but it is clear from a functional assessment that the person has impairments which are having a 'severe impact' on their life, then they should be eligible.

Early Intervention Requirements

Question: How should the Agency decide whether early intervention is likely: (a) to reduce a person's future need for supports? (b) to slow down or even stop someone from losing the ability to get around, communicate or take care of themselves? (c) to help families and other carers support them over the long term?

1.36 How will the NDIS ensure that health do not discharge people who would have otherwise been provided with rehab on the assumption that the NDIS will pay for 'early intervention'? Answer:

a. The Rules should require that health **complete** whatever they would ordinarily have done before they are discharged.

b. The Agency should assess whether or not this has happened before it 'takes on' the person — and returned to health if it has not. This will be a safety net for those who have been incorrectly dealt with or discharged too early.

1.37 Many people with ABI will not be aware that they are eligible for NDIS support after discharge from rehab.. So, the Rules should mandate that they are recommended to or referred by health to the NDIS for an assessment upon discharge from rehab.

1.38 The answers to the 3 questions above are largely up to rehab. So we need to ask rehab specialists to provide the NDIS Taskforce with a set of criteria by which the Agency can determine which 'early intervention' treatments are most likely to benefit people with ABI.

1.39 People with ABI should not be excluded from early intervention treatment (rehab) on the grounds of prior drug and alcohol use.

Question: What will the Agency need to look for in order to decide whether using a new kind of early intervention will offer the best outcome for a person with disability — while also making sure that money isn't wasted?

1.40 If (a) the provider has met the standard range of quality assurances, and (b) the person with a disability chooses to keep going with a new intervention, then this is not 'money wasted'.

Question: How will the Agency know when there is enough evidence to be reasonably confident that an early intervention is likely to result in the benefits listed above?

1.41 There should be a different benchmark for the amount of evidence required for early intervention, compared to normal treatments.

1.42 The evidence in favour of using a new intervention should include:

a. the person's own perspective on how successful the intervention has been, in terms of meeting their goals;

b. the fact that there is no evidence that an intervention is NOT likely to result in these benefits.

Participants' Plans

Reasonable and Necessary Supports

Question: How will the Agency work out which supports are (and are **not**) reasonable and necessary?

1.43 This would have to be justified for each individual on a case-by-case basis.

1.44 The Agency has to be clear about what else is available in that community – i.e. that the NDIS is not replacing what they would ordinarily access.

1.45 Both the Agency and the individual would need to agree on what is reasonable and necessary — taking account of budgetary limitations (e.g. identifying a list of possible supports from which the person can then choose).

1.46 An individual's capacity to perform an activity on their own does not always mean that support for that activity shouldn't be provided. For example, they might feel that the time or energy it would take to perform that activity themselves would prevent them from engaging in other activities that would enable them to achieve goals that are more important to them (e.g. staying in education or employment). So in cases such as this, if an individual decides that they need support for a particular activity — even if they *could* do it themselves — then that support should be available to them.

Management of Plans

Question: How will the Agency work out whether it would be an unreasonable risk to a person if they managed (some of all) of their own funding?

1.47 The Agency should look at their history and determine how they have managed their finances previously (e.g. are they in a substantial amount of debt?).

1.48 The Agency should make sure that the person will not be seen as a 'target' because they now have money attached to them.

1.49 The plan needs to be well monitored to make sure that the plan is being delivered. Reviews are critical.

Question: What are some things in a participant's plan that must not be managed by *any* participant?

1.50 Where there are issues around safety — e.g. the participant should not be able to cancel or change services that are mandatory for them (even if they don't want them).

Reviewing a Support Plan

Question: What kind of changes (if any) can a person make to their support arrangements without needing to have a review of their plan?

1.51 Changes to service provider, so long as (a) they meet relevant quality assurance standards or they are registered by the Agency; and (b) the person has not been pressured or manipulated by the new service provider into switching to them.

1.52 They can change how or when a support is delivered so long as it meets the broad goals of the support plan.

Other Matters

Supporting decision-making

Question: How should the Agency decide what kind of person should (or should not) be appointed as a nominee?

1.53 There should be some investigation into prior family disputes (e.g. where there has been a fight over money or assets).

1.54 We recommend a similar process to the OPA, in terms of appointing guardians.

1.55 The Agency should look into the history of the nominee – e.g. prior charges of fraud.

1.56 The Agency should take into account the sustainability of the nominee.

1.57 They should be someone who is well known to (and have a strong, long-term and stable link to) the person with disability.

1.58 They should have a strong enough relationship with the person to know what they might actually want. For example, family members can sometimes be biased in their decision-making: focusing on their own needs and worries, rather than the best interests of the person.

Question: What will the Rules need to say about how a nominee can show that they understand the participant's wishes, goals and life aspirations?

1.59 There could be a strictly binding written agreement between the nominee and the person that reflects (a) what the participant wants, their goals and aspirations and (b) what the nominee will do to ensure that these are taken into account.

1.60 The nominee needs to be supportive of and understand the participant's support plan, rather than determining what their goals and supports should be.

1.61 There should be an independent advocate that can protect the interests of the participant.

1.62 The nominee should be able to show that they can separate their own personal feelings from what the participant wants. This is particularly important where the nominee is a parent of the participant. This could be demonstrated by a regular monitoring and review process.

1.63 Get the nominee and the participant to create two separate lists of what they each think are the goals and aspirations for the participant — and then compare the two to test for consistency.

Question: How can the Agency tell that the decisions of a nominee are reasonably those the person would have made if they had the capacity to do so?

1.64 Make sure that the Agency is not only talking to the nominee, but also to the person's wider support network (family group, friends, etc.).

1.65 The decisions would have to reflect the specific background, age, gender, ethnicity, culture, religion etc. (e.g. if you are an adult, then decisions should reflect the fact that you would not ordinarily live at home with your parents; or in a nursing home if you are still a young adult, etc.)

1.66 The Agency should monitor how the client is progressing — e.g. have they gone backwards in their rehabilitation, has their mood changed, have they become depressed, are they 'lashing out'?

1.67 For people with ABI, they will have had a 'past life'. So this can be taken into account when deciding what the person 'would have done'. But the nominee will need to have access to or know a great deal about this 'past life' in some way. This could be done by including parents in the decision-making process (if they are not a nominee).

Question: What will the Agency need to put in place to make sure that the nominee arrangements can change?

1.68 A mandatory review after a certain amount of time — e.g. an initial review half way through the planned appointment.

1.69 If anyone (including the participant) can show that the nominee is not acting in the best interests of the participant, then they should be able to contact the Agency and request a review of the nominee arrangement.

1.70 If the sustainability of the nominee is in question (e.g. they are sick or are planning to move away), then a review should automatically be called.

Question: Nominees need to support a participant's decision making personally and give appropriate weight to their views. What other things will nominees need to do?

1.71 It depends on who is managing the funding. If it is the nominee, then there would need to be additional checks and balances (audits, accountability measures, etc.). If the participant, Agency or PMP is managing the funds, then it would be helpful if the nominee had some knowledge of expenditure to safeguard the spending.

1.72 The nominee could assess if there are any unnecessary risks (abuse and neglect) in the participant's life (e.g. from care providers, friends, etc.).

1.73 The nominee should not be given too much to do, otherwise that will dilute the extent to which the participant has control and choice.

Question: Do the Rules need to say that the appointment of nominees are for a fixed period? Or would it be better if the appointment was reviewed on a regular basis to make sure the person with disability was satisfied with their nominee?

1.74 The review would be better. If someone is working well as a nominee, then this would enable them to continue without the hassle of a re-appointment.

1.75 If there's a fixed appointment, then reviews are less likely to occur regularly.

1.76 Reviews of a nominee's role should set goals for them that are reasonable to expect them to achieve, linked to the support plan.

Question: What can the Agency do to make sure that the nominee arrangements continue to build the decision-making capacity of people with a disability?

1.77 The nominee must consistently use person-centred approaches — e.g. they should not by-pass the participant at any stage in the decision-making process (e.g. not informing them of reviews).

1.78 To show that the nominee is doing this, the Agency would need to request evidence of regular contact between the nominee and the participant.

1.79 Expectations of the extent to which a person's decision-making capacity can 'improve' must be both individualised and realistic.

1.80 Decision-making capacity should be assessed in a very specific, fine-tuned way. For example, someone can be capable of choosing their food, but not whether they should purchase a house. There shouldn't be a 'blanket' assessment that a participant does not have the capacity to decide for themselves *in any respect*.

Compensation

Question: What do the Rules need to say about how compensation payments for care and support are treated in working out how much care and support should be provided by the NDIS?

1.81 If any preclusion period is calculated it should be based upon the dollar figure after they have paid back any outstanding amounts from any health departments or centerlink.

2. Perth, WA: 9.30-11.30am, 5 Feb 2013

Meeting Called By:	Brain Injury Australia and Headwest	**Attendees:**	Pippa Cebis, Amanda Halfpenny, Janet Wagland, Caroline Watt
Facilitators:	Lee-Anne Brenssell and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Becoming a participant

Disability Requirements

Question: How should the Agency decide whether a person's impairments are (or are likely to be) permanent?

2.1 Use clinical information in the assessment process.

2.2 Must be a professional or standardised assessment covering all disciplines.

2.3 The Agency needs to take into account the variability in ABI over time, so that 'permanence' is not defined in such a way as to exclude variations in intensity, deterioration or improvement.

Question: How should the Agency decide whether a person's impairments are having a severe impact on their lives: that is, by substantially reducing their (a) functional and psychosocial capacity (e.g. to get around, communicate or take care of themselves); and/or (b) social and economic participation?

2.4 Must have formalised assessment processes that cover cognitive (not merely physical) impairments (e.g. Mayo-Portland)

2.5 Draw upon BIA's National Consultation Report on assessments.

2.6 Must be evidence-based, not merely anecdotal.

2.7 Requires talking to a range of people in their lives, not merely the person themselves (esp. for people with ABI).

Question: What do the Rules need to say about people being able to provide the Agency with existing assessments that show they meet the disability requirements?

2.8 If they have existing information that validates their impairments, then these should be accepted by the Agency.

2.9 Whose job will it be to investigate (a) whether a person has the information or medical assessments that the Agency requires, (b) whether these assessments are sufficiently current (and so valid)?

Question: What can the Rules say to make sure that the Agency's decision is based on an assessment of what a person can do or aspires to do, rather than a diagnosis?

2.10 For people with ABI, their diagnosis significantly impacts on what aspirations are realistic or possible (e.g. it may be highly unlikely that a person will ever be able to drive due to their brain injury).

2.11 But the science is inexact: a diagnosis of any particular kind of ABI cannot be taken as predictive of what they can do. Hence, while the diagnosis must be taken into account (so that people are not 'set up to fail'), people with ABI should be supported to reach their current goals and aspirations. In other words, goal setting must be within a realistic framework, whilst not preventing (e.g. de-motivating) people from trying to move beyond current expectations.

2.12 Assessing the relationship between diagnosis and functionality is an 'art', and must involve an inter-disciplinary perspective.

Early Intervention Requirements

Question: How should the Agency decide whether early intervention is likely: (a) to reduce a person's future need for supports? (b) to slow down or even stop someone from losing the ability to get around, communicate or take care of themselves? (c) to help families and other carers support them over the long term?

2.13 Clinical assessments would be required for people with ABI.

2.14 Professionals working in rehab could draw upon their experience of working with people with ABI — although these decisions should be evidence-based.

2.15 The Agency will need to know which experts to contact who can evaluate a particular case against the most current evidence for the effectiveness of a particular early intervention treatment.

2.16 The Agency should support research into early intervention treatments.

2.17 The Agency should monitor the use of early intervention and adjust the use/funding based on outcomes.

2.18 The individual (and/or the family) should take responsibility to (a) engage in the early intervention effectively, and (b) to continue the treatment over the appropriate time span (e.g. rehab can take 2 years). The Agency's assessment of (a) the effectiveness of a treatment and (b) it's continued funding of the treatment for a particular individual (and/or the family) must take this into account.

2.19 However, where an individual (and/or the family) has not engaged effectively in a treatment:

a. there should be provision for follow-up (by a certain time period) by the Agency to see if the situation has changed;

b. the Agency must take into account whether (or the extent to which) a service is using a person-centred approach to engage clients (e.g. if a service is not offering sufficient choice and control, then this may be the reason why the client is resisting engagement). For instance, rather than forcing a client to engage in rehab from day one, a service might offer a 3 day 'trial' in which a person can explore the rehab service, talk to other patients, without any pressure to continue.

2.20 If the intervention can improve a person's capacity to self-care, then (given that this is the most difficult aspect of personal care), that will in itself make the family/carer support more sustainable.

2.21 Incremental improvement is better than none at all. So an early intervention should not be assessed merely on its capacity to result in large-scale improvements.

2.22 If an early intervention can result in less 'outside care' coming into the house (given its intrusiveness), this is likely to make the family's/carer's support more sustainable.

Question: What will the Agency need to look for in order to decide whether using a new kind of early intervention will offer the best outcome for a person with disability — while also making sure that money isn't wasted?

2.23 Conduct a cost-benefit analysis.

Question: How will the Agency know when there is enough evidence to be reasonably confident that an early intervention is likely to result in the benefits listed above?

2.24 Give it a go.

Participants' Plans

Reasonable and Necessary Supports

Question: How will the Agency work out which supports are (and are not) reasonable and necessary?

2.25 A person should not be funded to engage in an activity to which someone without a disability would not ordinarily have access (e.g. building a swimming pool in their backyard, or music lessons, etc.).

2.26 The supports should begin with providing for fundamental needs (ensuring that a person can be showered, dressed, and fed), and then extend the support to other more 'aspirational' goals.

2.27 A person should not be able to exchange funds that are allocated in their plan to support fundamental needs (showering) so that they can meet the more 'aspirational' goals (going to a footy match).

2.28 However, 'fundamental needs' should not be pre-defined, but take into account cultural appropriateness (e.g. Indigenous persons may feel that 'social connection' is a fundamental need).

Registered providers of support

Question: How should the Agency decide whether it will register (or de-register) a provider?

2.29 Any provider of specialised care and support that is funded by the Agency must be registered by the Agency, not merely those providers that are used by a participant who has chosen to have the Agency manage their funding (this wouldn't include, e.g., using the gym or local swimming pool, etc.)

2.30 There should be a list of approved/registered providers held by the Agency.

2.31 The Agency should utilise existing state endorsements for disability support providers, rather than requiring that each organisation 're-apply' for approval with the Agency.

2.32 A provider should be de-registered upon non-compliance against standards (using the usual preliminary processes, with de-registration as a last resort).

Question: How will the Agency make sure providers don't have to go through a lot of red tape, while also making sure that services are delivered to the highest standard?

2.33 The Agency should use an audit process that is directly targeted to what they want to find out, rather than 'blanket' audits.

2.34 If clients are happy with their existing service, they should be able to remain without needing to go through 'red tape processes' (e.g. submitting forms to re-apply for or extend service provision).

2.35 The Agency should respect current and existing services, and relationships between services and their consumers.

Question: What kind of information will the Agency need to collect from registered providers of supports to make sure that people with disability are exercising choice and control over the supports they are getting?

2.36 It is impossible to measure the extent to which any individual is exercising choice and control. There are too many decisions in any day.

2.37 Hence, rather than evaluating individual outcomes, the Agency should focus on the systems or mechanisms that a provider has in place: e.g. (a) the policies and procedures that each provider uses, (b) hiring suitably skilled staff with relevant values, (c) training staff in person-centred approaches, (d) communication systems, (e) face-to-face interviews with staff, etc.. (e.g. the Agency should come out to a provider and ask the staff: 'How do you ensure that your clients are exercising choice and control?').

3. Perth, WA: 1-3pm, 5 Feb 2013

Meeting Called By:	Brain Injury Australia and Headwest	**Attendees:**	Jonine Collins, Anna Gubbay, Malika Jegeasothy (Jegea), Elspeth Kerr, Kate Langdon
Facilitators:	Lee-Anne Brenssell and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Becoming a participant

Early Intervention Requirements

Question: How should the Agency decide whether early intervention is likely: (a) to reduce a person's future need for supports? (b) to slow down or even stop someone from losing the ability to get around, communicate or take care of themselves? (c) to help families and other carers support them over the long term?

3.1 Make sure that their medical and allied health teams are accredited.

3.2 Case-by-case assessment.

3.3 It shouldn't be a service provider who makes this assessment if they will then be benefiting from the engagement (e.g. medical industry providing methadone).

3.4 The person should have on them a comprehensive description of their functionalities. They also need to nominate who should be the keeper of this updated report.

3.5 Every service provider must do a periodic review at set dates, together with an independent assessment team.

3.6 There must be an ABI-specific independent assessment team (outside service provision) that sends a report to the NDIS before the Agency even looks at the funding. This team must have enough expertise to be able to give an immediate, 5 year and 10 year projection regarding their support needs — not merely 6 months. This projection will be subject to changing evidence.

Question: What will the Agency need to look for in order to decide whether using a new kind of early intervention will offer the best outcome for a person with disability — while also making sure that money isn't wasted?

3.7 There should be transparency from the provider in terms of whether they can deliver the service that they claim.

3.8 The assessment of any new early intervention for specific conditions must be evidence-based (i.e. there must be evidence that it results in a positive outcome for a particular condition).

3.9 The Agency should have procedures in place to deal with 'practitioners' who fall short of their claims.

3.10 The Agency should fund research into a new intervention, rather than merely monitoring its outcomes.

Children

Question: What do the Rules need to say about the kind of person who can act on behalf of a child if they are not a parent?

3.11 They need to be a legal guardian. (Can't just be a neighbour).

3.12 The parents need to have given written permission for them to play this role.

3.13 They must have been vetted by child protection (note: this is not sufficient on its own).

3.14 Child protection agencies should not automatically be given this role.

3.15 It may be appropriate to assign an independent advocate to protect the interests of the child.

3.16 In specific (difficult) cases, an ethics multi-disciplinary board — within the Agency — could review applicants and make appointments.

Question: How can the Agency decide when a child under the age of 18 is able (or not able) to make decisions about their supports?

3.17 If they are over 16 and they don't have an intellectual disability or a significant psychiatric condition, then they should be able to make decisions about their supports.

3.18 A child can be involved in making decisions when the parent / carer takes into account their wishes — but they shouldn't be taking ultimate responsibility for decisions.

3.19 There should be 'consumer consultation' for the child.

Question: To ensure that a child or young person under the age of 18 is involved in decisions about the support they receive, what kind of additional supports could be given to (a) that child or young person and to (b) their parent or guardian?

3.20 Preparing children for independence begins at a very early age (4).

3.21 An NDIS advisory group could monitor the child's situation.

3.22 There should be a culture within the NDIS whereby independence is explicitly promoted and fostered.

3.23 The Agency could provide information about future living/vocational options, or linking children and parents to workshops that will educate them about promoting independence and involving children in decision-making.

3.24 There should be a child advocacy/complaints/crisis response team or department in the NDIS. This could also be a role for the LACs.

Question: What do the Rules need to say about the best way to help a child to express their views about the support that they receive?

3.25 The Agency could use technology (audio/video) to capture what a child is saying about what kind of supports they want.

3.26 It is more important that (a) they are safe and (b) there is evidence that their goals are met.

3.27 It is ultimately up to the parent to advocate for (speak on behalf of) the child in relation to their supports (e.g. children have a right to education, it needs to be safe and effective, but we don't base decisions about the kind of education they receive on the child's views).

3.28 There should be a 'transition education package' that helps children to move from paediatric to adult disability services, so that they have realistic expectations and an understanding of how best to use their new capacity to make choices as an adult.

4. Perth, WA: 5-7pm, 5 Feb 2013

Meeting Called By:	Brain Injury Australia and Headwest	**Attendees:**	Jonine Collins, Carol Franklin, Sarah-Jane Griffiths, Brenda Hogg, Ardis Hood, David Hounsome, Dr Shew-Lee Lee, Alicia Mason, Yvonne Patterson
Facilitators:	Lee-Anne Brenssell and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

The Different Functions of the NDIS

Connecting people to other systems

Question: To make sure that a person who is not eligible for NDIS funding can get the support they need from other systems, what will the Agency need to do?

4.1 Not refer to the Commonwealth Care and Respite Centre.

4.2 The Agency needs to ensure that the person actually receives necessary services from other agencies. That is, they should actively ensure that the referral has resulted in a person being connected to a provider. This is particularly important for people with cognitive impairments.

4.3 If the Agency doesn't follow-up, then there must be an advocacy type agency that can help the person to navigate their way through the other systems.

4.4 The referral process must be carefully coordinated, so that the person is connected to the most suitable provider for their needs. This is to avoid situations in which, for instance, a person receives calls from numerous service providers, requiring them to undertake multiple eligibility assessments.

4.5 The time it takes for a referral process to be finalised must be reasonable, taking into account their life circumstances and the personal cost of waiting.

Funding Community-Based Supports

Question: To make sure that community based supports which are funded by the Agency will assist people with disability to realise their potential and participate in all areas of life, what will the Agency need to do?

4.6 One problem is that the definition of 'community based support' is too nebulous to enable an assessment of its efficacy.

4.7 The funding will need to be small, locally managed, immediately available, discretionary, and directed toward meeting an individual's aspirations.

4.8 This kind of support should include small pockets of immediate but temporary funding for the provision of informal care and support (i.e. family members, friends, etc.).

4.9 If the Agency wants to stimulate the community to make sure that community-based supports are available to people with a disability (whether eligible or not), then the Agency would need to be working with the broader community and mainstream agencies at a systemic level to get them more engaged to be responsive to the needs of people with a disability.

Question: What will the Agency need to look for in order to decide whether using a new kind of early intervention will offer the best outcome for a person with disability — while also making sure that money isn't wasted?

4.10 The Agency should fund R&D for innovative rehabilitation treatments ('early interventions') for people with ABI.

Children

Question: What do the Rules need to say about the kind of person who can act on behalf of a child if they are not a parent?

4.11 They must have values and personal attributes that are conducive to ensuring the wellbeing of the child (e.g. compassion and empathy, not manipulative).

4.12 They should have an ongoing, positive relationship with the child — which the child affirms, where appropriate (i.e. assuming that the previous point obtains).

4.13 If no one is appropriate, there should be a fall back position so that decisions in relation to the child's needs can be made. For example:

a. there could be a 'circle of support' around the child, rather than an individual, that commits itself to ensuring that the child's plan is managed affectively, and so on;

b. the Agency could have the capacity to make decisions on behalf of the child as a last resort.

Question: How can the Agency decide when a child under the age of 18 is able (or not able) to make decisions about their supports?

4.14 The Agency will have to make an assessment, drawing on appropriately skilled professionals. These assessments would need to take account of their developmental age, cognitive capacity, the nature of the decision, and so on.

4.15 While a child with an ABI will have cognitive limitations, if (a) the child wants something that is clearly in their best interests, (b) it is clear that they understand the consequences, and (c) there is no evidence that the outcome would be harmful to the child (e.g. having a negative impact on their development or quality of life), then their decision should be respected.

Question: To ensure that a child or young person under the age of 18 is involved in decisions about the support they receive, what kind of additional supports could be given to (a) that child or young person and to (b) their parent or guardian?

4.16 It is not clear from the question whether the Agency intends to (or can) provide or fund this kind of additional support — given that there are mainstream supports of this kind already available (training, education, counselling, etc.).

4.17 Or is the Agency's role only to provide information or make referrals to these mainstream services?

5. Adelaide, SA: 1.30-4.30pm, 7 Feb 2013

Meeting Called By:	Brain Injury Australia and The Brain Injury Network of SA, Inc.	**Attendees:**	Frankie Anderson, Danny Carroll, Judy Clutterbuck, Pat Coidan, Chris Farrand, Alice Graham, Heather Hales, Sue Houston, Ivan Lawton, Nikki Ling, Fiona Macgregor, Mariann McNamara, Lauren Moulds, Amanda Quarrell, Shaneen Renshaw, Peter Rovira, Phil Saunders, Terry Sommerville
Facilitators:	Mariann McNamara and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

The Different Functions of the NDIS

Connecting people to other systems

Question: To make sure that a person who is not eligible for NDIS funding can get the support they need from other systems, what will the Agency need to do?

5.1 The Agency should have some clout over major services, and be able to advocate on behalf of the participant very strongly to make sure they get the services and support that they need.

5.2 The Agency would have to have in depth knowledge of the other services. This is likely to be incremental, over time. They should be open to collecting information from every service.

5.3 There is already a comprehensive list within FaHCSIA on the services that are funded by the government. This will be used by the NDIS.

5.4 There needs to be very clear processes to make sure that people are headed in the right direction.

5.5 The Agency should follow-up on any referrals it makes, and it should provide assistance to ensure that people are connected with a service when a referral is made.

5.6 The Agency needs to establish a relationship with the network of services, but also formal agreements that underpin these relationships (e.g. how they might respond should a referral be made to them).

5.7 There should be oversight over outcomes (positive or negative) by a body that has some clout, so that there can be a response.

5.8 The Agency will need to ensure that it has up to date information on each service, including (a) their current in-take capacity, (b) their eligibility criteria, (c) whether the service in fact remains (given the uncertainty of the transition to an NDIS).

5.9 The consumer should (or would?) have an appeals process.

5.10 It should be made clear that the Agency will (and should) not be the only source of information or referrals for ineligible persons. Mainstream services and NGOs will continue to play this role (of providing information and making referrals), and indeed may be better placed to play this kind of role. The NDIS should recognise that it is part of an existing network.

5.11 The Agency does have a responsibility (e.g. using a kiosk or portal format) to enable people to come back, have conversations, to ensure that their referral to other services is transparent. Those services should be well understood, with advocacy available.

5.12 The Agency should ensure that people with ABI are properly supported, in terms of referrals or accessing information.

5.13 There should be an independent body to which people can take their grievances or complaints so as to make sure they can be resolved.

5.14 If they are deemed ineligible, then they should not necessarily be excluded from making future requests of the Agency to be assessed. This is particularly important for people with ABI, who may lack the impetus or divergent thinking to engage with the scheme. They need to be presented with choices about what is now available to them, rather than a blank 'no'.

Early Intervention Requirements

Question: How should the Agency decide whether early intervention is likely: (a) to reduce a person's future need for supports? (b) to slow down or even stop someone from losing the ability to get around, communicate or take care of themselves? (c) to help families and other carers support them over the long term?

5.15 The Agency would need lots of case studies in order to make this kind of determination.

5.16 This would be determined by diagnosis/assessment. Then there would need to evidence about what treatments are available and reliable.

5.17 The Agency should establish some mechanism to engage agencies that have this expertise (wherever they are).

5.18 There should be a range of recognised 'flags' or symptoms that can ensure that people who may benefit from specific types of early intervention treatments or programs can be readily identified and referred to the appropriate program as early as possible.

5.19 People making these decisions should undergo training specific to ABI that ensure that they understand the benefits of early intervention for people with ABI.

5.20 There should be clarity and standards around the term 'early intervention': for example, the distinction between (a) working with children and (b) intervening soon after diagnosis/trauma.

5.21 There should be disability-specific assessors.

5.22 The Agency should recognise and respect the decisions and diagnoses of experts in the field, and the body of research underpinning this expertise — rather than attempt to make decisions for which they do not have the relevant expertise.

5.23 The Agency should take into account the fact that there will be individuals — particularly in remote locations — who are unable to access early intervention programs. The Agency should seek to address this situation.

5.24 The Agency should recognise well-established pathways to early intervention that exist already, rather than attempting to re-invent or 'take over' the process.

5.25 The Agency should recognise that there will be cases that benefit from a more intensive intervention than other cases.

5.26 Given that virtually all people will benefit from early intervention,

a. the question should really be 'what makes them ineligible for early intervention?' This is particularly true of people with ABI (regardless of a diagnosis of permanence).

b. In addition, families also almost always benefit from early intervention, in the ways specified.

c. So the question should be **what types** of early intervention are required not **whether** it is required.

d. Put another way, the distinction should not be between (a) '**disability** requirements' and (b) '**early intervention** requirements', but rather between (a) **permanent** disability and (b) **non-permanent** disability.

5.27 There should be greater clarity in the Rules in terms of the words "is likely to" (i.e. what kind of evidence will be needed to raise the probability to a sufficient level?)

5.28 A person's level of social and functional impairment should inform the decision about whether early intervention is likely to achieve the benefits listed.

5.29 There should be clarity as to whether early intervention refers to treatment **before** diagnosis and/or **after** diagnosis?

Participants' Plans

Reasonable and Necessary Supports

Question: How will the Agency work out which supports are (and are **not**) reasonable and necessary?

5.30 The Agency should determine by using functional assessments not a generic tool.

5.31 It is better not to define with too much precision what kind of supports satisfy these criteria, so that each individual can be assessed on their own.

5.32 It must be consistent with the principles and objects in the Bill and the UN Convention.

5.33 Questions relating to the possibility of people being 'caught in limbo' between systems:

a. How will crisis situations be funded? Will crisis management be built into each support plan?

b. How will disagreements about which agency/system is responsible for providing a reasonable and necessary support be resolved quickly and without impacting negatively on the care of the person with a disability?

5.34 There will be some disabilities where the conditions for reasonable and necessary are unlikely to be met (e.g. improving social participation for degenerative conditions). So they should be sufficient conditions, rather than necessary.

5.35 It would be better if the condition was 'reasonable **and/or** necessary', given that some supports might be reasonable without being strictly 'necessary' (at least where this term is defined as 'necessary **for survival'**).

5.36 The criteria of 'reasonable and necessary' does seem to place the emphasis on 'control' rather than 'choice'.

5.37 There should be a recognition that supports that improve one's mental well-being can have a significant impact on one's physical well-being.

5.38 A participant should be able to access supports under the NDIS outside Australia (e.g. a child with autism travelling to the UK in order to access a specialist or innovative service not available in Australia, as well as being able to purchase a health program or consultation online that is only available overseas).

5.39 There should be recognition that hobbies — particularly for people with ABI — can result in significant benefits.

Management of Plans

Question: How will the Agency work out whether it would be an unreasonable risk to a person if they managed (some of all) of their own funding? What will the Agency need to **do** and what will it need to **look for** in order to make this decision?

5.40 There should be an appropriate test (e.g. neuropsychological) that assesses a person's capacity (and the sustainability, duration of or changes to that capacity) to make decisions for themselves that are in the best interests of their welfare. This should be included in any review process.

5.41 The Bill (as national legislation) needs to be cognisant of state legislation with respect to public trustees, etc.

5.42 The Agency needs to be careful that it does not focus too much on risk aversion, rather than building the capacity of individuals to choose for themselves.

5.43 The Agency should involve all stakeholders involved in the person's life to ascertain their capacity to self-manage their plan.

5.44 There should be a review that focuses on other measures of stability so as to inform the decision about the person's capacity to self-manage (e.g. history of financial stability, family relationships, etc.).

5.45 If a person is currently under guardianship or a public trustee they should not be automatically considered too at risk to self-manage. There may still be decisions that a person can make in relation to managing their support plan. Hence, there should still be a review undertaken by the Agency, independent of the usual guardianship or public trustee processes of assessment.

5.46 In cases where the individual does not have the capacity to make a decision **about who will manage their plan**, will that decision default to current decision-making arrangement (i.e. the family, legal guardian, etc.)? Or will the Agency be responsible for making this decision by default? If not, who will make the assessment about whether or not, e.g., the family can make this decision?

6. Adelaide, SA: 10am-1pm, 8 Feb 2013

Meeting Called By:	Brain Injury Australia and The Brain Injury Network of SA, Inc.	**Attendees:**	Karen Arthur, Alan Bevan, Anne Bunning, Joanna Goldsworthy, Enrico Grani, Jeff Leunig, Jim Plenderleith, Doreen Schulz, Marcia Stewart, Mary-Anne White, Victoria Zelipski
Facilitators:	Mariann McNamara and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Management of Plans

Question: How will the Agency work out whether it would be an unreasonable risk to a person if they managed (some or all) of their own funding? What will the Agency need to do and what will it need to look for in order to make this decision?

6.1 When they are intellectually incapable of doing it.

6.2 They don't have enough life experience to be able to manage money.

6.3 They might be vulnerable to undue influence.

6.4 If the person has a history of making impulsive inappropriate decisions, then this would be too much of a risk for that person.

6.5 The Agency should not assume that a person is incapable of making ANY kind of decision. They may be capable of making good decisions in some areas and not in others. So they may need assistance in some areas, but not in others.

6.6 If their goals are unrealistic.

6.7 If someone has a history of the misuse of money – e.g. they have been bankrupt or have a criminal conviction.

6.8 In situations where there is conflict in the person's family or informal network about how a plan should be managed.

6.9 If someone does not have the skills to manage their own funding — however, if they have the potential to do so, then the Agency should provide them with training first so that they can manage their own funding.

Question: What are some things in a participant's plan that must not be managed by *any* participant?

6.10 They should not do the review by themselves (i.e. without help from others), and they shouldn't be able to opt out of a review.

Reviewing a Support Plan

Question: What kind of changes (if any) can a person make to their support arrangements without needing to have a review of their plan?

6.11 If they wanted to change their care agency or any provider, as long as you're replacing it with the same kind of agency or provider. For instance, if you are using a service and you are offered an improvement to the service (e.g. because of a medical advance or a change of staff).

6.12 If they have finished using a service.

6.13 If you want to stop something (like physio or assistance), e.g. to have a break from it (e.g. for a fortnight).

6.14 If you need some crisis treatment or intervention, but this is not in your plan and you need it immediately.

6.15 As long as it is consistent with the basic goals or fundamentals in the support plan, then a review should not be necessary.

6.16 There should be a threshold under which you can make changes to the plan (e.g. where it doesn't change the nature of the plan or the budget).

Supporting decision-making

Question: How should the Agency decide what kind of person should (or should not) be appointed as a nominee?

6.17 The person must not be involved in criminal activity.

6.18 The person must be well trained and also has empathy and is concerned with the needs of the person rather than their own ego.

6.19 They should be independent, in the sense that they are not benefiting directly from this role. They should be looking out for what the person wants, not what they want.

6.20 Someone should be able to apply to the guardianship to identify a person who can be appointed as their nominee.

6.21 They should have proven abilities as a decision-maker.

6.22 They should not have obvious emotional or psychiatric impairment that would prevent them from making a rational decision.

6.23 They should be genuinely motivated to do the right thing by the person (i.e. not just doing it for the money — and a view was expressed in the group that nominees should not be paid).

6.24 They would need a good relationship with the person so that they know them well enough to be able to make good decisions on their behalf.

6.25 There was an Office of SA Public Advocates supported decision-making project trial. The outcomes of this trial could be used to inform the criteria for selecting nominees in the Rules.

Question: What will the Rules need to say about how a nominee can show that they understand the participant's wishes, goals and life aspirations?

6.26 That the nominee has a direct relationship with or understanding of the person.

6.27 The Agency should not assume, however, that those who have a direct relationship are automatically able to understand the participant's wishes etc. (e.g. a partner may be overbearing, egoistic, non-empathetic or have problems themselves).

6.28 If the person has been instrumental in making a participant's goals happen, then that would demonstrate that they had an understanding of the participant's wishes etc.

6.29 If the participant doesn't want that person to be a nominee, then that counts as evidence that they are not (or are unlikely to be) understanding.

6.30 If there is evidence that the participant has been talked into, pressured or manipulated by a person into agreeing that they will be their nominee, then that demonstrates that this person does not understand their goals, wishes, etc.

6.31 If the nominated person isn't performing in accordance with what they said they would do. (Questions were raised in the group about how this would be monitored and by whom).

Question: Do the Rules need to say that the appointment of nominees are for a fixed period? Or would it be better if the appointment was reviewed on a regular basis to make sure the person with disability was satisfied with their nominee?

6.32 It should be reviewed on a regular basis.

a. Because with brain injury neuroplasticity takes place within the first 6 months, and so relationships can change, it is crucial that reviews of the nominee arrangement take place bi-annually.

b. You want to make sure that the plans have been put in place, the goals have been met, the services put in place, etc.

c. You want to make sure that the participant is being respected.

d. The nominee might want to change their minds about the arrangement without leaving the participant in the lurch (nominees should have the choice to opt out).

7. Melbourne, VIC: 10.30-12.30pm, 11 Feb 2013

Meeting Called By:	Brain Injury Australia, Brainlink and VCASP	**Attendees:**	Laura Corda, Deborah Farrell, Bronwyn Harding, Rodney Harris, Tyrell Heathcote, Maric Hugg, Maureen Mac Phail, Vanessa Marrama, Julie McConnell, Bronwyn Morkham, Melanie Muir, Marc Paradin, Wayne Pfeiffer, Rhonda Lawson Street, Kerry Stringer, Michael Summers, Nikla Wickremasinghe, Tom Worsnop
Facilitators:	Sharon Strugnell and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

The Different Functions of the NDIS

Connecting people to other systems

Question: To make sure that a person with ABI who is not eligible for NDIS funding can get the support they need from other systems, what will the Agency need to do?

7.1 It needs to develop pro-active relationships with other portfolio areas. e.g. rehab, housing.

7.2 The Agency will need to identify (a) how they know what is available and then (b) which is the best of what is available. They also need to ensure that these other services are financially sustainable.

7.3 They need to draw on resources that are already available and work well for people — e.g. service directories in primary care partnerships, electronic referral services.

7.4 The Agency needs to clarify how those who are not eligible can appeal the decision. Is there an appeals process, for instance?

7.5 The support must be much more than information and referral. They will require support to access services, particularly for people with complex needs or in certain institutional contexts (e.g. within and transitioning out of the prison system, hospitals, etc.). The focus must be the transition process.

7.6 The Agency should build in regulations to prevent discrimination (e.g. ensuring that it is a no-fault system).

7.7 The Agency should ensure that people who — due to the episodic nature of their disability — are not yet ready to engage in the planning process are able to supported. The Agency should contract this work to those with specific expertise.

7.8 There should be an obligation upon the Agency to ensure that a person is not only referred to a service but that a connection is made (e.g. going back to the person to check).

7.9 The Agency should not assume that there is adequate support for people with disability in other systems (e.g. education).

7.10 The Agency should clarify why you are not eligible or included within the scheme.

7.11 The Agency should value, support and fund organisations that (a) are already engaging with people with a disability, and (b) the substantial amount of work that needs to be done in that engagement (i.e. in referring people on, following through, oversight, etc.). This is particularly the case in relation to ABI-specific organisations.

7.12 The Agency should provide some short-term case management or supports to people with significant cognitive deficits, so that they can more effectively navigate their way through the 'other systems'. This kind of support must be specialist and ongoing, given the time it takes to build trust and identify the impact of cognitive deficits.

7.13 The Agency would need to ensure that substantial respite options are available to ensure the quality of life for family and carers — even for those who are not eligible for NDIS funding.

7.14 The Agency should provide general support (information and referral service) to both those who are eligible and those who are not.

7.15 There should be some capacity for discretionary funding, (e.g. when a simple and immediate response by the NDIS would be more effective than a longer-term referral).

7.16 The Agency needs to take account of the lack of (i) general disability services that are sensitive to the needs of people with ABI and (ii) ABI-specific expertise available in (a) remote and rural communities, and (b) for people with ABI in general. In other words, the current capacity to provide information and referrals will be extremely limited in those areas or for those individuals, and so the Agency — working in partnership with state governments — must also be engaged in (i.e. by funding or supporting) a long-term and sustainable capacity-building program in order to address this issue.

7.17 To provide general support, the Agency should have an ongoing developmental responsibility for ensuring that there are system-wide (a) ABI-specific protocols, (b) shared responsibility and (c) best practice for clients with multiple and complex needs who 'sit across' systems (e.g. education, drug and alcohol, mental health, aged care, etc.). (See Multiple and Complex Needs Initiative, VIC and SA).

7.18 The NDIS should have a role in driving a move toward a needs assessment that can decide on eligibility for mainstream disability services. This should be available to every person with disability prior to (and separate from) the eligibility assessment for NDIS-funding, so as to ensure that the NDIS can make appropriate referrals and information and in a more proactive way.

8. Melbourne, VIC: 1.30-3.30pm, 11 Feb 2013

Meeting Called By:	Brain Injury Australia, Brainlink and VCASP	**Attendees:**	Anj Barker, Helen Barker, Helen Caligiuri, Simon Chong, Peta Ferguson, Ray Freda Cole, Debbie Finch, Sally Green, Paul Kefford, Robyn Kefford, Florence Kingsley-Matthews, Lyn Macdonald, Warren Phillips, Dharmendra Prasad, Di Winkler
Facilitators:	Sharon Strugnell and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Management of Plans

Question: How will the Agency work out whether it would be too risky for a person with ABI if they managed (some of all) of their own funding?

8.1 There should be something like the state trustees overseeing the whole process, and people like parents or guardians who can submit in a formal process the view that the person can or cannot manage some part of their plan. Someone would then need to gauge whether that submission is in the best interests of the person.

8.2 If there is evidence that the person would not make a decision about how to spend their money in a way that meets their needs or is in their own best interest, then someone else should make a decision on their behalf.

8.3 The person should be involved in deciding about what they need and who they want it from, but the process of purchasing supports (paying bills) should be done by someone else.

8.4 It would be useful to have a check-list on what supports need to be purchased and bills paid – and this should be monitored by someone.

8.5 This shouldn't be applied to everyone automatically — there should be evidence that this kind of assistance or guidance is needed and wanted (e.g. some guardians are too strict — people should still have a say).

8.6 The system should also allow for the fact that people can change — at a later time, they may be able to manage more parts of their plan.

8.7 The Agency needs to recognise that people's needs change over time, so the way a plan is managed should take this into account — always liaising with and providing information to the person and the care-givers.

8.8 The Agency also needs to recognise that people with ABI can 'present' as able to do more than they can in reality. It can depend on the day (due to the episodic nature of ABI). It cannot be assumed that people with a generalist medical training have sufficient knowledge to be able to assess the cognitive limitations of a person with

ABI. So ongoing specialist assessments need to be involved (e.g. neuropsychologists and OTs).

8.9 There is a concern about people with ABI who live on their own, particularly where (a) their disability is 'invisible' or (b) where they don't speak English well, or (c) where their family don't understand the nature and impact of ABI. They will need an advocate or case-manager to help them to access or navigate the NDIS.

8.10 Reviews for people with ABI need to be face-to-face, because there will be individuals with ABI who can present well on the phone or on the internet, and so a true picture of their situation will not come through. It also gives them an opportunity to look at their living conditions.

8.11 The Agency needs to take into account the fact that, for some people with ABI, their sense of time can make it hard to pay bills on time or meet deadlines (e.g. time can seem to pass very quickly or very slowly).

Other Matters

Supporting decision-making

Question: How should the Agency decide what kind of person should (or should not) be appointed as a nominee for a person with ABI?

8.12 The person with ABI should be asked who they would like to nominate and why (e.g. how well do you know this person? how long have you known them?)

8.13 It can be useful to have an independent party, who is not so emotionally involved and so can make more objective decisions (of course liaising with the person and the family).

8.14 The nominee should have the patience to listen to the person with ABI so that they can find out what they want — rather than just assuming they think they know.

8.15 It would be good to have someone who is able to play the role of a nominee over the long term (particularly since other professionals in the person's life can be very temporary). And you don't want to have a number of people going through your finances and personal details.

8.16 It might be useful to have a 'personality test' for nominees (e.g. ensuring that they are not just doing it to get paid, but are there because they care and want to be doing it).

8.17 They need to be practical, have common sense and a sense of empathy. They should be compatible with the person, perhaps having a 'trial period' to see whether it works for both people.

8.18 There will need to be safeguards like checks (a) for a criminal record, (b) for any personal and professional liabilities, (c) that they are of sound body and mind, and (d) that they understand the obligations of a nominee.

8.19 They need to be reliable, trustworthy, and compassionate. They should be good people, and nonjudgmental (particularly about how the person got their ABI). They should leave the judgments up to the participant.

8.20 If a nominee purchases a support that you are not happy with, can you get your money back? What will happen to your money if the nominee misuses it?

8.21 There will need to be a lot of fail safes to protect people with a disability.

8.22 The nominee must be willing to be assessed for their professionalism and financial competence by the Agency. They will need to be audited too.

8.23 The nominee should be adequately paid to recognise the work they are doing (but there should be a safeguard to make sure they are not just doing it for the money).

9. Launceston, TAS: 1-4pm, 12 Feb 2013

Meeting Called By:	Brain Injury Australia and Brain Injury Association of Tasmania	**Attendees:**	Kim Ackerly, Meagan Barker, Mandy Brown, Adrian Caelli, Stephanie Campion, Lyn Cameron, Janne Cowan, Mandy Curtis, Stephanie Curtis, Theraze Deegan, Chris Demeyer, Kate Frame, Fiona Girkin, Christopher Hill, Cathy Hurst, Neville James, Fay Krushka, P. Mansfield, Maggie McKenzie, Leanne Sanderson, Lisa Shearing, Steve Swenson, Debbie Taylor, Marg Vaessen, Jamie West
Type of Meeting:	Consultation		
Facilitators:	Deb Byrne and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the Consultation Paper on the NDIS Rules, as given by those who attended this consultation meeting.

Becoming a participant

Early Intervention Requirements

Question: What will the Agency need to look for in order to decide whether using a new kind of early intervention will offer the best outcome for a **person with ABI** — while also making sure that money isn't wasted?

9.1 The Agency would need to look at what has already been put in place and what the outcomes of this have been (from both consumer and provider perspectives).

9.2 There should be a clear, consistent, validated and standardised assessment and priority and screening assessment tools by an adequately and comprehensively qualified professional who is trained to use it (this can't be done in a few days or by correspondence).

9.3 The Rules need to provide more clarity on the definition of 'early intervention' — in particular *when* an intervention qualifies as 'early' (e.g. can it be used to *prevent* a stroke?)

9.4 The question about whether an early intervention would produce benefits should take account of the context in which that person is living or a whether there has been a change in context (e.g. moving from hospital to home, a primary carer has left, etc.). In other words, since the context can change (and this may have a significant impact on a person's functionality) it follows that 'early intervention' could occur at several points in a person's life.

9.5 The Agency must look at not only whether early intervention is likely to benefit, but also whether there are sufficient funds or resources to implement that intervention when it will provide the optimum outcome.

9.6 Interventions need to be needs driven not time driven. People shouldn't be ruled out simply because it is 'too late' (i.e. the intervention cannot be categorised as 'early' for that person, for whatever reason).

9.7 The Agency should take into account cases in which there is a traumatic incident (e.g. a fall, a failed suicide, etc.) where the focus is so much on the physical injuries that the cognitive injury is over-looked or not properly identified — and yet early intervention for the cognitive injury would be highly beneficial. Hence, there should be improved education for medical professionals so that early intervention for cognitive impairments can be put in place.

9.8 The Agency should take into account the fact that families of people with ABI are often either not aware of the cognitive limitation or have not yet accepted it (intellectually and/or emotionally) — and so will resist the use of early intervention. For this reason, early intervention should *include* counselling and the provision of information and resources for families and carers (esp. in the transition from hospital to home).

9.9 Given that resources will be variable depending on the location, the Agency should be flexible about the kind of early interventions that might be most beneficial for a particular intervention (e.g. support for swimming may be the optimal treatment, given that a physio is not available in that person's area).

9.10 The Agency should include, as early intervention, providing supports when and as a person needs it. Early intervention doesn't always have to be medically or therapeutically based (e.g. activities that 'normalise' a person with ABI's experience, such as community activities).

9.11 Early intervention needs to be based on evidence-based practice. This needs to be reviewed periodically to ensure that treatments are consistent with the most advanced evidence/research.

9.12 Early intervention should be available at points of critical life changes, environmental changes and cognitive (episodic) changes. For instance, in hospital, moving to a sub-acute ward, transition to home, to work, major life changes (e.g. having a baby), episodes or 'windows of opportunity' in a person's life when an intervention would be most effective for them.

9.13 People with ABI should be involved in the development and planning of interventions (i.e. taking a person-centred approach). It must be meaningful for the person themselves, rather than merely prescribed *for* them by others.

9.14 Interventions should always be appropriate to the needs and interests of the person. So, e.g., an early intervention should not be ongoing if it is no longer meeting the person's needs or if it is no longer meaningful to them.

9.15 The Agency should funding research into new, innovative early interventions (real-time, real-life, qualitative, quantitative research). The onus should be on the Agency to initiate or conduct comprehensive surveys of innovative interventions.

9.16 The Agency should take into account the fact that people with ABI and their families may, over time, come to have expectations about what is and is not possible. Hence, early intervention can be critical as a way of ensuring that the potential of a person

for improvement or recovery can be met — i.e. by avoiding the resistance of the family's or the person's assumptions.

9.17 If the Agency is to avoid crisis-driven, then it should be pro-active about ensuring that people can access the system.

9.18 The Agency should commit to ensuring that the assessors have adequate skills and knowledge required.

9.19 The Agency should ensure that there is equity of support provision between states/territories (e.g. if good outcomes are being achieved elsewhere, then the relevant services or interventions should be made available in every location).

Participants' Plans

Reasonable and Necessary Supports

Question: What **ABI-specific issues** will the Agency need to consider when it is deciding whether or not a support is reasonable and necessary?

9.20 Given it's based on the goals by the participant, it would need to ensure that the goals are realistic — however, even unrealistic goals can be re-defined or broken down into a set of goals that are achievable.

9.21 The Agency will need to work through the goals and objectives of primary caregivers, where these are in conflict with the participant.

9.22 There needs to be an exit strategy and capacity building, so that people do not become more dependent on supports than they need to be.

9.23 To ascertain what supports would be 'reasonable and necessary', the assessment should focus on what a person can do, and then identify the 'gaps'.

9.24 In deciding on supports needed for people with ABI, the Agency should consult with providers working directly with people with ABI and their families, rather than merely rely upon statistics.

9.25 Transition (e.g. between hospital and home) and case-management (ideally not life-long, but for a period of time) are the two biggest gaps in terms of the supports currently available to people with ABI.

9.26 Cognitive, social and emotional rehabilitation (not just physical) is a necessary support for people with ABI.

Other Matters

Children

Question: What do the Rules need to say about the kind of person who can act on behalf of a **child with ABI** if they are not a parent?

9.27 The Rules should be consistent with existing legislation and best practice relating to the question of persons who represent children.

9.28 The Rules should recognise the difference between what is ideal for a child and when a child is at risk.

9.29 There should be an external (non-Agency) person who can advocate for the child — but this role must be funded, otherwise cases are likely to end up with Child Protection.

9.30 Where a child has an ABI, the Agency should provide (or ensure that there is) independent oversight — but only in cases where there is evidence of deprivation, neglect, risk or making decisions against the best interests of the child. But in doing so, the Agency will need to work with and refer to existing services. For example: (a) only Child Protection can decide that a parent's actions are detrimental to the child; (b) 'Relationships Australia', 'Reconnect', etc. can be made available where there is family conflict.

Question: How can the Agency decide when **a child with ABI** under the age of 18 is able (or not able) to make decisions about their supports?

9.31 The Agency should draw on existing criteria for making consents. The wheel should not be re-invented.

10. Launceston, TAS: 10am-1pm, 13 Feb 2013

Meeting Called By:	Brain Injury Australia, Brain Injury Association of Tasmania	**Attendees:**	John Barwick, Kerry Barwick, Ashling Buchanan, Sue Linnett, Ian Roden, Kim Roden
Facilitators:	Deb Byrne and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Management of Plans

Question: How will the Agency work out whether it would be too risky for a person with ABI to manage (some of all) of their own funding?

10.1 A person with ABI who cannot manage their own funding (e.g. because they are in hospital or in a coma), then a guardian could help with managing the funding.

10.2 If the person with the ABI feel that they can manage and would like to try, then there could be a trial period (e.g. 3 months), and if they can show that they have all the receipts for what they've purchased, then this will show that they can manage their funding. But if the money is spent but hasn't been used on the service they said they needed (and they don't have the receipts), then they will need to look for an alternative.

10.3 The first step should be for the Agency to provide caring and sensitive negotiation as to what kind of assistance the person needs in order to manage (some or all) of their plan. The Agency should not simply take away control completely if the trial period isn't entirely successful.

10.4 If the person with ABI is properly assessed — in consultation with family members or carers — as not being capable of managing their plan (e.g. due to memory, lack of insight into their cognitive limitations or organisation issues).

10.5 Where there is evidence from that someone is suffering from a severe drug or gambling addiction.

Other Matters

Supporting decision-making

Question: How should the Agency decide what kind of person should (or should not) be appointed as a nominee for a person with ABI?

10.6 Set up two separate appointments with the person with ABI and the potential nominee. In these meetings they can assess whether the person with ABI wants that person as their nominee.

10.7 This meeting [see 10.6] should also involve others who know the person with ABI well, like their doctor.

10.8 The nominee should have a police check first, to make sure they are safe and trustworthy.

10.9 The nominee shouldn't be someone who has a legal proceeding against them (e.g. they have a violence order against them).

10.10 The Agency should make sure there is no conflict of interest between the nominee and what they will be doing (e.g. where a family member is motivated by their own interests when they buy services or use the money in a certain way).

Question: What will the Rules need to say about how a nominee can show that they understand the wishes, goals and life aspirations of a person with ABI?

10.11 Make sure that there are regular meetings with both the nominee the person with ABI so that they are talking to each other about what the person wants.

10.12 The Agency should have two separate meetings with the nominee and the person with ABI on a regular basis and (a) ask each of them what the wishes, goals and aspirations of the person with ABI are — and then (b) compare both versions with each other.

10.13 The Agency will need to take into account the fact that the nominee may know what the person with ABI wants, but also recognise that some of these goals will need to be redefined or adapted so that they are realistic. For example, the person with an ABI might be very keen to get a license so that they can be independent, but the nominee knows that that person will not, at this time, be able to get a licence — so the nominee has instead arranged for the person to have access to independent transport.

10.14 The Agency shouldn't assume that family members have the best interests of the person with ABI at heart. There should be ongoing reviews of the nominee arrangement to make sure that the nominee is making sure that the person with ABI is receiving the supports that they need.

10.15 If the person with ABI cannot make a decision about who should be the nominee for themselves, then there should be a group of people (a 'circle of support') that can make sure that the nominee is the right person and monitor the arrangement to make sure that their needs are met. Then the responsibility is not left entirely on one person. This circle of support could be made up of at least 3 people, and might include:

a. a psychologist,

b. an occupational therapist,

c. a social worker,

d. an independent advocate (depending on the quality of the person or organisation),

e. the doctor of the person,

f. family member(s) or friend(s) who love and care for the person,

g. someone who the person knows from an existing support organisation — although conflict of interest issues will need to be addressed (e.g. they can't be the only person making the decision about who should be the nominee), etc..

10.16 If professionals are invited or expected to participate in the 'circle of support', then the Agency will need to fund their attendance.

10.17 Non-professionals or carers should also be supported (either financially or in other ways) so that they can take part in the 'circle of support' (e.g. providing transport or looking after children while they are there).

Question: How can the Agency tell that the decisions of a nominee are those the person with ABI would have made if they had the capacity to do so?

10.18 If the person with ABI hasn't got the capacity to communicate, this is really hard. But if they can communicate, then they can voice their opinions in the independent interview.

10.19 The Agency could tell by how they are progressing, whether they are managing their day to day life as well as they can, their health is not going backward (physically, emotionally, etc.). Even if they don't have the capacity to communicate in words, there are other signs that can show that someone's wishes are not being respected (e.g. they are resisting food, body language, they are constantly angry or depressed etc.).

10.20 The circle of support could offer an objective view of the person's situation and their responses — since the nominee may be too close to the person or the situation, and so either cannot see what is happening or they may see it but don't know what to do about it.

Question: What will the Agency need to put in place to make sure that a person with ABI's nominee arrangements can change?

10.21 The Agency should have a regular assessment to see whether or not the arrangement is still working.

10.22 The person with ABI should be able to request that the arrangement changes. Or if they are unable to do so, then the circle of support could request this. Or the nominee could request a change.

10.23 The Agency would need to take into account the fact that a person with ABI can be impulsive, and so may request a change of nominee on the spur of the moment. So

a. there has to be some evidence that the request has been thought through and can be justified or explained by the person;

b. there should also be a 'cooling off' period, and if they still feel the same way, then the request can go through;

c. if there is a circle of support they should be consulted.

10.24 The Agency would need to ensure that it doesn't automatically take the side of the participant against a nominee. There should be a process of negotiation, to guard against situations where the nominee is being falsely accused or manipulated by the participant.

10.25 The Agency should consider the use of a disability-specific 'professional nominee service', for (a) those who do not want a family member, friend or carer to play the role of a nominee and (b) where there are no suitable plan management providers available.

Question: What can the Agency do to make sure that the nominee arrangements continue to build the decision-making capacity of a person with an ABI?

10.26 Someone who has a good knowledge of ABI should speak to and educate the nominee about ABI.

10.27 The Agency should support the nominee: for instance, they should be encouraged and reminded to 'let go' of areas over which they have previously had control — even just for trial periods to see how the participant goes (but these trials should be ongoing, even when it doesn't work first time so as to allow for the possibility of future improvements).

10.28 The review of a person's support plan should identify whether the person's decision-making capacity has increased (since the last review).

10.29 For the nominee to be reappointed, they would need to show what steps they have taken to ensure that the participant's decision-making capacity has increased.

a. This could be done by (i) the participant writing down (perhaps using a tick-box survey) or explaining what they can now do, and (ii) the nominee doing the same, and then (iii) comparing the two versions. If there is a disparity in some areas, then the Agency can encourage and support the nominee to work more on 'letting go' of their control over these areas (e.g. doing trials).

b. The nominee could also show that they have attended a course which aims to teach them how to increase their decision-making capacity.

11. Hobart, TAS: 10am-1pm, 14 Feb 2013

Meeting Called By:	Brain Injury Australia, Brain Injury Association of Tasmania	**Attendees:**	Paul Allen, Leigh Castles, Nicholas Cooper, Rodney Dale, Lesley Field, Lynn Francis, Roger Genge, Robert Hillier, Sue Hodgson, Diane Lynd, Stuart Maughan, Brett McCallum, Darren Osborn, Belinda Payne, Anthony Rodman, Craig E Scott, Julie Smith, Rebecca Tedeschi, Leanne Whitney, Chantal Wright
Facilitators:	Deb Byrne and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports do people with ABI need? (2) Why?

11.1 (1) Cab fares – to go to pay bills, to go to employment, etc.. (2) I need this because catching a bus is too hard.

11.2 (1) They need support to access family and friends on a regular basis. (2) Because it is important to them emotionally, and to maintain relationships.

11.3 (1) Assistance to access community (e.g. shopping, getting to the metro). (2) Because previously it was possible, but now it is not as possible because of the disability (i.e. I need assistance to direct me when I am shopping – e.g. to make sure that I am able to choose from amongst a variety of products and decide).

11.4 (1) Having a productive social life and being able to contribute to community. (2) I can get there on my own but I have lost the motivation to get out and do things socially. I become too tired, and feel that I have to explain certain problems or mistakes I am making — and this takes away from my enjoyment.

11.5 (1) I as a member of society can go and make choices and do what I like. People with a disability should be supported to be able to have the same access to the community and to have a normal life of their choice. (2) Because no matter what disability a person has, they have the right to this same access.

11.6 (1) No person with ABI is the same. So their level of support differs. But one of the biggest problems is money handling. So to make sure that they are as independent as possible, they need someone to help them and guide them. (2) It depends on their level of ABI. For some people, it could be (a) for every day routines of life; for others, it could be (b) just on days or times when they are going out into the community and need to purchase things.

11.7 (1) Day-to-day support for living, a home to live in, with toilet and shower facilities, etc.. (2) These are necessary and reasonable all the time, every day due to my physical constraints.

11.8 (1) I need support with caring for myself, going shopping, etc. (2) Because I don't want to impose on my family or be a burden on them — they have family of their own, or are living somewhere else, or the support that they can provide is too limited.

11.9 (1) I need to access community services (like Headway). (2) But the cost of doing this is adding to my financial burden, given that I am buying a house and caring for my daughter. And I need to access this service because it is helping me to rehabilitate myself.

11.10 (1) I have support to go sailing. (2) Because I couldn't sail if I didn't have this support (because I don't have balance anymore). And sailing is my life: I have a group of friends who also sail who have stuck with me and so this is part of my social life. And my family are not close, and have not taken an interest in helping me.

11.11 (1) When I got my head injury, all the friends that I had couldn't cope seeing a different me — someone who had changed 180 degrees, to a completely different person. They would stick by me for a while, but it was too hard to do this over time — and so they disappeared. At the moment, my mother looks after me. She is around 70 years old. I am also living in a nursing home. I have problems handling money, but my mother has organised a 'book-keeping' system which helps me to manage my money carefully. In terms of additional support, I need hydrotherapy and the gym. (2) I need this to keep me active and for my physical rehabilitation. If this doesn't happen, I can experience severe pain in my neck and shoulders. This is an indirect result of my injury. And it is likely to get worse as I get older. But I don't have the funds to pay for this.

11.12 (1) ABI isolates and segregates people from society. They lose existing social networks and find it difficult to establish new networks. This can result in the development of very negative behaviours and patterns of thought — resulting in depression, criminality, drug and alcohol issues. This is because their capacity to make these connections is reduced by, for example, their cognitive limitations, communication limitations, etc.. (2) So they need supports there to help them maintain and build new relationships — e.g. by having someone who is a 'Coordinator of Social Networks' and/or a 'Circle of Support'. The benefits of this include improved mental health, self-confidence, improved ability to make friends, etc.. In other words, funded support should not be limited to physical issues, but include social and emotional support.

11.13 (1) I live in my own home, and rent the front property out to Headway. I receive 20 hours of support, and my mum plays an active role in helping to pay bills, etc.. But I do my own shopping, and I live fairly independently. (2) Because there was a big cost-benefit in moving out of a residential facility into my own home, but I couldn't have done this without funded support. And I am now far more independent than I used to be.

11.14 (1) (a) I have needed a 'life-style support person' to go back to education — someone who was suitably (i.e. academically) qualified to be able to support me (e.g. who knew enough about the topic). (b) I don't have support to help me with difficult family members — e.g. when (i) they have a mental illness themselves or (ii) they don't understand the results of ABI, or (iii) they do understand the impact of ABI and use it to their advantage. (c) I am aiming to use my degree to start up a business that can help other people with a disability (i.e. a paraplegic employment service to produce niche furniture). But I have no experience in starting a business from scratch. And business planning is not one of my interests. I want to focus on the creative side, not the paperwork. (2) (a-c) Because I want a role. I want to feel like I am achieving something in life. I need to (and I have a right to) have a purpose and to feel valued in life. Getting support and funding from the NDIS to help me start up and run this kind of 'social enterprise' would bring these benefits — as well as increase my social network. (b) With regard to difficult family members, it is devastating to me that I do not have better relationships and support to deal with them.

11.15 (1) Normally, I am fine. But (a) there are episodes when I experience the impact of my ABI, and need personal care 24/7 during these times (e.g. being showered, taken to the toilet, brushing my teeth). (b) During these episodes I cannot drive, and taking a bus from where I live is impossible. So I need to catch cabs. However, the system doesn't recognise the episodic nature of my ABI – so they will take away my licence for 6-12 months because I can't drive during these episodes, but I can't get cab vouchers because I will be getting my licence in 6-12 months time (even though my condition is permanent). So I have to pay taxis myself, which is $30 a day. (2) The system needs to recognise that my condition is permanent, but episodic — and it needs to provide (a) funded support for basic every day living, because my parents are now too old and physically incapable of caring for me; and (b) I need funding for taxis during these episodes (and afterwards), because I cannot afford to pay for taxis. And without transport I will be unable (i) to get out into the community, (ii) to get to work and (iii) to access support services, and so I will become even more isolated, introverted and I will become far less independent.

11.16 (1) The NDIS should look at encouraging people with ABI to explore other ways of getting support — i.e. not just depending on disability services, but also using mainstream services (e.g. by helping a person to join a knitting group in the community, rather than a knitting group that is only for people with a disability). It should also focus not just on deficits and maintenance, but on what people can do, and the potential they have for increasing their independence and quality of life. (2) Because the person can reduce their dependency on the NDIS (and so their disability funding), as well as helping them to increase their social networks in the community.

12. Hobart, TAS: 9am-12pm, 15 Feb 2013

Meeting Called By:	Brain Injury Australia and Brain Injury Association of Tasmania	**Attendees:**	Louise Arnold, Natan Ayele, Jenny Buckingham, Michael Ellis, Dan English, Mary Evans, Tracey Dean, Connie Digolis, Debra Drew, Paul Duncombe, Alice Fitzpatrick, Jennie Gamble, Mary Gays, Wendy Groot, Jason Hall, Robyn Hamilton-Smith, Janine Martin, Bonnie Matthews, Paul Miltenburg, Robyn Montgomery, Darren Osborn, Kerry Pearce, Daniella Polita, Natalie Rose, Caitlin Saunders, Clive Skilbeck, Francis Touber, Jackie Witt, Leanne Whitney
Facilitators:	Deb Byrne and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports are 'reasonable and necessary' for people with ABI? (2) Why?

12.1 (1) Personal care. (2) Some of our clients don't see this as a priority – they choose instead to spend their money on the nice things in life.

12.2 (1) Social inclusion supports. (2) When paying their bills, there is not much left for those things.

12.3 (1) Recognition within Centerlink that people with ABI don't always understand correspondence, return dates and forms, forgetting appointments, etc. and (2) so are cut off — simply because they don't know how to navigate the system (and are often falsely accused of being resistant or 'non-compliant').

12.4 (1) Equipment (e.g. communication device, like a mobile or an iPad). (2) This enables them to access all aspects of social inclusion experiences (e.g. helps them to open their door or blinds.

12.5 (1) Access to Botox (2) for people who have issues with tight ligaments and limbs..

12.6 (1) Wheelchairs (OT assessed) (2) without which they have limited access to the community.

12.7 (1) Access to services that can (a) maintain and adjust equipment, (b) ensure that (it is mandatory that) the participant receives equipment that is safe and appropriate to their needs, and (c) provide training on how to use the equipment, including safety issues. (2) In order to ensure (a) sustainability of the equipment, (b) to prevent any deterioration of their health and well-being (injuries, loss of function), and (c) to prevent injury to the person pushing/operating the equipment.

12.8 (1) Counselling relationship and mentoring services, (2) to help with grief, anxiety, relationship breakdown with children, partners and parents.

12.9 (1) Support with articulating goals and objectives, (2) without which they will find it very difficult to articulate what they need and want.

12.10 (1) Support and education in making decisions (e.g. utilising a decision-making model, or problem setting approach, within the limits of their abilities, with a suitably trained facilitator), (2) so as to build and sustain their capacity to make decisions for themselves.

12.11 (1) Carers need to be educated about what is realistic for a person with ABI, (2) so that they can (a) gain a greater understanding of the cognitive limitations and (b) help to reduce their anxiety.

12.12 (1) Carers may also have cognitive limitations, and so need support themselves (2) in order to provide better support (i.e. better decision-making, more realistic expectations) when caring for the person with ABI.

12.13 (1) They often require expert feeding and feeding equipment (by a dietician), (2) because (a) they may not tolerate a varied diet, and — if feeding is not done effectively, it will have a considerable impact on their quality of life (e.g. they could experience aspiration, which can lead to infections; and if the client is a child, their consideration about their development is crucial); and (b) nutritional intake is difficult given their feeding difficulties (e.g. swallowing problems).

12.14 (1) There needs to be future planning, (2) because the needs are going to constantly change over time.

12.15 (1) The NDIS should ensure that, where required to support a client effectively, it is mandatory for the health system to provide an integrated health check (2) to ensure the maintenance of their overall health and well being over the long term.

12.16 (1) Carers need to be educated about nutrition, (2) so that they help to prevent chronic disease development and maintain patient safety (e.g. preventing swallow issues).

12.17 (1) Agency staff need to be trained in ABI. (2) This is because this condition is so broad and complicated (i.e. it is impossible to categorise cognitive disability in the same way that we do physical disability) that any assessment of support needs to be individualised (each person with ABI will be different).

12.18 (1) The Agency needs to ensure that people with ABI have their assessments reviewed on a regular basis (e.g. as part of a yearly health check), (2) because their condition will inevitably change over time, and to prevent future health issues.

12.19 (1) Access to rehabilitation in an appropriate setting, proper assessment (i.e. cognitive, functional, psychosocial), and immediate support for both the person with ABI and their family, (2) because this will have (a) a much better outcome for a person with ABI and (b) be more cost-effective in the long run (e.g. sustainability of family relationships is more likely).

12.20 (1) People need supports for the indirect consequences of their ABI (e.g. physical pain, deterioration), (2) because this will have a direct impact on their well-being.

12.21 (1) The kind of supports used should be flexible, rather than too fixed — looking for naturally occurring networks, rather than paid support; (2) so as to allow for creative, more effective, socially inclusive and cost-beneficial options (e.g. the Agency provides funds to enable the participant to buy a season ticket for a game for a 'suitably qualified' friend, rather than paying a support worker per hour).

12.22 (1) Delivery of consumables, like peg feeding, suppositories, gloves, catheters, medications, etc.. (2) These are procedures that cannot be done by someone who isn't credentialed; and it is expensive for RNs or credentialed people to come out and provide this. There are also problems of availability outside normal hours.

12.23 (1) There should be (a) ongoing training for carers to ensure that they can adjust to changing conditions in the person of ABI; and (b) training provided to people with ABI so that they can learn that it is good to move (e.g. this is required because of (i) the high propensity of type 2 diabetes in the population, (ii) a statistically low level of exercise among Tasmanians in general, plus (iii) the impact of disability) — (2) because (a) neither of which will be available without funding, particularly where the family is not involved or interested in providing this kind of support; (b) exercise can significantly enhance the motivation and emotional well being of a person with ABI; (c) without proper supervision, a person with ABI who undertakes exercise may experience injuries (e.g. because a person with ABI used the wrong shoes, they needed amputation, which could have been avoided if a podiatrist had been involved).

12.24 (1) The Agency should ensure that all health professional are educated to encourage people with a disability to exercise or know where to send them, (2) to ensure maintenance of health and well being.

12.25 (1) Some equipment is 'mainstream', (2) but would be too expensive for most people with a disability and yet are (a) a cheaper option than, e.g. specialised communication devices, (b) universally available, (c) more socially acceptable.

12.26 (1) Access to transport, (2) because otherwise they won't have access to the services.

12.27 (1) The 'leaders for tomorrow' program (2) because it was consistent with my aspirations, it was intellectually stimulating, and it enhanced my participation in all the boards and committees that I sit on.

Question: What will the Agency need to do to make sure that the supports it decides to fund are reasonable and necessary (for each person with ABI)?

12.28 Information should be shared (in a protected way – e.g. using E.health) so that the Agency can collect the information required.

12.29 It needs to support its staff in making sure that they have the most up to date information or know where it might be (i.e. filtering the information).

12.30 The Agency needs to take advice from and negotiate with people who are in the best position to judge the position of any individual, including the individual themselves.

12.31 The culture of the disability industry should change in the sense of empowering the person with ABI to become more independent, rather than support staff putting as a priority the protection of their own jobs/hours (taking into account the fact that some people with ABI will prefer or have previously been encouraged to remain dependent, and some families may not want to change current arrangements).

12.32 The Agency should ensure that there are an appropriate number of support staff in any local area who are properly educated about brain injury so that they do not, e.g. misunderstand certain behaviours (e.g. a few workers are trained, but they don't end up being the support worker for a person with ABI).

12.33 The Agency needs to be responsive to change, conducting quick reviews, so as to ensure that the right supports are provided when and as needed.

12.34 The Agency needs to put in place preventative health measures rather than waiting for a person with disability to develop problems. This will be far more cost-effective and be far more likely to maintain a person's quality of life and independence.

12.35 The Agency needs to have (a) a good assessment process and (b) ongoing accountability in place to ensure that the person who is in control of the funds has the appropriate ability to allocate and manage the funds.

12.36 Families need a consistent support person (e.g. the PMP) who knows the system and the services available.

12.37 The Agency should ensure that people with ABI and their families have the information they need to access to evidence-based therapies.

13. Brisbane, QLD: 9.20-11.20am, 18 Feb 2013

Meeting Called By:	Brain Injury Australia and Synapse	**Attendees:**	Alice Corcoran, Marilyn Ginn, Maria Hoogstrate, Donna Sanderson
Facilitators:	Alice Corcoran and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports are 'reasonable and necessary' for people with ABI? (2) Why?

13.1 (1) I need support with managing money and paying bills, (2) because (a) if I don't pay it on time I accrue costs, and (b) I can't manage it on my own.

13.2 (1) I would like support to build my capacity to enable me to manage more and more of my money and other administrative tasks, (2) (a) to find out what my capabilities are, (b) to develop and expand the range of my skills and abilities, and (c) to push the industry to develop more creative, innovation solutions.

13.3 (1) I'd like to have support to enable me to go back to school or TAFE. (2) Due to issues with organisation skills and memory loss, I am scared that I won't be able to cope with (a) learning in the classroom, (b) getting the assignments in on time, and so on. If I don't cope I will go into meltdown, and everything will come to a stop.

13.4 (1) I need funded specialist support with returning to driving, (2) because I will need a driving school instructor who has experience with working with someone with ABI.

13.5 (1) Some people with ABI need to have funded support to live in their own homes; (2) because (a) otherwise they have to be helped by family members — but often parents are too elderly to look after them; also (b) support will help them to be more independent.

13.6 (1) People with ABI need access to a multi-disciplinary support team (e.g. neuropsychologist, OT, etc.), (2) so that they can learn (a) new ways of doing tasks, and (b) strategies to be able to do tasks that they used to do, (e.g. planning, organising how to get somewhere).

13.7 (1) People with ABI need aids and equipment (e.g. GPS, iPad, iPhones, hoists, electronic wheelchairs), (2) (a) to access community, (b) to live a more productive life (e.g. going to work, getting to work on time), and (c) to increase their independence.

13.8 (1) People with ABI need support in social and recreational engagement, (2) because they need a sense of purpose and engagement with the community (e.g. ABI can prevent people from connecting with their work, their network of friends, and social activities).

13.9 (1) People with ABI need support and education (from professionals in the field of sexuality) in finding appropriate outlets or ways to form and manage relationships and sexual intimacy, (2) because otherwise they can find themselves in trouble with the law.

13.10 (1) People with ABI need support in helping them to manage challenging behaviour (e.g. by doing effective functional behaviour assessments, drawing on a multi-disciplinary team), (2) because otherwise (a) they can find themselves in trouble with the law, (b) it limits their capacity to engage in community, and (b) it can lead to increased social isolation.

13.11 (1) People with ABI need support to manage basic household tasks — some of which are 'hidden' or 'not obvious' (e.g. when to eat, that they have to eat, checking the letterbox, opening letters) — (2) because otherwise (a) they can end up with significant health issues (e.g. becoming underweight or sick from eating 'out of date' food) and (b) there is an increased risk of bills not being paid (e.g. which can result losing their funding or phone connections, or their electricity being cut off).

13.12 (1) I need support to fund a physio in the community who can give me continuous help and practice in walking. (2) Being in a wheelchair I have the capacity to walk, but I only get 6 weeks of physio a year. But with an ABI you need continuous repetition to help you undertake a task.

13.13 (1) People with ABI need support to reduce their social isolation — like groups or 'buddies' that can motivate you and take you to mainstream activities (e.g. learning how to surf, going for a coffee or to the movies, or shopping). (2) This is because (a) a lot of people don't understand ABI. For example, they think that because I can talk and communicate, I am fine. (Some even deny that I have a brain injury); (b) more broadly, social isolation can contribute to mental health issues and substance misuse —including the abuse of medication; and (c) mainstream supports are often not suitable (e.g. hours are not flexible, lifeline has no idea about brain injury, etc.).

13.14 (1) People with ABI need support with managing substance misuse issues, (2) because (a) mainstream services that deal with substance misuse don't understand ABI issues, and (b) before they can access ABI supports, they need to be free of using a substance.

13.15 (1) There are not sufficient services regionally for people with ABI, (2) so (a) they can't be accessed, or (b) if they do re-locate in order to access the services they lose their family networks and can become socially isolated.

13.16 (1) There needs to be support for children with ABI who are transitioning to adult services, (2) because the existing approach is inadequate.

13.17 (1) There needs to be support for family planning, (2) because people with ABI can believe that someone is in a relationship with them and so children are brought into the picture, but they may not have the skills to parent the children or the relationship may break down — in which case they become financially responsible for the child which creates additional hardships for someone with a disability. This can happen several times as multiple relationships are started and ended with the same results.7

14. Brisbane, QLD: 1-3pm, 18 Feb 2013

Meeting Called By:	Brain Injury Australia and Synapse	**Attendees:**	Mark Burns, Dianne Cavanagh, Janelle Cooper, Ron Cousemacker, Shannon Galletly, Lee Hearn, Thea Isles, Brooke Kooymans, Owen Lloyd, Sanjeeta Mackrani, Emma Pawley, Cathy Pilecki, Ray Quinn, Margaret Rae, Kellie Sheridan, Ben Turner, Viki Walters
Facilitator:	Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports are 'reasonable and necessary' for people with ABI? (2) Why?

14.1 (1) People with ABI will need supervision or personal assistance in practical tasks (e.g. going shopping, preparing meals, etc.), (2) so as to meet the objectives of making sure that they have quality of life and can participate in the community.

14.2 (1) People with ABI need neuropsychological assessments (2) so as (a) to determine the strengths and barriers that they need to address in a return to work situation (e.g. learning new information, breaking down tasks) and (b) to educate the employer on how best to support them in the workplace.

14.3 (1) After an assessment, people with ABI need ongoing support to use strategies to cope in everyday life, in work, at home in relationships, (2) so that they are able to participate in life far more effectively than they would without this support.

14.4 (1) People with long-term ABI (i.e. 15-20 years post ABI) who want to return to work may need to be referred back to an assessment of their support needs, (2) because they will often have had no proper assessment or community support in the last 10 years, and so will require a more current assessment.

14.5 (1) Currently, people with ABI may not receive support unless they have a dual diagnosis (e.g. of both ABI and a mental health condition). This should not be duplicated under the NDIS, (2) otherwise people with ABI who do not have a dual diagnosis will continue to be disadvantaged.

14.6 (1) There should be recognition that supports will be needed some time down the track post-ABI, not only in the immediate aftermath, (2) because many issues requiring support only emerge (or are only identified) sometimes several years later.

14.7 (1) People with ABI need one-on-one support in relation to planning and decision-making, (2) because people with ABI can be articulate, but planning and decision making issues can stop them from going back to work, making appointments, etc.

14.8 (1) There is a difference between **support** (i.e. helping people to access services without doing it for them, facilitating independence, etc.) and **care** (i.e. non-paid, hands on, active, helping people to shower, brush teeth, etc.). The Agency should not assume that if people with ABI don't need care (because they can cook, shower, etc.) then they don't need support (e.g. with planning, organising, regaining independence, reconnecting with the community, etc.).

14.9 (1) People with ABI will need ongoing and consistent care and support (physio, speech therapist), (2) because, whilst improvements in certain areas can be made, other areas will emerge over time and so will also need addressing.

14.10 (1) People with ABI need funding in order to access other health services (like dental, podiatry, etc.), (2) because otherwise they will be unaffordable for many.

14.11 (1) People with ABI — particularly those who live in rural and remote areas — need equitable and timely access to support services.

14.12 (1) Young people with ABI need access to appropriate placement (2) (a) to ensure that they have age appropriate social interactions, and (b) because it is more cost effective.

14.13 (1) There should be funding for assistive technologies (e.g. smart homes that are put up for rent so that they could be shared by people with a disability), (2) because it would allow people with ABI to live independently and with dignity (e.g. you don't have hands on intrusive care, with support being provided more remotely).

14.14 (1) People with ABI who have unique and challenging behaviours need education and support (e.g. through housing or community-based services) (2) because otherwise (a) they can be disenfranchised from mainstream services, and (b) it is more likely that mental health services will be used inappropriately.

14.15 (1) People with ABI need funding for transport (bus or taxi fares), (2) because this can be the single biggest barrier for people to access support or health services.

14.16 (1) People with ABI who need to get an on-off road assessment to return to drive require a funded OT assessment, (2) which, because it is prohibitively expensive, excludes many people from returning to work (esp. those who have been tradies).

14.17 (1) Support services will often fund transport to social activities or support during the activity but not the activity itself. (2) Without this funding, many people with ABI won't be able to afford these activities, and so will be less likely to be able to achieve their social participation goals (e.g. reducing social isolation, creating friendship networks).

14.18 (1) People with ABI need additional educational and social support (i.e. over and above what is covered by education), (2) because (a) children with ABI fall 'between the cracks' in mainstream education — unless they are profoundly impaired, (b) they are frequently victims of bullying (e.g. due to speech difficulties, physical, cognitive and behavioural issues), and (c) adults trying to access TAFE or distance education are

not supported (e.g. with planning, the extra time needed to comprehend course content).

14.19 (1) People with ABI need support with equipment and aids over and above what government agencies will provide (e.g. aids around cognition and physical aids) (2) to allow access and participation and increase independence.

14.20 (1) Long-term holistic support for parents, siblings and partners is needed (which can include education about self-care, counselling, etc.), (2) because (a) parents need help with adjusting to their child's condition, and addressing specific issues that arise over time; (b) without this support, relationships break down, parents 'burn out', siblings need to be able to thrive and develop appropriately, and so on.

14.21 (1) Self-directed, flexible family respite should be funded, (2) because it can free the family from the carer's role for a while (recognising that this may involve employing someone to support the person with ABI *during* the respite, rather than the family taking respite without the person with ABI).

14.22 (1) Support should be provided to people with ABI during their transition from childhood to adulthood (e.g. ongoing information, vocational support, mental health, independent living) rather than leaving the responsibility for this up to the parent — (2) because (a) parents may not have enough information, which can be highly stressful to them, (b) they are now caring for an adult, which can involve more challenging behaviours, (c) it can result in family conflict and relationship breakdown, and (d) it can perpetuate the person with ABI's dependence on the parent.

14.23 (1) The person with ABI must be a part of the decision-making process regarding their support, rather than leaving the decision entirely up to (what is perceived to be) cost saving.

14.24 (1) There should be someone to advocate for a young adult to ensure that they are supported in making decisions for themselves, (2) otherwise it is likely that the person will have the goals and perspectives of others (e.g. parents) imposed upon them.

14.25 (1) There should be a greater coordination of care and support for people with ABI over the long term (i.e. case management); (2) because people with ABI have difficulties negotiating systems themselves and organising supports for a variety of goals, and so need a case manager *who understands ABI* to assist them (i.e. knowledge of how to case manage alone is not sufficient).

14.26 (1) There should be access to people within the Agency who have specialist knowledge of ABI across the board, rather than someone who has only a generic understanding of disability, (2) because ABI is a complex condition, and specialist expertise is required if the Agency is to fund or provide more efficient and effective services.

14.27 (1) There should be access to longer-term psychological support (2) so that people with ABI can adjust to and become better aware of the impact of their brain injury.

14.28 (1) People with ABI need support at the stage of creating their support plan (2) because they often struggle to identify meaningful and realistic goals (because of lack of self-awareness, neurological impairments, etc.), and so would be significantly disadvantaged without this support.

14.29 (1) GPs should be better educated about ABI, (2) so that they are able to identify emerging issues for people with ABI and so that they can be directed to more specialist expertise and assessments.

14.30 (1) The Agency needs to encourage and promote better access to specialised slow-stream rehab units, (2) because (a) these services are currently inadequate, and (b) this kind of rehab enables people to return to their community, etc..

14.31 (1) The Agency needs to encourage and promote better access to services that address dual diagnosis, (2) so that there is no 'wrong door' for people with ABI and a mental health condition.

15. Penrith, NSW: 10am-12.30pm, 20 Feb 2013

Meeting Called By:	Brain Injury Australia, Brain Injury Association of NSW	**Attendees:**	Galia Ayala, Vicki Lovegreen, Ian Lovegreen, Nicole Lucas, Julie Satterly, Penny Stephen, Bev Taylor, Lionel Verwey, Kaye Weaver, Beverley Williams, Gillian Woodcock
Facilitators:	Rachel Merton and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports are 'reasonable and necessary' for people with ABI? (2) Why?

15.1 (1) The supports should be flexible over time (e.g. there should be periodic reviews), (2) because it is not always possible to decide *now* what will be reasonable and necessary *in 10 years time*.

15.2 (1) People with ABI in remote or rural locations need access to appropriate therapies (e.g. OT) that (a) are provided within the home, (b) are fully funded (in terms of filling the funding gap left by mainstream health, and that accounts for travel time), and (c) take into account new technologies, (2) because otherwise (a) they will be at a significant disadvantage — particularly if the therapy is not provided within the first 16 months post-injury and ongoing, as needed, (b) therapy in the home is essential for short-term memory loss, (c) mainstream health only funds a limited number of visits, and travel time is charged at the cost of therapy time.

15.3 (1) People with ABI should not be excluded from rehab because of short-term memory loss (i.e. where the justification is: "they can't learn"), (2) because (a) this discriminates against people with a particular type of impairment, (b) people with short-term memory loss *can* learn tasks if they are repeated enough, (c) this kind of 'defeatist' response unnecessarily demotivates both the person with ABI and their family/carers.

15.4 (1) There should be (a) immediate post-injury support and education made available to people with ABI and their carers, and (b) better public awareness about the availability of this kind of support (e.g. through the hospital or GPs), (2) because (a) (i) the transition to someone who now has a brain injury, and (ii) the transition from a 'spouse', 'partner' or a 'significant other' to a 'carer' is immediate and overwhelming (emotionally, physically and intellectually), and (b) they do not have the time, energy or knowledge about how to access this kind of support or education.

15.5 (1) Carers of people with ABI should be provided with respite (including information about what is available), rather than have to ask for it, (2) because (a) they would not

otherwise know what is out there, (b) it may help to avoid the breakdown of important relationships, and/or the abandonment of the person with ABI.

15.6 (1) The Agency needs to ensure that carers of people with ABI are not over-burdened with the process of navigating the system, (2) because then, even with additional external funded support for the person with ABI, the stress and energy required of the carer can still be overwhelming.

15.7 (1) The Agency must not only provide funding for necessary supports, but also ensure that the workforce required to deliver these supports is adequate (i.e. in terms of numbers and relevant skills), (2) otherwise the person with ABI will not have their necessary needs met within a reasonable time period or to a reasonable level of quality.

15.8 (1) When a participant is putting together their support plan, the Agency needs to ensure that they consider not only short-term goals, but also long-term goals— particularly when the participant is a child, (2) due to the developmental issues and changing needs that will arise for children with a disability (e.g. in the transition to adulthood, completely new circumstances will emerge — such as learning how to drive, sexuality, social interaction, relationships, educational and vocational goals, learning to take responsibility for their own life, etc.).

15.9 (1) The Agency should fund aids and equipment that are (a) individualised for the specific needs of a person with ABI, (b) provided at the time that it is needed (not in 2 or 5 years time), and (c) accompanied by the support that they need to use the equipment as their needs change, (2) (a) so as to make sure they have access to the community, and (b) so that their quality of life does not deteriorate while they are waiting for the equipment, (c) if the waiting time is too long, then the situation is likely to have changed to the detriment of their quality of life, (d) having access to the right kind of equipment can, for people with ABI, be the difference between life and death — because people with ABI commonly suffer from deep depression and frustration over what they've lost, how they are treated by others and coping with their new reality.

15.10 (1) To avoid the pitfalls of other schemes that exist (e.g. Lifetime Care and Support), any goal connected with leisure, pleasure or recreation must not be automatically declined, (2) because these are the kinds of things that will (a) help people feel worthwhile again, (b) connect them to a social life (i.e. avoiding social isolation), and (c) help them to meet the kind of goals that they had prior to their injury.

15.11 (1) Grief counselling should be made available to both the person with ABI and their carers, for as long as (and whenever) it is required, (2) because (a) both have an suffered immense losses (e.g. the person they used to know, the future they had planned and hoped for, prior relationships with 'significant others', etc.), and (b) given that the grieving process is not time-limited, the current mainstream funding for a fixed number of sessions with a counsellor or psychologist is insufficient, and (c) the lack of ongoing counselling, as and when needed, is very likely to contribute the deterioration of both the person with ABI and their carers' quality of life and mental health.

16. Penrith, NSW: 1.30-4pm, 20 Feb 2013

Meeting Called By:	Brain Injury Australia, Brain Injury Association of NSW	**Attendees:**	Galia Ayala, Michelle Barrett, Rita Blundell, Karina Clarke, Fiona Curtis, Muriel Dalmasso, Nerida Johnston, Kate Loxton, Nicole Lucas, Rachel Merton, Jennifer Moon, Kerry Stafford
Facilitators:	Bev Taylor and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports are 'reasonable and necessary' for people with ABI? (2) Why?

16.1 (1) Some people with ABI will need attendant care (but should not be over supported if they have skills to do it themselves), (2) (a) to meet their rehabilitation goals, (b) to maintain them in the community (e.g. budgeting, diary management, etc.), (c) to develop skills, (d) to progress over time, meeting new goals to fit their changing life circumstances and personal aspirations, (e) to build their self-esteem (f) to increase their independence, (g) to do so in a way that helps to maintain and improve family relationships (e.g. without intruding on their family environment).

16.2 (1) People with ABI will need transport (including supervision on public transport), (2) in order to live more independently.

16.3 (1) People with ABI may need an increase of services as they progress through life, (2) because there is evidence that for people who age with a disability, the aging process accelerates.

16.4 (1) The Agency should consider a range of alternative models of support for people with ABI — especially accommodation, which might include 'cluster housing' (rather than relying entirely upon traditional attendant care or 'living at home with family-as-primary-carer' models), (2) because of the risks associated with these traditional models (e.g. family burn out, increased dependency, the need for consistent monitoring for high risk clients, clients with challenging behaviour, etc.).

16.5 (1) Where possible and appropriate, there should be consistency in the staff who are working with a person with ABI, (2) so that relationships are built and maintained between the support staff and the person with ABI.

16.6 (1) Where a support (such as a wheelchair) could be provided by a non-NDIS organisation, but it is not of a suitable quality or doesn't meet the specific needs of a person with ABI, then the NDIS should be required to supply the funds necessary to purchase that support, (2) so that the person is not disadvantaged simply because

mainstream services are not able to provide the necessary support (e.g. where a mainstream service will only provide a one-size-fits-all wheelchair, and this does not fit the person in question).

16.7 (1) The assessment of what supports are reasonable and necessary for a person should not be entirely dependent upon one individual's perspective (e.g. an Agency staff member who happens to be your assessor on the day), there should instead be a multi-disciplinary approach to this assessment, (2) otherwise the assessment is likely to be flawed and inaccurate.

16.8 (1) Service providers should be required to enable participants to become active members of the community — which includes components for transport, costs of going to community activities, like the gym (rather than focusing merely on medical issues), (2) so as to increase social inclusion and quality of life (e.g. depression levels, behavioural issues, etc.)

16.9 (1) There should be long term ABI-specific case management for each person with ABI, (2) to ensure that (a) there is consistency over time, which is critical given (i) the episodic nature of ABI; (ii) pre-existing social, familial, drug and alcohol issues, which are exacerbated post-ABI and which are less likely to be identified without consistent long-term oversight, and (iii) the organisational, memory, problem-solving and other executive functional issues that people with ABI commonly experience.

16.10 (1) There should be a consistent pathway of support for any person with ABI post-injury, regardless of the cause and circumstance of their injury. For instance, people who don't go through a brain injury rehab unit or who are not compensable should still have access — under the NDIS — to early intervention therapies (e.g. physio, OT, speech therapy, social work, etc.), (2) because (a) there will be better outcomes, (b) they will be more inclined to participate in terms of doing what is required to achieve their goals, etc.

16.11 (1) If a person with ABI has not received necessary support from a mainstream service within a reasonable period of time (at any time after the injury), then the NDIS should step in to provide this kind of support.

16.12 (1) There should not be pre-determined time-scales or 'cut off' dates connected to particular budget areas (e.g. making respite unavailable for people who have been receiving support to transition out of home for 2 years), (2) because the funding should be connected to a person's actual needs and life circumstances.

16.13 (1) People with ABI and their families need to be provided with education about how to set goals in the context of the NDIS, (2) because (a) they may be used to a very different funding approach (e.g. rationing), and (b) they are unlikely to know how the new system works, or what is possible, and so they may develop plans that are not as beneficial or effective as they could be.

16.14 (1) Support workers need to be funded for training that relates to the specific care needs of the participant (e.g. an intensive daily physio or behaviour management plan which (a) is unique to the client, and (b) requires specific training for safety and quality purposes), (2) because this kind of training is not currently funded.

17. Nowra, NSW: 10am-12.30pm, 21 Feb 2013

Meeting Called By:	Brain Injury Australia, Brain Injury Association of NSW	**Attendees:**	Tina Chapman, Naomi Cartledge, Tammy Jones, Zachary Jones, Helen Parker, Larry Tibbets, Debbie Whittaker, Gina Wilson-Burns, Mike Wootten
Facilitators:	Marilyn Styles and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports are 'reasonable and necessary' for people with ABI? (2) Why?

17.1 (1) My son needs support to live a normal life — that is, to get back into the workforce, transport training to his workplace, assistance with public transport, social activities, independent living support (which uses a personal assistant), (2) because, due to the ABI, he has short term memory loss, and so cannot plan ahead or for himself, he has no initiative so needs prompting, he needs to repeat things over and over again to learn things, and he has seizures, he gets too tired to do anything in the afternoons, he also suffers from depression and loneliness, lack of motivation and initiative, and lack of concentration, etc..

17.2 (1) I need carers to be able to take my son out to do things (2) because he has an intellectual impairment and so is vulnerable and needs assistance with doing things.

17.3 (1) My wife and I look after our son, but, due to his ABI, his behaviour is such that my wife can't look after him for more than 2 to 5 hours at a time because he can become too aggressive. So at the moment we need (a) enough support in the home, (b) community based access, (c) sufficient respite for us as carers, and (d) emergency care when this is not covered by mainstream services. In the long term, we want to have (e) fully supported 24/7 care (i.e. in a facility which is age appropriate, where all his needs are met, where he has full access to the community and his own child, where he has as much independence and control over his life as possible. (2) We need (a)-(d) in order to keep him at home and out of nursing home. We need (e) so that, as we age, we can know that he will be fully cared for.

17.4 (1) My son's condition has improved, but he still has seizures and so needs to be with a carer for outings (e.g. on public transport, going to the shops). He needs us as carers to teach him what to do and to help him remember the steps (e.g. tending to the plants, being with him when he is using high speed tools during sculpture). We need more respite as carers, to have a holiday from our son would be very beneficial because we are with him 24/7. He has short-term memory loss. Depression can be a

problem at times, and so needs psychiatric help that is (a) local, and (b) specifically for people with ABI. In the long-term, he would need to have support at the home, visits every day, help with transport to shopping, and someone to meet with for social support. As a family member and carer, I have needed psychological and psychiatric support over the years to meet their emotional needs. This is very expensive, and so should be funded. People who are inside psychiatric work should treat people with ABI with respect (e.g. they should not make judgments about a person on the basis of how the ABI was caused).

17.5 (A) My son's injury is relatively recent. He will continue to improve, but there is strong evidence that it is more rapid in the early stages. That is why, in the first two years, intensive therapy is very important. So more funding should be available during that initial stage. (B) After hospital, we were sent home with no support — other than speech therapy, which was not ABI specific and so inadequate. If the hospital had been able to access the internet, my son could have been sent home and continued with speech therapy by Skype (i.e. 2 times a day, at flexible times suited to the energy levels of my son) with the resident speech OT / physio. But Skype was not available. More generally, health workers (e.g. speech therapist) should attend the home or school rather than require us to go to the hospital. (C) It would also be useful to have one or two week sabbaticals at the hospital or 3-day camps to access OT, physiotherapy, a neuropsychologist and speech therapy. Access to these should not be limited to certain age groups. (D) He is 16 and because we live in a rural area, cannot access the local brain injury service, so we must travel to the nearest city. (E) As a carer I need appropriate mental health support, because I am still suffering from the trauma of my son's ABI, and because I want to maintain my relationship with my son, which is all he has at the moment. (F) In the long term, I want to be confident that if I am not there his needs will be met. (G) We need trained staff that understand brain injury. The current level of training is insufficient (e.g. they can be extremely negative when it comes to setting goals for my son, minutes during meetings are inaccurate, being referred by a GP to a specialist in a distant location when there is one locally, case managers who don't understand the specific needs of people with ABI). (H) We need innovative and flexible approaches to support (e.g. paying a university student to provide engaging support and assistance). (I) We need a repository of appropriate literature and information about what is available for people with ABI. (J) He needs a lot more help at school and transitioning to the workforce. Currently school funding for disability support (e.g. one-on-one teacher's aide) is inadequate, so we would hope to get additional funding to supplement what the school provides.

17.6 (1) (A) My son has both ABI and a physical disability, so we need equipment, mobility options to access everyday life, home and vehicle modifications (so he can own his own car) and technology for augmented communication and access. (B) From a personal support perspective, he needs assistance for personal care, including feeding. (C) We would like him to be supported for post-secondary education and open employment support, and (D) living in his own home with other people of his choosing, and by people who respect and support his own vision for his life. (2) These things mean that he can live his life, i.e. enabling him to have a job and income and independence.

17.7 (A) My daughter (9 yrs old) has ABI, epilepsy, anxiety and oppositional. We are the primary carers, but eventually she will need a carer, ongoing support and guidance, if she will allow this. She gets very tired, she is not reading or writing at the moment. So we need more funding for ongoing speech therapy (for as long as required), and the choice about who to use and where. (B) We want to keep her in school, but that depends on the continuation of disability support funding (i.e. currently she has an aide during class, but not in the playground — which is needed, given her epilepsy). (C) She also needs technology to help her to learn to write. (E) We need help with the transition from hospital to home, to provide guidance and information.

17.8 Staff who support people with ABI need to be better trained in terms of treating them with dignity and respect, and acknowledging their abilities and intelligence (e.g. they should not use humiliation as a form of behaviour management).

The following are additional comments provided in 3 written submissions, subsequent to this consultation session:

17.9 More thoughts for the submission:

a. Our son's ABI has resulted in severe intellectual and physical disability with psychiatric problems eg psychosis, all of which appear to be increasing, possibly due to seizure activity. Resulting in unpredictable mood swings with physical and verbal abuse. Incontinence and soiling also occur. Also regular sleepless nights for him and us. Medication adjustment is an ingoing issue.
b. We had little support post recovery with rehab more focused on mature age stroke recovery then ABI recovery
c. We were not informed initially about the range of support services we may have been able to access- in Canberra, better in NSW.
d. 24/7 care covers full 1:1 help with dressing, toileting, eating, hygiene, all activities need close monitoring, house and yard must be secure to prevent wandering, very unsteady on feet so falls regularly- needs some help sitting standing.
e. Closest psychiatrist is in Wollongong- 3 hours round trip.
f. All outside activities must be 1:1.
g. Important that carers are compatible with our son and change is kept to a minimum to avert behavioral episodes.
h. Cannot be left alone for even short periods.
i. Personnel in support organisations have limited hours of work so emergency contact is compromised. [Mike Wootten and Julie Love]

17.10 In one the objects of the Act it states: raise community awareness of the issues that affect the social and economic participation of people with disability, and facilitate greater community inclusion of people with disability. Personally, I am over raising community awareness of the issues that affect people with disability; I would prefer it if we could raise awareness through prevention measures of what caused the injury or illness or disability. [Tammy Jones]

18. Nowra, NSW: 1.30-3.30pm, 21 Feb 2013

Meeting Called By:	Brain Injury Australia, Brain Injury Association of NSW	**Attendees:**	John Dostine, Kathy Griffiths, Irena Gordon, Donnella Robinson, Robyn Russell, Marilyn Styles, Drew Sullivan, Margaret Whyman
Facilitators:	Bev Taylor and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports are 'reasonable and necessary' for people with ABI? (2) Why?

18.1 (1) People with ABI need suitable age-appropriate accommodation supports (or other options). Currently if they're not supported by their family they are put into residential aged care, (2) which can impact on them further (e.g. if they don't recognise that they have an ABI, being in a home with aged people can affect their mental health, leading to depression, suicide, their independence and choice about who they live with is taken away from them. Generally, if they are not accommodated appropriately, it makes them vulnerable to being taken advantage of financially, drugs and alcohol. If they are forced to live with their families, this can put the family at risk of further breakdown due to violence, etc..

18.2 (1) People with ABI need social supports (e.g. being linked in with their old friends, networks they had pre-injury, and to explore new interests and activities), (2) this can have a very positive effect if they can maintain or establish new social networks; with these supports, there can be significant cost-reductions and a limited need for formal service provision, and it helps to avoid social isolation and depression.

18.3 (1) People with ABI need a wide group of people available to help them decide what they need, as opposed to just parents or a guardian (e.g. work colleagues, a neighbour, etc.) (2) to ensure that a full range of perspectives can be brought to the decision making (e.g. the person will have different needs in different contexts — home, work, education, social activities, etc.).

18.4 (1) Equipment modifications that are necessary to meeting your goals (e.g. returning to work) and that are not paid by existing schemes, should be covered by the NDIS, (2) to ensure that they are able to meet their goals and social and economic participation.

18.5 (1) Services should be delivered (a) in a flexible manner, to adjust to changes in their functioning and circumstance (e.g. where there is a transition to independence, due to, say, aging parents), and (b) in a person-centred way, (2) in order to optimise their

functionality, i.e. where possible to enable them to return to a pre-injury status; and to bring the quality of care up to the highest possible standard, and to ensure that their dignity as a person is upheld.

18.6 (1) The assessments of a person with ABI's support needs should be targeted for ABI and individualised for that person, not generic, (2) otherwise the person's needs will not be captured effectively and they will eventually need to be re-assessed.

18.7 (1) Currently people who can engage within a group have an advantage over those who need one-on-one support —because the cost of providing the latter is higher than the former (e.g. the cost of extra support workers, travel costs, etc.). But many people with ABI need one-on-one support, so this should be funded (2) so that they are not disadvantaged due to the uniqueness of their disability.

18.8 (1) In some cases (e.g. rural areas), there should be sufficient flexibility in the plan to allow a participant can pay family members to provide support — however, there are many risks involved, so there must be adequate standards and regulation applied, particularly for high risk participants, (2) in order to meet the clients goals and social and economic participation, particularly in areas where there are insufficient numbers of trained professional support workers or culturally appropriate personnel.

18.9 (1) Anything that is not covered by Medicare or existing organisations and agencies (e.g. ongoing psychology, speech therapy, OT, etc.), participants should be able to obtain continuity of support through the NDIS, (2)

18.10 (1) The NDIS should provide funding for adaptive technologies (e.g. smart phones to help with organisation, planning, modifying their car to enable them to drive again, Skype for their friends, specially made toothbrush), (2) so that they can meet their personal, vocational, educational or social goals (e.g. to return to work, school, feeling more included within their community, etc.).

18.11 (1) People with ABI have significant problems with relationships (e.g. some want a full-blown relationship, others only want a sexual relationship) — so support is required to enable these areas to be explored in a safe and respectful way, (2) because these are basic human needs that should not be denied to someone just because they have a disability.

18.12 (1) Many people with ABI need access to and funding for transport — especially in rural and remote areas; and they may not be able to use public transport (e.g. if existing services do not follow a strict routine, or if they need a support person to assist them), (2) because otherwise they will not be able to get to services, can't participate in social and economic activities, etc.

18.13 Every person with an ABI who does not have the ability to return to employment due to severe physical and/or cognitive disability and/or challenging behaviour related issues must receive adequate funds to facilitate a range of meaningful activities on a daily basis because an ongoing lack of regular, meaningful activity and social interaction leads to depression, low self-esteem/self-worth and increased social isolation. [Written submission by Bev Taylor]

19. Canberra, ACT: 10am-12.30pm, 22 Feb 2013

Meeting Called By:	Brain Injury Australia, National Brain Injury Foundation	**Attendees:**	Adam Bode, Jeanette Budak, Tricia Hoad, Peter McCullagh, Julie McRoy, Nick Rushworth, Libby Steeper.
Facilitators:	Nic Stuart and Derek Brookes		
Notes Taken By:	Derek Brookes		

The following is a record of the responses to the Questions in the NDIS Rules Consultation Paper, as given by those who attended this consultation meeting.

Participants' Plans

Reasonable and Necessary Supports

Question: (1) What kind of supports are 'reasonable and necessary' for people with ABI? (2) Why?

19.1 (1) People with ABI need equipment that is age-appropriate, timely and non-damaging (e.g. wheelchairs, nappies, etc.) and home modifications, especially for children, (2) because as the child grows it will be damaged and unable to live without discomfort if the equipment doesn't fit, parents have to find vast sums that they don't have to make home modifications. (Note, it would be cost-effective to have an equipment pool, so that — where appropriate — equipment can be 're-cycled').

19.2 (1) Group therapeutic organisations should be supported (e.g. horse-riding for disabled children and adults), (2) so that they are able to deliver services in a more cost-effective way.

19.3 (1) People with ABI need funding for communication devices (e.g. iPads), (2) so that they can communicate outside of their network (e.g. with shops), and so reduce barriers to social inclusion.

19.4 (1) Support for extended networks of people with a similar disability may be needed, (2) so as to allow for further peer support and assisting in allowing people to share information and recognise that continuous improvements can be made (i.e. social participation).

19.5 (1) People with ABI need access to and funding for *ongoing* health maintenance (e.g. OTs, physio, counselling, etc.), rather than having time-limited access, (2) to maintain and improve their long-term health and well being.

19.6 (1) Support is reasonable and necessary when the quality of life or standard of living for a person with disability is as similar as possible to people without a disability, (2) so as to eliminate the effects of the disability, to reduce the level of inequality.

19.7 (1) People with ABI should have supported access to participate in mainstream recreational activities (e.g. art therapy, fitness, living skills programs, etc.), including

funding for transport, (2) so as to increase their social and community connections, to make friends, and re-establish their social network.

19.8 (1) The assessment of a person's support should (a) be done in an objective way, and (b) it is paramount that the retained capacity of the individual who is being assessed is taken into account, (2) otherwise necessary supports may be excluded because (a) of an assessor's subjective perspective or judgements, or because (b) the assessor is not equipped with the skills and knowledge required to identify both the cognitive limitations and the cognitive abilities that have been retained.

19.9 (1) Access to funded legal services, the full range of financial services, child protection or protection for vulnerable parents and comprehensive management would be important for people with ABI, (2) because people with ABI might do things that would create legal or financial difficulties (e.g. substantial mobile phone bills, taking part in scams that they don't have the capacity to consent to), and support workers shouldn't be providing advice where they don't have the skills to do so, and because some people with ABI will be quite good at managing their finances, and others will not.

19.10 (1) People with ABI need to have access to qualified assessments and expert assessors, (2) because otherwise their needs won't be adequately identified and the program they use will inevitably be inadequate (Note, sometimes a person's needs are hidden by the way that they are cared for (e.g. a parent fills in support gaps, in a way that is unsustainable); or a program is designed primarily to meet the needs of parents/carers)

Question: What will the Agency need to do to make sure that the supports it decides to fund are reasonable and necessary (for each person with ABI)?

19.11 The support plan will need to be reviewed on an early and regular basis, and may require further bedding down or changing. There must be an opportunity to re-direct the program of support without going through a lot of red tape (e.g. changing a program of hydrotherapy to another type of therapy depending on the responses of the participant or its effectiveness).

19.12 There should be a range of supports that are uncontroversially 'reasonable and necessary' so as to reduce administrative oversight (e.g. cleaning services, personal care).

19.13 There should be feedback from the participant as to whether the supports really are meeting their needs.

19.14 In terms of what is reasonable and necessary, there should be broad consistency across different locations (e.g. a person in a rural location should have access to the same level of personal care as someone in an urban location if their needs are identical).

19.15 What is 'reasonable and necessary' needs to take into account the views of different cultures.

19.16 Expectations about what is reasonable and necessary should not be limited to or determined by what is currently available.

19.17 What is deemed reasonable and necessary at any particular point must sufficiently flexible so as to take into account the kind of changes that can occur during major life transitions.

Management of Plans

Question: How will the Agency work out whether it would be an unreasonable risk to a person with ABI if they managed (some of all) of their own funding?

19.18 If there is evidence of incompetence in relation to a person's capacity to make specific types of management decisions, then it may be an unreasonable risk for them to make *those* kinds of decisions.

19.19 There needs to be ongoing monitoring of people who are managing their own finances — and evidence of unreasonable risk would be (a) they are purchasing services that are not related to their support plan, (b) they are making a lot of purchases in a short period of time, which is inconsistent with their support plan, (c) not making the purchases that were specified in their support plan.

19.20 If they are not able to understand how budgets work (although there should be some level of capacity building and an 'enabling infrastructure').

19.21 The people who are making these decisions about risk must be relevantly skilled and qualified.

Supporting decision-making

Question: How should the Agency decide what kind of person should (or should not) be appointed as a nominee for a person with ABI?

19.22 Wherever possible, the person with ABI should be making decisions for themselves; but otherwise it would be better for the person responsible for their care on a day-to-day level (i.e. family members).

19.23 They should know a lot about the wishes and personality of the participant.

19.24 They should be capable of putting themselves in the shoes of the participant, rather than imposing their own views on them.

19.25 A person who is a legal guardian should be considered as a possible nominee.

20. Written Submissions

Invited by:	Brain Injury Australia	**Contributors [and abbreviations]:**	**Consultation Location:**
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The following are written responses to various questions in the NDIS Rules Consultation Paper, as provided by attendees subsequent to their consultation session.

The Different Functions of the NDIS

Connecting people to other systems

Question: To make sure that a person who is not eligible for NDIS funding can get the support they need from other systems, what will the Agency need to do?

20.1 Document why person did not qualify for NDIS. [GJ]

20.2 Forward supporting documents, to whichever agency client is being referred to. [GJ]

20.3 Require written response from service, client was referred to. [GJ]

20.4 Have a pathway, for dealing with clients who are rejected by services, that NDIS referred client to. [GJ]

20.5 Undertake Stakeholder Analysis to provide a definitive list of programs across Federal and State jurisdictions used to support people with disabilities.

20.6 Maintain the list of programs and their prerequisites or eligibility criteria.

20.7 Establish the terms of reference for the NDIS and set the precedence for each scheme/program.

20.8 Establish whether other schemes or programs will be:

a. mutually exclusive from the NDIS (i.e. Schemes or programs that cannot be accessed if the participant is being supported by the NDIS);

[7] Helen Caligiuri's responses were typed by Sophie Siegel (Advocate) during a phone conversation with her.

b. stand alone (i.e. Schemes or programs that can be accessed whether the participant is in receiving support from the NDIS or not);

c. dependent (i.e. Schemes or programs where access eligibility depends upon the participant being eligible for NDIS support as a prerequisite).

20.9 Define the levels of NDIS support that will be used to determine accessibility to other schemes or programs mentioned in paragraph 4.

Question: To make sure that **a person with ABI** who is not eligible for NDIS funding can get the support they need from other systems, what will the Agency need to do?[8]

20.10 Sets up appropriate links with a medical practitioner/provider of the services that are required by the individual. [FK-M]

20.11 Ensure there is a proper support network for the individual especially if there are some language or speech difficulties. [FK-M]

20.12 Everything that is now in place should be better monitored. There's currently little accountability and people just tend to get referred on without anyone being accountable of the outcome. There should be more streamlining, less passing the buck. [HC]

20.13 Needs to be more accountability, more action and more result. Bureaucracy makes it difficult to do good for clients, it seems there's no happy medium and staff often end up doing the bare minimum because doing "what's right" is either too difficult or gets them in trouble. In some organisations people need to re-apply for their jobs every few months - This is terrible for staff morale and thus impacts immensely on clients and the service they receive. [HC]

20.14 There is a need to follow things up for clients. Even if someone is not eligible for the NDIS they may still need physical assistance with things they can't follow up on themselves. Eg, filling out paperwork, feedback questionaries!, navigating the system etc. People just want a rich and fulfilling life again. [HC]

20.15 Increase awareness training of ABI, and the requisite support needs. Awareness training should be promoted within the Agency, and within all community providers of support. Such training and awareness raising can be achieved through mentoring with suitably skilled ABI specialists from within the ABI sector. [An.]

20.16 Provide clear and easy to understand information (easy English format). [KF]

20.17 Provide assistance and/or information on referral pathways (actually make referral where this level of support is needed). [KF]

20.18 Able to provide child/adolescent, family and important others (eg education staff) with reliable information on available supports and how to be referred; because what may seem like only mild symptomatology can lead to secondary conditions if

[8] Following the initial consultation sessions in Perth and Adelaide, the facilitator reframed the consultation questions so as to encourage respondents to focus on ABI-specific concerns. Both sets of questions (generic and ABI-specific) are included here to ensure that each response is read in the right context. (Please note that this does not entail that every response to an ABI-specific question should be read as applying only to ABI-specific concerns.)

not recognised and supported e.g. mild cognitive changes may lead to anxiety for child and family and diminished participation. [R&L]

20.19 Education in community particularly GP's, Centrelink, educators, re the sequelae of ABI; so that behaviours, change in function are not misdiagnosed or mislabelled and to prevent secondary symptoms e.g. depression. [R&L]

20.20 (1) Provide a referral to other systems with clear information about contact details and possible support. This should be provided to the most appropriate person as established by the initial assessment process (i.e. if the person with ABI is not able to make decisions or follow through themselves). What would be even better is to send an alert to the other support system to follow up on the person with ABI. (2) This is because people with ABI are less likely to follow up on their own accord and could be discouraged quite easily and therefore 'fall through the cracks'. [MD]

20.21 Look firstly at the ABI problem and address the needs to the relevant NGOs that can help. [VL]

20.22 Follow up to ensure that the service given or provided is relevant. [VL]

20.23 The Agency should allow access to any ABI supports currently in place in a person who has an ABI's location. This means that my son, who is currently 16 years old and who lives in Nowra should be able to access the Shoalhaven Brain Injury Service in Nowra (stipulated for adults – 18 years and over). Something is better than nothing and extensive travel is inappropriate. Otherwise, two-week sabbaticals at an appropriate Brain Injury Clinic in the nearest capital city would be of benefit. [TJ]

Funding Community-Based Supports

Question: To make sure that community based supports which are funded by the Agency will assist people with disability to realise their potential and participate in all areas of life, what will the Agency need to do?

20.24 Agency set a criteria of suitability. Community based supports, both government and non-government, are assessed along the predetermined criteria. Clients will be referred to these organisations, according to services offered. [GJ]

20.25 Some criteria essential are, evidence to show experience in:

a. age suitable services;

b. system of regular review and pathway in place, covering immediate needs and a projected 5 year pathway. Some needs that must be included are education, vocational, recreational, housing, therapy, medical and respite – both emergency and planned. [GJ]

20.26 Retain a growing data base of community based supports – govt and non govt. There may not be suitable services existing in many places. A group of experienced individuals, who are willing to come together and provide an assessment team or a service team should be considered. [GJ]

20.27 Community based supports should be able to map a pathway which clearly describes what services are suitable. They must also be able to show a pathway when the community support cannot meet client's needs. [GJ]

20.28 There must be a pathway for referring clients who have to move out of community-based supports, into high care. This is an ever growing reality of aging with a disability. [GJ]

20.29 Clearly promote and communicate the supports available for Clients; and their Careers. [TJ]

20.30 Use all available means and technologies available; including the Print Media, Television; and the Internet (In the form of an Interactive Website); All Health Sector Agencies, as well as Hard Copy Brochure mail out to all Australian homes. [TJ]

20.31 Could the use of SMS text messages be used; similar to what has occurred when Natural Disasters are declared in each State? This was used successfully so that evacuations could occur. (Look at each State's Natural Disaster Plans). [TJ]

20.32 The agency will need to setup a quality control process that monitors:

a. Provider registration;
   - Suitable qualifications for the services offered.
   - Police checked for dealing with vulnerable people

b. Provider accreditation;
   - Currency
   - Relevance to the services provided

c. Provider / participant performance against the participants goals, aspirations, and key performance indicators.

d. The participant's participation rate. [SM]

20.33 The Agency will need to conduct surveys and regular reviews with participants and providers. [SM]

Question: To make sure that community based supports which are funded by the Agency will assist **a person with ABI** to realise their potential and participate in all areas of life, what will the Agency need to do?

20.34 Make sure that the follow up is a face-to-face consultation preferably at the residence of the participant. [FK-M]

20.35 Request feedback on the providers of the service from the participants and their families/carers. [FK-M]

20.36 When setting up a client's goals have some trigger questions to assist the participant in thinking through what is it they want out of life and give them enough preparation time. [FK-M]

20.37 Follow up is the key. Assessment from someone who has worked with ABI's. Someone with knowledge of the person's history. Not someone with preconceived ideas (someone who thinks they know 'what's best' for a person without actually

respecting their wishes, or someone who takes a very textbook approach and put everyone with ABI in the same basket). Someone who realises potential for future. And an open understanding of the importance of trying new things. [HC]

20.38 Don't predict that NDIS will get everyone back in to the workforce within 3 years – be realistic with what peoples physical capacities and how they will be able to return and in what capacity, and what they actually want out of life. [HC]

20.39 (1) Assessment tools used need to be tailored to ABI specific needs and assessments must be attended by specialists of ABI (2) because people with ABI have multiple facets (social, familial, dual- diagnosis, and of course neurological) that will impact on their quality of life and also on their ability to effectively assess firstly what their potential could be and how to pick the right supports to reach that potential. They can also be very convincing in asserting what they feel are their true needs or what the true situation is when it may not be entirely accurate or in their best interest. [MD]

20.40 Have trained counsellors in the services who have had experience in this field of clients having an ABI. [VL]

Becoming a participant

Age Requirements

Question: Do the Rules need to say exactly what kind of information the Agency needs in order to make sure that people meet the age requirements?

20.41 Age Requirement should not be used to exclude clients. If there has to be a cut off point , it should be only on basis that there is a more age suited funding pathway, for the client. [GJ]

20.42 Assessment of short term and long term needs and services, need to be age appropriate. Pathway must reflect changing needs are anticipated and taken care of. [GJ]

20.43 For below 18s parent / legal guardian must be identified. This needs to be reviewed regularly to update info. [GJ]

20.44 For older clients, including those not under aged care services, guardian / power of attorney/ advocate, needs to be identified, for monetary and life style decisions including decisions regarding end of life care. [GJ]

20.45 For young age group – paeds to 55, 60- system of review of changing needs- every 5 years if client is not complex. [GJ]

20.46 Complex care review must be every 2 years. Yearly, if client's medical diagnosis points to a unstable and changing health condition. [GJ]

20.47 Yes, for both Children and Adults. [TJ]

20.48 No. Eligibility can be checked against DHS and DoHA data. The legislation should state that DHS and/or other government departments will be used to check the eligibility of the potential participant. [SM]

Question: Do the Rules need to say exactly what kind of information the Agency needs in order to make sure that **a person with ABI** meets the age requirements?

20.49 Definitely otherwise you will be wasting everybody's time. [FK-M]

20.50 Yes. They're going to need to know the basic kind of information so that they can do the best in order to do their jobs properly and help people. [HC]

20.51 Our understanding is that the Rules and legislation is currently saying that the 'request for access' to become a participant in the NDIS has to have occurred before the person turns 65. The concern is with those people that may have applied for access to NDIS before the age of 65, but may have turned 65 whilst waiting for NDIS. Current wording does not negate the potential that they will miss out. [An.]

20.52 There is no set age limit for a person with an ABI. Minors need to have their carers involved. [VL]

Residence Requirements

Question: To sort out who will count as a 'resident' in a launch site, do the Rules need to say that a person must: (1) live there on a date or date in a period of time? (2) have lived there for a certain length of time? (3) continue to live there?

20.53 For effective assessment and service planning, it is essential that client must be resident at the address for at least previous 2 years and plans to be resident for next 5 years. It does take time to set up services and monitor them. If services require staff and residence – it is imperative clients will continue to live there for at least 5 years. [GJ]

20.54 There must be flexibility where underlying medical condition does not allow for stability, deteriorating conditions, ABI clients with moderate to severe cognitive problems and mental health clients are some examples. [GJ]

20.55 There must be flexibility to allow client to move from one area of residence to another, when medical and social situations warrant the move. [GJ]

20.56 My own situation is: for the past seven years my daughter has been receiving treatment in Hong Kong. She has spent a total 3 years and 236 days in Hong Kong receiving treatment for her Cerebral Palsy. During this time we have maintained our residence in Canberra and most of the time my wife has travelled with my daughter leaving me with our youngest. We have never had the intention to migrate yet Centrelink has cancelled our Carer's Allowance each time she has spent more than 13 weeks out of the country. The treatment my daughter receives in Hong Kong is Traditional Chinese Medicine. I have documented proof that the treatment has resulted in significant progress from her paediatrician and therapists. So a much fairer interpretation of the term 'Resident' would be this:

A resident is a person who normally resides in a household either singly or as a family within a defined area. The person remains a resident of the household until such time as:

a. The person moves under their own free will and the person has control of where they reside.

b. The person is found guilty of criminal offences and incarcerated for those criminal offences.

c. The person is moved into permanent accommodation by a lawfully appointed guardian with power of attorney for the person.

A resident does not lose their resident status for a defined area if the person is moved to temporary accommodation for one of the following reasons:

a. The person is moved to the temporary location for the purposes of receiving medical treatment.

b. The person is required to move following an evacuation order and it is likely the person will return once the evacuation order is lifted.

c. The person is incarcerated pending a criminal trial.

d. The person moves to a temporary location for the purposes of work and the period the person is absent is less than 1 year and it is likely the person will take up residence at the same location on completion of the temporary assignment.

A person of no fixed address is deemed to be a resident of a defined area if that person (a) resides within the boundary of that area for more than 1 month and the person utilises any services provided by: Federal Government, State or Territory Government, Local Government, Community organisation or (b) Resides in the area for the purposes of employment. [SM]

Question: To sort out whether a **person with ABI** will count as a 'resident' in a launch site, do the Rules need to say that they must: (1) live there on a date or date in a period of time? (2) have lived there for a certain length of time? (3) continue to live there?

20.57 Have live in the area for at least 3 months before the consultation and have the intention of continuing to live there for the foreseeable future. [FK-M]

20.58 Should already be living there – need to stop people flooding to the area, otherwise it might not work, and if they can't make it work within their infrastructure, they won't succeed. [HC]

20.59 There is a commitment to continue to live there. If there are limited places, I believe that the decision should be made on risk factors for that person and support needs, current support in place etc. rather than on length of time living in the area. I understand that there is a concern that people may move to try to get into the NDIS so perhaps there may need to be a date from which they were already living in the area, such as prior to the business rules coming out? [MD]

20.60 How do you qualify this – do they live there or do their support/immediate carers live there? [VL]

Question: What other 'boundary issues' (between launch and non-launch locations) are likely to arise? What could the Rules say to prevent or sort out these issues?

20.61 In WA the role of different service agencies must be delineated – especially funding of services from State and Federal govt agencies. [GJ]

20.62 Rules must prevent buck passing. [GJ]

20.63 Rules must allow for deficit of services to be funded without one agency "dumping" on the other. [GJ]

20.64 The inability of clients residing in Rural parts of Australia to receive up to date information about the NDIS.

a. As mentioned above, could the use of SMS text messages be used; similar to what has occurred when Natural Disasters are declared in each State to minimise boundary issues?

b. Consider additional mail outs added to individual car registration renewals; by post. [TJ]

20.65 People are also likely to use family or friends to make false claims of residence. The rules need to state the evidential requirements for establishing residence in a defined area, this evidence could be: Rates Notices, Rent payments, Utilities charges, DHS correspondence and records.

The body of evidence could be accumulated in much the same way as the points system for passport applicants. [SM]

Question: What other 'boundary issues' (between launch and non-launch locations) are likely to arise for **people with ABI**? What could the Rules say to prevent or sort out these issues?

20.66 Clearly state that this is an initial launch and the intent is that once the bugs have been ironed out it will be available everywhere around Australia. [FK-M]

20.67 Need to stay here to receive NDIS because they should be spending their funding locally to prop up the medical field and service providers to further improve them for the future. [HC]

20.68 People Relocating – will they then drop out of the system only to reply and go through the system again on National Launch. [VL]

20.69 People of the same culture and nationality as the person with the ABI to be involved i.e. case works, doctors. For example, the doctor who assessed me had a heavy Asian accent and I did not respond to his questions. My husband asked the same questions and I responded as I could understand what was being asked. The same would apply to aboriginals, people from other non-Australian backgrounds i.e English as a second language. [VL]

Continuity of Support

Question: To sort out whether a person can still get the kind of support they were getting before the NDIS started up, what do the Rules need to say about: (1) when they were getting this support (it will be ok if they are still getting the support when they first contact the Agency, but what if this support stopped a month before then — or even longer)? (2) the kind of program that was delivering this support? (3) how long they had been getting this support?

20.69a Rules should allow for client who is currently in a service, applying, while the service is running. It should be a prerequisite. Otherwise, clients will be "dumped". [GJ]

20.69b There needs to be a requirement in writing from an "assessor" as to what programme the client was on and reasons for the current service not meeting client's needs. The assessor can be family, an advocate, LAC, an allied health professional or a medical/ allied health team or a GP. A medical report should never be the only criteria. [GJ]

20.69c Private Care agencies need to be held to their own initial service plans, laid out for client. Any funds forwarded by client, not used to fulfil service agreement must be returned to the client. [GJ]

20.69d (1) There needs to have an initial Start Up date included that gives the Client some sort of Term of Reference. (2) Similarly, on the above document, (Membership Card); this would include the type of program that the Client is or will eligible for. (3) Same as for Answer (2), above. Include the Start Up date, so that the Client can quickly and easily see how long they have been receiving support. [TJ]

20.70 (1) Evidence of the support being delivered by the program within a year preceding the introduction of the NDIS. (2) The program must be ongoing or must have an end date post the introduction of the NDIS. (3) This is irrelevant. [SM]

Question: To sort out whether **a person with ABI** can still get the kind of support they were getting before the NDIS started up, what do the Rules need to say about: (1) when they were getting this support (it will be ok if they are still getting the support when they first contact the Agency, but what if this support stopped a month before then — or even longer)? (2) the kind of program that was delivering this support? (3) how long they had been getting this support?

20.71 Does the person require that support? If so the NDIS should provide that support. Sometimes support is stopped because people can't afford it not because the participant does not need it. [FK-M]

20.72 Some people are going to need support long term. My thinking is it's great they are asking ABI's this info. Currently there is an assessment done, which allocates funding and hours based on this, and depending on the council you're in depends on how they allocate funds. They have everything streamlined already. Already well set up. [HC]

20.73 Currently highest density of people with disabilities 1:5 in Darebin – makes funding allocation far more competitive. To get linkages would have to give up some of funding. Ideally with NDIS, people would continue to get current services and be able to ask for more. If council could provide more hours it would be ideal as they have it streamlined. Although they could be better – things still take too long. [HC]

20.74 Should be less services doing the same things. When outsourced – everything gets slowed down. [HC]

20.75 No one should be disadvantaged and have any services reduced to fit into the NDIS. [VL]

Disability Requirements

Question: How should the Agency decide whether a person's impairments are (or are likely to be) permanent?

20.76 Error in using word 'permanent' with 'impairment'. Medical science seeks to address impairment. Allied health and nursing seek to minimise disability, address participation issues and resolve environment issues before they become a handicap. [GJ]

20.77 The word 'permanent' should be explained further. There is a case to be made to include : -

a. Rules should define disability not impairment .-

- WHO redefined 'impairment' as pathology – and does not point to impairment or pathology being permanent. [ICDC 10]
- Medical science has not advanced far enough to make a definition of impairment will be permanent. Any impairment left unattended will be permanent.

b. If left unresolved, could impact on functional ability –

- e.g RSI involving the hand can make become a permanent disability if not addressed early. There are many medical examples of minor problems becoming permanent – chronic pain is a very good example.

c. Disability should be assessed by a medical team made up by a medical specialist and allied health personal with experience in providing service for the disability. Only a team experienced in the field, can make the judgement of permanency. One individual – however qualified, cannot make this call. [GJ]

20.78 By receiving an initial assessment from the Client's local GP; or a Specialist with either 12 month, 2 year Updates. [TJ]

20.79 In the case of an eligible impairment clinical diagnosis or, a person centred appraisal of needs similar to the SCAN process used for schooling backed up by a statement

from a doctor or relevant health professional that the impairment is likely to be permanent. [SM]

20.80 In the case of non-specific impairments a person centred appraisal of needs similar to the SCAN process used for schooling backed up by a statement from a doctor or relevant health professional that the impairment is likely to be permanent. [SM]

Question: How should the Agency decide whether the impairments of a **person with ABI** are (or are likely to be) permanent?

20.81 Differing views of specialists – how does one know? No one can say you will definitely get back the use or part use of an arm. You can't always tell if someone is going to have a permanent disability, but it doesn't mean they need the support any less at that particular time. [HC]

20.82 This question can in many ways be read in parallel with the questions on Early Intervention. If early intervention access and practice is done well, then this increases the opportunities for reduction of permanent impact. [An.]

20.83 Consideration should be given to the reality that many individual ABI outcomes are changeable and varied, ie. rather than a constant rate of improvement, a person's condition may be marked by periods of improvements and decline. [An.]

20.84 Many impacts of an ABI may not always be visibly evident, but may remain permanent in nature, eg. Memory retention, social skills, etc. [An.]

20.85 In considering whether the injury is permanent, aspects to consider are: Severity of injury, recency of injury, and degree of prior access to rehabilitation. Consideration of whether the individual has reached neurological potential and functional potential over a likely early recovery period. [An.]

20.86 Determination of the permanency of an ABI requires - High level of expertise, specialist knowledge of ABI, access to appropriately skilled rehabilitation doctors, and other health professionals. [An.]

20.87 Basically Neuro psych report guidelines have been set. Any other relevant criteria that is available now. We should not have to reinvent the wheel. [VL]

Question: How should the Agency decide whether a person's impairments are having a severe impact on their lives: that is, by substantially reducing their (a) functional and psychosocial capacity (e.g. to get around, communicate or take care of themselves); and/or (b) social and economic participation

20.88 Only criteria used should be by a qualified team with experience in the field of Rehabilitation — physical and mental, paeds, adults and aged care. Each of these rehabilitation fields is specialised. [GJ]

20.89 Social and economic participation needs its own qualified team. A rehabilitation team cannot do this. [GJ]

20.90 By receiving an initial assessment from the Client's local GP; or a Specialist with either 12 month, 2 year Updates. [TJ]

20.91 Possibly, utilising an appreciation of the Client's social and economic participation from a Minister of Religion, School Principal; Bank Manager, Centrelink Social Security Counsellor. [TJ]

20.92 The claims are bona fide, this will be evidenced by the Agency's facilitator. [SM]

20.93 Evidence episodic events took place e.g. hospital / police records. [SM]

20.94 Clinical diagnosis. [SM]

Question: How should the Agency decide whether the impairments of a **person with ABI** are having a severe impact on their lives: that is, by substantially reducing their (a) functional and psychosocial capacity (e.g. to get around, communicate or take care of themselves); and/or (b) social and economic participation

20.95 Both of the above. They would both qualify. Neuropsych would say I'm fine, but if actually seen, they would realise there was a bit of an issue there. It is not an either/or, it is both. [HC]

20.96 'Real to life' assessments need to be done – more time needs to be spent with the client to actually assess how these parts of their lives are impacted. This is not something that can be judged in an hour, or over the phone, or even in one day, or in the one place. Assessments should be done over multiple visits and in multiple different locations involving many different daily activities. (*added after form filled) [HC]

20.97 By assessments, observations, self-reporting – to gather evidence to indicate whether an individual can safely and effectively meet their social and functional needs – within this, there is a need for an assessment of what the individual wants to do, mapped against current skills or opportunities. [An.]

20.98 As supports allow the person to do more, and realize that they could expand their goals, then ongoing periodic assessment for safety and skill development would be needed. [An.]

Question: What do the Rules need to say about people being able to provide the Agency with existing assessments that show they meet the disability requirements?

20.99 Rules must require assessment in writing, by teams nominated and recognised by the Agency. [GJ]

20.100 Assessment provided is up to date – 6 months margin. [GJ]

20.101 Ongoing funding and change in funding must have same criteria — a level of review that was done in last 4-6 months. [GJ]

20.102 Make the process simple using Centrelink, Department of SocialSecurity; or even Medicare information held on their own particular Databases about individual Clients. [TJ]

20.103 Existing assessments will be taken into consideration on a case by case basis and weighted in accordance with:

a. Currency of the assessment

b. The role of the person that provided the assessment

c. The outcomes of the NDIS assessment. [SM]

Question: What do the Rules need to say about a **person with ABI** being able to provide the Agency with existing assessments that show they meet the disability requirements?

20.104 How will the cost for these additional reports be met? That needs to be very clear as most participants will not be able to pay for these reports themselves. [FK-M]

20.105 They need to have them. Centrelink have a system set up where you provide them with xyz. They should negotiate with centrelink who already do all that stuff to assess whether they are eligible. [HC]

20.106 This system will overload GP's because they are required to provide evidence for so many people. Every three months. [HC]

20.107 People with definite permanent disabilities should be reviewed less. Everything repeats itself every year, it would be handy if things didn't need reviewing so often eg every 3 months. Home visits will establish if someone requires more – how they live etc – during audits. [HC]

20.108 Logistical issues eg not being able to get to IKEA to buy furniture to put clothes away, are often overlooked because reviews aren't usually involving home visit. If no one visited a house, no one would realise little issues that indicate someone is not coping. People need to be aware. Reviews done by case management auditing team through NDIS – someone independent who is accountable. [HC]

20.109 The Agency should have representative expertise to judge the validity of earlier reports in the current time – and if possible a process to ensure those reports are part of the Agency's assessment, and that only further assessment that would provide new info is brought to bear on the planning process. [An.]

20.110 These assessments, including Formal assessment, self report, contextual observation, may provide demonstration of the functional impact of the disability in the context of a complex lifestyle where an individual may have concurrent health issues such as mental health and AoD issues, co-morbidity issues. [An.]

20.111 Outside impacts of relevance – such as Criminal Justice involvement; mental health issues, which may often be an outcome of ABI, should be recognized in that diagnosis and response. [An.]

20.112 Overall, there is a need to encourage the 'lowering of the bar' of access to NDIS for ABI, in particular with mild ABI with severe impact, e.g. Co-morbidity of AoD, etc. Such provision of access to NDIS has social and financial benefits to both the individual and to the wider community, such as reductions in parallel support expenditures e.g. Potential reduced rates of Criminal Justice involvement. [An.]

Question: What can the Rules say to make sure that the Agency's decision is based on an assessment of what a person can do or aspires to do, rather than a diagnosis?

20.113 Change the words 'permanent impairment' for start. [GJ]

20.114 A team familiar with assessing short and long term rehabilitation needs, should always state clients ability, Clients current 'problems' or 'participation difficulties' and clients goals for short term and long term needs. [GJ]

20.115 Should prescribe management pathway, plan implemented and future direction which must include review date. [GJ]

20.116 In cases where there is a mismatch between ability and aspiration, an interim plan needs to be documented. Client's aspiration should be documented as future direction. [GJ]

20.117 You must have a base point of reference, so that assessments can be made when compared with the expectations of what can be achieved by a normal prudent person; taking into consideration, Gender, Age, etc. This burden of proof should be based on the balance of probabilities; NOT beyond all reasonable doubt! It is not a Court of Law! You are dealing with a person with a disability. Any systems must be humane, sensitive and morally right! [TJ]

20.118 The Agency's assessment is to ensure that the applicants eligibility under the NDIS takes into account:

a. The level of the person's abilities.

b. The physiological, psychological, and health and well being goals and aspirations of the applicant.

c. The likelihood of the applicant achieving those goals. [SM]

Question: What can the Rules say to make sure that the Agency's decision is based on an assessment of what a **person with ABI** can do or aspires to do, rather than a diagnosis?

20.119 Meeting with the prospective participant and having the RIGHT people conducting the interview/assessment. Many people with an ABI are very good with pretending that everything is okay because of the way NORMAL people may view us. If there is an intent to use medical professionals they have to be very carefully chosen. [FK-M]

20.120 Base it on potential as an individual. Some will never be independent, but could be in a better situation if given the right support and attention. People should never be told, "this is it", and given a level of acceptance. [HC]

20.121 The rules should state that the agency is required to make regular home visits, and make a personal plan based on the needs and aspirations of a person – after they have met - whether or not the agency can help them to achieve it all. (*added after form filled out) [HC]

20.122 A key consideration for appropriate response to ABI 'aspirations' should be the recognition of a person's life prior to their injury. Pre-injury goals, lifestyles and social attributes should be acknowledged. [An.]

20.123 There is also a need to indicate what 'aspire' is — and for a recognition of goal planning techniques for individuals with potential difficulty with idea generation, lack of experience, and potentially still learning what might be possible after a severe brain injury. [An.]

20.124 The understanding of what a person aspires to do may need to be revisited over time, periodically. [An.]

20.125 The appropriate evaluation and assessment requires a high level of specialist ABI knowledge within the Agency/providers, that needs to be related to that very area of goal setting in the context of changed identity, limited experience, and cognitive disorders. [An.]

Early Intervention Requirements

Question: How should the Agency decide whether early intervention is likely: (a) to reduce a a person's future need for supports? (b) to slow down or even stop a person from losing the ability to get around, communicate or take care of themselves? (c) to help families and other carers support a person over the long term?

20.126 With respect to (a), the Agency needs to perform:

a. Risk analysis and management to ascertain the impacts of: (i) Proceeding with the early intervention, (ii) not proceeding with the early intervention

b. Verification there is evidence to suggest the intervention produces positive results.

c. Frequency, Intensity and duration of the therapy.

d. Risk analysis that the net effect of the intervention will be positive rather than negative.

e. In the same way Private Health Insurance companies maintains lists the Agency needs to maintain and publish a list of: (i) Acceptable preventative measures, and (ii) Acceptable therapeutic measures. [SM]

20.127 With respect to (b), the Agency will need to see that any therapy or procedures for early intervention has evidence to show:

a. The therapy or procedure has improved the lives of others.

b. Frequency, Intensity and Duration of the therapy.

c. In the same way Private Health Insurance companies maintains lists the Agency needs to maintain and publish a list of: (i) Acceptable preventative measures, and (ii) Acceptable therapeutic measures. [SM]

20.128 With respect to (c), the Agency needs to:

a. See that the support is sustainable. For example: A child requires therapy 7 days a week, how will a single parent in the workforce meet the obligations for an hour a day 7 days a week during working hours. The therapist may need to travel to school to do the therapy and the parent might need to learn the

techniques for the weekend. A support worker or taxi may need to be booked to help transport the child to and from the therapist.

b. Measurable Key Performance Indicators and milestones in the intervention plan.

c. Cost / Benefit analysis [SM]

Question: How should the Agency decide whether early intervention is likely: (a) to reduce a **person with ABI's** future need for supports? (b) to slow down or even stop a **person with ABI** from losing the ability to get around, communicate or take care of themselves? (c) to help families and other carers support **a person with ABI** over the long term?

20.129 Everyone's journey is unique so that needs to be covered in the rules so there are no preconceptions that everybody should be able to walk in 6 months etc.. [FK-M]

20.130 It needs to be individualised and carers feedback should be taken into account as well. [FK-M]

20.131 All the above. There are varying degrees. OT's etc are basically used to gain some independence and a plan for how to achieve this, but then nothing…. The plan fizzles out because no one has taken responsibility to see it through. The people who said they would always be there get burned out and are gone. [HC]

20.132 With respect to (a): Evidence based practice, neuro recovery examples, which map the potential to benefit over the early recovery stage, and the presence or absence of opportunities to access early intervention. NB: Early Intervention might increase skill levels, and additionally, where it may not change skills, it may provide for more capacity to compensate effectively for lost skills. [An.]

20.133 With respect to (b): If a person has significantly reduced initiation, without Early Intervention to impose structured environment and programming, (routines),then the person may deteriorate due to inability to retain capacities. [An.]

20.134 With respect to (c):

a. Early Intervention offers the opportunity for education for family/carers, about ABI and expectations for recovery – and to ensure that respite is part of the long-term routine. It can offer early and long term indicators of expectations and support needs.

b. People involved in the Agency and/or evaluation process, should have the ABI knowledge and skills to recognise the specific and individualised social, family and community impacts of ABI, many of which may not be immediately evident or tangible. [An.]

20.135 Ask for expert advice from recognised ABI rehabilitation specialists (including the person's treating team). [R&L]

20.136 Reasonable and necessary will include activities/participation carried out by others in the community/neighbourhood; culturally significant. [R&L]

20.137 Evidence in literature to support; thought to be best practice by ABI experts

20.138 Ensuring assessments are functional and in context. [R&L]

20.139 a) and b) once more I believe that this comes back to having specialist assessment tools and specialists carrying out these assessments, in order to make this decision. A lot of time and consultation should be put into these tools and deciding what the capability requirements will be to be an assessor for clients with an ABI (and other specialised disabilities). The development of these tools and framework would need to take into account recent research on brain plasticity etc.. From experience, all people with ABI would benefit from early intervention and comprehensive programs that would aim at building capacity so that they could be maintained cost effectively and outside support could decrease over time. However, we feel that people with ABI would always need some form of support in place or at least very regular reviews to pick up on any underlying issues that could cause a regression long before too much progress is lost. We have an example of a client who received almost 24 hour care and is now down to 2 hours per week. No care was trialed for a short period, but there was a relapse. [MD]

Question: What will the Agency need to look for in order to decide whether using a new kind of early intervention will offer the best outcome for a person with a disability — while also making sure that money isn't wasted?

20.140 I don't like the use of the word best I think an acceptable outcome is better because some therapies cannot be undertaken for some people. For example, pain relief: Some people use drugs for pain relief whilst others use acupuncture. Which is the best? For a person with allergies to the medication acupuncture offers pain relief, but for someone who is terrified by needles drugs are the preferred option. [SM]

Question: What will the Agency need to look for in order to decide whether using a new kind of early intervention will offer the best outcome for a **person with ABI** — while also making sure that money isn't wasted?

20.141 Perhaps the age of the individual although this may cause some controversy. [FK-M]

20.142 Nothing should be considered a waste of money if there is even just a chance it will benefit someone. People shouldn't feel like they're on their own, and shouldn't feel like they're just "surviving", because people have to do something in life, otherwise it's demoralising. [HC]

20.143 There's a lot of time and money put in to assessments and setting things up, but no follow up – people drop the ball. It's often up to the client to follow things up and a lot don't have that ability. Something needs to happen so that follow up happens after therapist assessments – accountability and sustainability. [HC]

20.144 Organisations move the goal posts all the time – it's too difficult to keep up. Funding goes around in circles and just funds itself. [HC]

20.145 Evidence based practice – the link between the intervention, and the person's capacity to do what is required to reach their goals.. [An.]

20.146 Secondary outcomes - motivational factors. [An.]

20.147 ABI interventions require individual responses with the broad context in mind — the Early Intervention may have lower outcomes but may be a 'hook' that promotes further outcomes – (NB: this 'money not being wasted' question seems to be looking for a generic answer, a 'one wheelchair fits all' scenario, which is not appropriate to ABI support needs). ABI support must recognise individual needs and be specific to the (often changing) requirements of the setting/condition. [An.]

20.148 Pre and post evaluation. [R&L]

20.149 Goal setting-ensure that clear goals are formulated that can be measured. [R&L]

20.150 Gather information about early interventions-know what is evidence based or deemed to be best practice. [R&L]

20.151 Set up contract with person with ABI, whereby their obligations are clearly stated. Ie attendance to a program, participation in intervention etc.. [R&L]

20.152 Perhaps clear guidelines on being able to apply for and attend pilot programs on a test group first, with clear parameters as well as very clear goals that must be achieved by a certain date for it to be deployed nationally. This would allow NDIS to be a driver for research that could benefit globally also. [MD]

20.153 Parameters could include measuring success in the following areas against 'base results' with other tested interventions (this would mean getting some good baseline information);

a. Decrease in support hours (especially timeframe in which it occurs).

b. Decrease in behaviours of concern and therefore need for crisis intervention.

c. Decrease in package cost for that person. [MD]

20.154 They need to look at individual tailored approach plans -immediate and long term. [VL]

Questions: How will the Agency know when there is enough evidence to be reasonably confident that an early intervention is likely to result in the benefits listed above?

20.155 By initially funding the intervention as a trial and following up if successful with the full funding. [SM]

20.156 Looking for other precedents where the therapy has helped. [SM]

20.157 Checking the status of the therapy with Private Health Insurance companies or the Departments of Health and Ageing and Human Services (Medicare). [SM]

Question: How will the Agency know when there is enough evidence to be reasonably confident that using an early intervention with a **person with ABI** is likely to result in the benefits listed above?

20.158 Continued good mental health, and support from sufficient family and friends. [HC]

20.159 How family relationships are coping. How someone is managing their level of debt. [HC]

20.160 Funding for aspirations is important – depression as a secondary disability is overlooked too often. [HC]

20.161 Better understanding of people with ABI in the community so to not be judged. Would be nice to have assistance to put thoughts on paper and be published – funding aspirations for people to write and be able to educate the community through this medium – this would assist people with ABI and other disabilities both in respect to feeling part of the community, and to contribute to ongoing education of those in their community to not be judged. It would be nice for people to have a bit more compassion and understanding. [HC]

20.162 Observations and self-report as per comments previously mentioned. [An.]

20.163 Research findings. [R&L]

20.164 Thorough assessment/knowledge of the person's strengths and weaknesses. [R&L]

20.165 I think that this should be established at the onset of considering the pilot program. Once more, if they had baseline data, beating that baseline would be an indicator of success. Also, the pilot program would have to be large enough to ensure that the results can be duplicated across enough situations and people. [MD]

20.166 Be advised by the relevant diagnosis. Realising that and ABI from early stages changes as people progress through the different stage of neurological impairment and recovery/coping. [VL]

Participants' Plans

Reasonable and Necessary Supports

Question: How will the Agency work out which supports are (and are **not**) reasonable and necessary?

20.167 There is no simple direct answer to this question. What one does not do however is to list supports which may appear on average to be non normative. For example the WA Public Trustee some years ago determined that the personal funds of a young woman could not be spent on air-conditioning her room as this was not at the time common practice. She was bed fast, profoundly disabled, had little need for money and the air conditioning was about the only thing one could do for her (with her own money) to make her more comfortable. Judgements have to be made relative to each individual. [DH]

20.168 In the course of the Agency or the other parties pursuing their legitimate business. Inappropriate privacy considerations have in the past been restricted information sharing to the cost and frustration of many people with a disability and resulted in many additional assessments and reports. [DH]

20.169 Agency must have case management or case coordination – personal with qualifications for this role. [GJ]

20.170 Assessment of necessary and reasonable – will be based on assessment recommendations that clients come with. There must be time frames attached. [GJ]

20.171 What is implemented will need a team meeting between client, family/advocate, LAC and case coordinator. [GJ]

20.172 It is the role of an LAC, to ensure that there is no duplication of funded services. It is role of an LAC, to ensure clients do receive the services agreed to in a timely manner. BUT - LAC does not make a judgement call of which services client will need. [GJ]

20.173 Firstly they need to divide the goals up into classes: Physiological, Cognitive, Social and Economic. Then they need to divide the classes into categories (For example, 'Physiological' could be broken down into: Gross Motor, Fine Motor, Balance and Coordination, Speech). Then the categories need to be weighted firstly in isolation then as an aggregate of all classes. Then the Agency will need to determine the score that determines what the baseline is for reasonable and necessary. A risk analysis template matching impact against likelihood could be used to display what constitutes both reasonable and necessary. [SM]

Question: What **ABI-specific issues** will the Agency need to consider when it is deciding whether or not a support is reasonable and necessary?

20.174 That it incorporates the fact that our lives can change suddenly like from a fall and our needs may change depending on that incident. We may have been totally independent before that. [FK-M]

20.175 If all needs relating to a persons disability were covered by funding – people would have enough money for food and bills. If pressure was taken off other expenses then they would be able to afford those things. [HC]

20.176 If funding covered all necessities outside the "norm" – there would be an ability to save for other items eg. Computers, which are also not funded by anyone. But currently people live in private rental, and still need to pay for aids and equipment and subsidise support whilst on a DSP, leaving no room to buy "luxuries" which will provide opportunities to realise aspirations, and increase communication and a persons support network. [HC]

20.177 Acceptable to the client, linked to their goals. [An.]

20.178 The agency needs to recognise cognitive and communication supports, and not only those supports relevant to basic functional survival. For example,

a. mobile phone 'apps', that prompt the routine, assist with communication and compensate for short term memory loss etc.; and

b. photos that assist with memory retention and reconstruction of identity. [An.]

20.179 'Reasonable' needs to be seen in the context of the need to provide ongoing ABI support rather than short term, whilst complex skills are developed. [An.]

20.180 Reasonable support should provide the capacity to respond to issues which have historically been poorly addressed. Eg. retention of access to housing, Criminal justice and legal support, Mental Health support, typically in the context of ABI where aligned with co-morbidities. [An.]

20.181 'Reasonable' may also need to be seen in the context of the longevity of support required. Family and informal support which may typically be provided at a younger age, should not be assumed to continue to be offered by parents/carers at a high level at adult stages. Such care requires an NDIS response. [An.]

Question: How will the Agency make sure that the supports it decides to fund are in fact reasonable and necessary (especially for **people with ABI**)?

20.182 Do not pose threat to themselves or others. [R&L]

20.183 Do not jeopardise their health/wellbeing. [R&L]

20.184 Reasonable and necessary will include activities/participation carried out by others in the community/neighbourhood; culturally significant. [R&L]

20.185 Evidence in literature to support; thought to be best practice by ABI experts. [R&L]

20.186 Treatment relevant to the plan not something out of left field. [VL]

20.187 Regarding provision/purchase of equipment: My opinion is that the criteria & process as used for both Enable and also LTCSA & Workcover funded items should be followed, because they embody good clinical reasoning with some important checks and balances to make sure money is not wasted on items that are not appropriate or just the wrong thing because someone. These were developed by an experienced group of clinicians from a wide variety of organisations and background, of which I was one, so I know of the intent, extent and rigour of our discussions on these matters. [BT]

20.188 There should be broadening of the criteria of what is funded, to definitely include items related to recreation for example e.g. sports wheelchairs or hand trikes, however I would be very uneasy if the money was used to fund the most expensive item in an equipment category just because that was what the participant wanted (wouldn't we all like to have the top level model with all the gadgets?), not because there was any specific need to justify this. In that instance, then a mechanism should be put in place to contribute to the cost of an item with the participant funding the upgrade perhaps? [BT]

Question: What do the Rules need to say about the way in which the supports are to be funded?

20.189 The following options should be paid by the Agency

a. Reimbursement to the recipient of the service (full or partial)

b. Direct payment to the provider of the service on presentation of a valid invoice.

c. Blanket Order (Funds are committed once per year and expended throughout the year on the presentation of a valid invoice.)

d. Expenditure over more than one financial year (Reg 10 FFMA Act). [SM]

Question: What do the Rules need to say about the kind or persons or organisations that are allowed to provide the supports that are funded by the NDIS?

20.190 Standards clauses: i.e.

a. Providers must: be registered, have insurance, be financially viable, meet the criteria required for the police check.

b. Providers must not: be under suspension, be de-registered, be on the list of companies blacklisted for Workplace Health and Safety and Industrial Democracy issues, have unresolved criminal history. [SM]

Question: Are there any issues to do with how the Agency makes a decision about what supports are reasonable and necessary that are not covered by the questions above?

20.191 In the case of young children there is a potential for the child to say that they want to follow a course of action without fully understanding what it will mean over the short, medium and long term. A child might see it as not being necessary to speak if they are easily understood by their parents but once they hit school their ideas may well change. In our own case if we had understood the basic concept of removing the barriers that limited speech, we would have started therapy much sooner and had a more eloquent child by the time she hit school. As it was we only found out the barriers when she was 9 years old and over the past three years her speech has improved remarkably to the point where she now can hold short conversations with strangers. If the Agency were to take the child's view then windows of opportunity will be closed. If the Agency takes the parent/guardian view they may be overriding the child's wishes albeit for the greater good. The "Greater Good" concept should be applied in these situations and the rules need to articulate this. [SM]

Management of Plans

Question: How will the Agency work out whether it would be an unreasonable risk to a person if they managed (some of all) of their own funding? What will the Agency need to do and what will it need to look for in order to make this decision?

20.192 Lack of competency needs to follow current legal requirements. [GJ]

20.193 Clients who demonstrate risk need to be reviewed by social workers. There must be documentation of risk behaviour. [GJ]

20.194 The Agency can used basic procurement techniques to ascertain if an individual has the capacity to maintain control of their own funding. This is similar to getting a provisional licence to drive. [SM]

20.195 Start with low value items ensure there is a reconciliation process similar to petty cash. [SM]

20.196 If the individual exhibits the ability to handle this then give them greater delegation. Allow them to pay therapists. [SM]

20.197 Analyse the plans for expenditure. [SM]

20.198 Analyse any reports regarding the person's mental capacity/ability. [SM]

Question: How will the Agency work out whether it would be an unreasonable risk to a **person with ABI** if they managed (some of all) of their own funding? What will the Agency need to do and what will it need to look for in order to make this decision?

20.199 There is a need for a balance between individual rights and risk management, in a manner which requires an educated approach, ABI knowledge, and a common-sense approach. [An.]

20.200 'Test the hypothesis' [An.]

20.201 When obvious, there is co-lateral evidence, e.g. Cognitive assessments, sector and family feedback. [An.]

20.202 Demonstrated competence/demonstrated incompetence in breakdowns in performance around handling money/decision making. [R&L]

20.203 Agency to gather data from professionals/ stakeholders. [R&L]

20.204 If the person was able to manage their own daily living and competence to do things like, going shopping with their own money, paying bills, managing a budget the. Then in would be assumed by the Agency that the person could manage their own funding. [G&H]

20.205 Clarification would need to be ascertained that the person could manage the book keeping around the funding, this part of the job may need to be outsourced. Personal experience is this e.g. [G&H]

20.206 Look at person's history, is the Public Trust, or Office of AG involved in person's life, or is it in their future planning? This reflects competence.

20.207 Look for evidence of current competence (how has the person been going since their ABI), ask people in the persons life, carer, family, spouse, children, etc. If managing their lives independently what safe guards have they in place to manage their financial circumstances, i.e auto BPay. [G&H]

20.208 Once more I think it comes back to the assessment tool being developed by specialists and very carefully. The results from the assessment tool should outline whether there is a risk and rate that risk. This is a difficult one for ABI as we want to enable choice and independence, however, in most cases that we have, there would be a high risk of funds not being managed appropriately if it were managed by the clients themselves with no support. [MD]

20.209 Depends on the Neuropsychological test. There would have to be check and balance to see if a person can do what they think they can do. [VL]

20.210 Provide regular budget balances. [TJ]

Question: What are some things in a participant's plan that must not be managed by *any* participant?

20.211 If they have the cognitive ability and have been trained to do so – all of the plan except buying of services. Client must be involved in weighing the pro and cons of service providers. There needs to be a very good reason, if client's wishes are not taken into account. All final decisions and rationale for decisions, should be in writing. [GJ]

20.212 Medical procedures at any stage in life – should not be made by one person. [GJ]

20.213 Medical procedures that have the potential to lead to further disability. [GJ]

20.214 Purchase of Services and costly equipment, that purport to 'cure' or make 'miraculous changes ' to clients physical /mental status. [GJ]

20.215 Whether the Client has been convicted or not. This is confidential information. [TJ]

20.216 Whether the Client is a carrier of Aids, or any other Sexually Transmitted Disease. Hepatitis; and the like. [TJ]

Question: What are some things in the plan of a **person with ABI** that must not be managed by them?

20.217 Paying the providers for their services. [FK-M]

20.218 Current system generally does not include everything the client wants/needs, only what clients and family have already done, or things that they think they can do. Plans get muddied – no capacity to help with things that come up because "not in the plan" so not their responsibility. There needs to be a system whereby a plan includes every aspect of a person's wants and needs so that a holistic approach can be made - there needs to be more solutions than problems. [HC]

20.219 Finances are a high risk. [MD]

20.220 When reviews should occur (as they may not be able to assess whether it is required and also do not like their routine to be changed so they may avoid reviews). [MD]

20.221 This can only be answered on an individual basis as impairment manifests itself in many ways i.e. over stating ability to be able to do anything and everything. [VL]

20.222 'A person with ABI' does this also mean 'a person with ABI and/or their carer/guardian'? [TJ]

Reviewing a Support Plan

Question: What kind of changes (if any) can a person make to their support arrangements without needing to have a review of their plan?

20.223 Within the defined funding – clients should be able to change support arrangements but must show that there has been discussion and agreement with advocate and family . Client must have evidence in writing, that discussion has occurred with current support arrangement. [GJ]

20.224 Support arrangements dealing with – :

a. living conditions e.g time of carer service, type of recreational service , change of GP, transport arrangements. These can be changed by client. [GJ]

b. Changes to services provided – frequency of service, change from exercise activity to recreational, purchase of therapy and equipment must have some oversight. [GJ]

20.225 Change to agency providing support service must come back to the Agency. [GJ]

20.226 Changes to a provider where the changes were made necessary by the unavailability of the provider. [SM]

20.227 Purchase of alternative equipment that fills the same functions at the same price or less when the model approved is made obsolete or removed from the market. [SM]

20.228 Change of the goods supplier when the person can get a better deal or the supplier ceases to trade. [SM]

Question: What kind of changes (if any) could a **person with ABI** make to their support arrangements without needing to have a review of their plan?

20.229 Change of provider. [FK-M]

20.230 Should be ongoing. Do things in-house if possible. Council refuses to put certain things on care plans eg. kitty litter for OHS reasons. Carers come in who will not do something even if its just simple. NDIS will mean people can put on care plan what they want. People will argue that its against OHS. [HC]

20.231 On the flip side, there's OHS issues with the things that don't get done due to lack of funding e.g., not enough funding for time to dust, increases asthma etc. People should be able to add things to their plan without unreasonable bureaucracy getting in way and slowing down or stopping it. [HC]

20.232 I believe once more that the rules should not state this and that it should be down to the assessment tool and assessor to determine this. I believe that there should be a safety guard of a minimum amount of support hours that they would have to keep regardless, so that there can be that constant assessment that they are coping and are not at risk of a crisis or regression. [MD]

20.233 This can only be answered on an individual basis as impairment manifests itself in many ways i.e. over stating ability to be able to do anything and everything. [VL]

20.234 ANY change is inevitable with a person with ABI and change is constant. It is a constant trial and error. [TJ]

Question: What kind of circumstances can trigger an automatic review of a person's plan?

20.235 The Agency needs to see that the person has an annual assessment. [SM]

20.236 An application for increased services. [SM]

20.237 An application for goods or services above a threshold value. [SM]

20.238 Notification of a change in circumstances. [SM]

Other Matters

Information Sharing

Question: When would it reasonable for the Agency to share a person's private information with a Commonwealth or state or territory authority?

20.239 Death- no longer needs the funding. [LW]

20.240 Fraud.

20.241 Limited private information for auditing purposes, i.e. gender, age, locality by postcode maybe. [LW]

20.242 YES- with the proviso that information will not be used to exclude client from the provision of services. [GJ]

20.243 When the Client relocates from one State, or Territory to another; and presents themself for treatment. [TJ]

20.244 When the Client seeks assistance from any Nominee or Service Provider. [TJ]

20.245 The same conditions that apply to a person's Medicare records should apply to the Agency's data holdings. See The Health Act (1953) Section 130, The Heath Insurance Act (1973) Section 135, The Privacy Act (1988). [SM]

Question: When would it reasonable for the Agency to share the private information of a **person with ABI** with a Commonwealth or state or territory authority?

20.246 If they are requesting some type of additional funding from either of these bodies. [FK-M]

20.247 Depends what you're after. Stats without names should be fine. [HC]

20.248 Only for legal matters as per usual legislation. [MD]

20.249 De-identified information on pilot programs for research outcomes? [MD]

20.250 Never, unless they have the expressed permission and the exact requirement of what is being given and why. [TJ]

Question: How can the Agency make sure that people with a disability can get the support that they need, while respecting their privacy at all times?

20.251 Only disclose necessary information relevant to their support. [LW]

20.252 Respect the client's right to withhold certain information that is not relevant. [LW]

20.253 Build in review system at onset – before funding is agreed to. Review, at predetermined intervals, of needs and services must be a legal requirement of funding. [GJ]

20.254 The Agency must maintain client records in a secure environment and have a workable Security plan in accordance with the Defence Signals Directorate Information Security Manual. [SM]

Question: How can the Agency make sure that a **person with ABI** can get the support that they need, while respecting their privacy at all times?

20.255 Asking them individually what support they need and not assuming what they need and making sure this information is not available to all and sundry as it can make people very vulnerable. Everyone who has access to this information should be police checked and some sort of audits/controls put in place to ensure staff are not accessing files they should not need to see. [FK-M]

20.256 By respecting a person's confidential information – share info if needed but no need to give out names etc. [HC]

20.257 Once more a good assessment tool would establish what the agency must know in order to make the right decision and in order to develop an effective plan to reach the person's goals. Those would be the parameters of what the person with ABI would have to be prepared to share to get the package (and clearly explained beforehand). [MD]

20.258 If people can be reassured that their information will not be used for other reasons, it would be more accepted. [MD]

20.259 Ask them for permission each time, its not hard!! [TJ]

Registered providers of support

Question: How should the Agency decide whether it will register (or de-register) a provider?

20.260 Set of competencies that must follow, maybe based on Disability Services Standards? [LW]

20.261 Providers that are already established and have been providing support should get priority over 'new' providers who may have been set up to access the funding. [LW]

20.262 Both require agency to have criteria established- job description for a provider. [GJ]

20.263 Providers must submit along guidelines set by Agency. [GJ]

20.264 To be registered a service provider must show:

a. They have the appropriately qualified staff to do what has been claimed.
b. There is evidence of up-skilling and ongoing training of staff.
c. In complex care cases, provider must show clear evidence that staff have been trained to take on clients particular needs- physical and mental.
d. Provider must have a pathway to review client's needs at least x1/year. The review to be done by appropriately qualified personal, in house or external.
e. There must be in-house reviews at set intervals.
f. Pathway for external review should be evident. Preferably by professionals recognised, as an assessment centre by the NDIS agency. [GJ]

20.265 Provider is de-registered when:

a. latter do not full-fill their service requirements.

b. Provider is deregistered if there is misconduct or funds miss-management. [GJ]

20.266 Determine first what a breach is. Every Act of Parliament, lists definitions that that Act/ and or Regulations uses at the front of the Act/Regulations. Include the definition of a breach in this list. [TJ]

20.267 Determine how many breaches must occur before de-registering occurs (e.g. three Strikes and you're out! Etc.) [TJ]

20.268 This must be clear, concise and succinct! [TJ]

20.269 [Registered providers of support] needs to potentially include (or not exclude) employees of government funded organisations, such as myself for example.[9] Currently there is an issue re Better Start early intervention funding (another Commonwealth Government initiative), in that employees of govt organisations are specifically not eligible to provide services. This impacts on families trying to buy therapeutic equipment such as walking frames or modified trikes, as my recommendation is not recognised for the purpose of funding (Children who have their brain injuries at a young age can be diagnosed with cerebral palsy, and thus eligible for this funding). I understand re not funding of the service we provide, but there needs to be a way to ensure that we can make or assist with other recommendations regarding other things equipment for example. [BT]

20.270 Department of Health and Ageing would be a good source for rules for accreditation as they have responsibility for Aged Care and Health Professionals. [SM]

Question: How should the Agency decide whether it will **register** (or **de-register**) a service that is providing support to a **person with ABI**?

20.271 By obtaining feedback from the participants, their families and their carers. [FK-M]

20.272 They should work out if case management for example, has solved more problems than it has created. Has it benefitted the client, compared to how much funding has gone to supporting the client, as opposed to gone in to their own pocket. [HC]

20.273 Register: to keep things simple is really important. I think to be a legal entity and have accreditation relevant to Attendant Care Industry. However, it is really important that the actual accreditation not be listed (ACIMMS, ISO...) as there are many and service providers have different ones. It would be good to just list that they must be accredited against a system that is JAS ANZ approved and relevant to Attendant Care Industry. Having these two things means that the Service Provider is then liable for all legal and quality requirements but removes the need for a huge quality management process for the Agency. [MD]

20.274 De-register: any of the two items above changes or criminal charges against company or head of company. They could have a list of reportable items that would mean de-registration that must be reported within a defined time-period. And then consequences if not reported. [MD]

20.275 In relation to ABI specifically – could there be a link to BIA? [MD]

[9] This respondent (Bronwyn Thomas) is a Senior Physiotherapist with the Brain Injury Service, Kids Rehab. at The Children's Hospital, Westmead, NSW.

Question: How will the Agency make sure providers don't have to go through a lot of red tape, while also making sure that services are delivered to the highest standard?

20.276 Set of 'care standards' that providers must abide by and unannounced audit/inspections to see if they are adhering to them. These standards made a part of registration with the Agency. [LW]

20.277 Self-assessments and mandatory reports that providers must provide to the Agency. [LW]

20.278 To ensure that services are delivered to the highest standard, the NDIS agency needs to have a data base of recognised assessment centers.

a. Assessors have the experience and qualification, to assess clients.

b. All reports lay out current client status, disability that will restrict clients participation, pathways and rationale – based on clinical reasoning- to meet immediate needs and future needs - 5 year and 10 years.

c. This recommendation, in particular, for clients who need substantial support, needs to be agreed to by client, family /advisor, and LAC. This is then submitted to NDIS agency. [GJ]

20.279 To reduce red tape,

a. when funding is approved, clients/advocate, to liaise with the Agency directly, by way of direct access to a case manager/ case coordinator, from the Agency.

b. On case by case basis – medical personal and assessing team members, be able to highlight issues , needs, change in status, unmet needs , communicating this directly to case manager from Agency.

c. Carers and clients should be able to request review, if changes in mobility, self - care and self- management, become evident.

d. First review to be done by the agency providing care.

e. If there is controversy or disagreement – clients and carers should be allowed to get second opinion and submit this to Agency directly. [GJ]

20.280 Keep it Simple! [TJ]

20.281 Recommend that a Systems, Efficiency Consultant, be employed to come up with what system the Agency and others will use. [TJ]

20.282 Consult with the sector. [SM]

20.283 Provide the ability to submit data over the internet via a web browser on internally supported application. [SM]

20.284 Maintain and publish publicly the meta data for the input required. [SM]

20.285 Provide user guidelines for data submission. [SM]

Question: How will the Agency make sure services that provide support to **people with ABI** don't have to go through a lot of **red tape**, while also making sure that services are delivered to a the **highest standard**?

20.286 Regular auditing, and independent auditing, and asking the clients and family, and not just relying on the service providers for feedback. [HC]

20.287 Exactly, if I want to hire the services of a friend or (extended) family member I should be able to do so without any red tape. Persons with ABI require services from someone familiar and they need to feel comfortable with them. [TJ]

Question: What kind of information will the Agency need to collect from registered providers of supports to make sure that people with disability are exercising choice and control over the supports they are getting?

20.288 Intake documents and what information providers require before they agree to provide the service, do their documents 'read' in a client centred way? Are they in/available in an accessible format? [LW]

20.289 Client 'get out' clause, how easy is it for a client to suspend that service if they no longer wish to use it? Do they have the choice to suspend that service? [LW]

20.290 Policies and procedures relating to service delivery, do they 'read' in a client centred way, is the client the centre of how they deliver a service? [LW]

20.291 Agency needs to match the goals or aims set by client, family or professionals, to service provided by care agency. [GJ]

20.292 Agency must have a team of allied health and medical personal who can discern that the care plan provided, will service the client's needs and goals. A panel of qualified persons- an assessment or review sub- committee, especially for contentious cases. [GJ]

20.293 Care agency must be required to send in written reviews of service provided. This should match details submitted in initial funding. [GJ]

20.294 Clients and advocate should have prescribed forms, that will allow them to write directly to case manager. Matching the 2 sets of information will allow for some over sight. [GJ]

20.295 Whether the Client is receiving treatment, seeking Exercise Programs, thereby reducing claims against Medicare. Eg. Key Performance Indicator (KPI). [TJ]

20.296 By receiving an initial assessment from the Client's local GP; or a Specialist with either 12 month, 2 year Updates. [TJ]

20.297 ABN, Company information, Quality Standards attained, Services and goods provided. [SM]

Question: What kind of information will the Agency need to collect from registered providers of supports to make sure that a **person with ABI** is **exercising choice and control** over the supports they are getting?

20.298 Evaluations or feedback collected when services are delivered on an ongoing basis. [FK-M]

20.299 Current care plans are going to be handed over with things on them that the service has not actually done, so they need to speak with the clients directly to find out what the agency has done, and what the person did for themselves – need a measurable gauge between what they want and how they feel the process went for them. [HC]

20.300 Proof of accreditation and reaccreditation. [MD]

20.301 Reportable items. [MD]

Question: What kind of information will the Agency need to collect from registered providers of supports to make sure that the Agency can make decisions about the NDIS that are based upon good evidence?

20.302 Satisfaction survey results, ACCC information, DoHA / DHS accreditation (Health Professional Provider Numbers), Access to Personally Controlled Health Electronic Records (PCEHR) at the clients discretion. [SM]

Children

Question: What do the Rules need to say about the kind of person who can act on behalf of a child if they are not a parent?

20.303 Determine the connection/relationship between the person and the Child is. E.g., Parent, Foster Parent, Carer. [TJ]

20.304 Consider any other legalities? [TJ]

20.305 What if the Client/Child is convicted and imprisoned; in a Gaol; or on remand/awaiting trial; pending matter(s), yet to be heard or finalised? [TJ]

20.306 What if the Client/Child has been detained, vide a S23 Order of the Mental Health Act? [TJ]

20.307 What if the Client/Child is a Ward of the State? [TJ]

20.308 Who acts on behalf of these persons? [TJ]

20.309 The plan nominee or correspondence must have legal guardianship of the child and power of attorney. [SM]

Question: What do the Rules need to say about the kind of person who can act on behalf of a **child with ABI** if they are not a parent?

20.310 Police Checks need to be carried out that the individuals concerned are fit to carry out this role and they should be audited and proper controls put in place to ensure they are carrying out their duties appropriately. Ensure they are taking the needs of the child into consideration always. [FK-M]

20.311 Someone with their head on their shoulders, who does not have an invested interest (if financial) but has an understanding. [HC]

20.312 I would imagine that the same rules around legal responsibility for a child should apply in this case. [VW]

20.313 Legally mandated guardian; court ordered; deemed to be suitable as per department of child safety. [R&L]

20.314 The guardian needs to have demonstrated skills to care for a child/adolescent with special needs and to understand normal development as well as the impact of ABI on normal development. [R&L]

20.315 The guardian needs to be able to demonstrate specialist skills required in caring for the child/adolescent e.g. providing PEG feeds, transferring using a hoist; handling difficult behaviours. [R&L]

20.316 The guardian needs to fully understand the medico-legal aspects, confidentiality, their rights and the rights of the child/adolescent. To ensure the well being of the child/adolescent. [R&L]

Question: How can the Agency decide when a child under the age of 18 is able (or not able) to make decisions about their supports?

20.317 Gillick competency (UK based frame work for assessing children's competency) - Can the child understand the decision they are making? Can they understand the implications of their decision/choice? Do they know and understand the risks/benefits? If so does this show they have the capacity to make that choice? [LW]

20.318 Are the parent's decisions for the child's best interests or are they biased with parents wants and needs? [LW]

20.319 This will be subjective and not objective, based on each individual's state of mind, maturity, ability; disability. [TJ]

20.320 Will Authorised Officers, eg Correctional Services, Youth Services, etc. [TJ]

20.321 The Agency needs a flag to indicate who lodged the application the person with the disability or a third party. [SM]

Question: How can the Agency decide when **a child with ABI** under the age of 18 is able (or not able) to make decisions about their supports?

20.322 Assessment with each child to ascertain their capabilities to make decisions about their requirements. [FK-M]

20.323 Neuropsych assessment. Mental health assessment. If no parents. [HC]

20.324 To cover the range of age and cognitive abilities in children with ABI, I feel that discussions should take place with at least one parent/legal guardian present. The discussions about support should be inclusive and educative so that any decisions a child might make will be informed and supported by their family/carers. [VW]

20.325 Primary principal should be that child is included as much as possible; however, legal guardian/parent has final decision making capacity until age 19. [R&L]

20.326 Assessment of cognitive capacity, mood, self awareness etc. reasonable in context of children and families. [R&L]

20.327 Agency should seek to gather information from specialists (treating teams) and stakeholders (teachers, care-givers, parents). [R&L]

20.328 Risk needs to be assessed-high risk situations require more thorough assessment and input from others. [R&L]

Question: To ensure that a child or young person under the age of 18 is involved in decisions about the support they receive, what kind of additional supports could be given to (a) that child or young person and to (b) their parent or guardian?

20.329 Easy to read information that the child can understand so they can make an informed choice. [LW]

20.330 Collect a number of opinions from other Support Agencies, NGO's that either the child has been in contact with' including Parent's, Foster Parent, and/or Careers Guardian's, etc. [TJ]

20.331 With respect to (a): Access to a facilitator or an independent third party to record participation or non-participation of the NDIS client or verification at interview that consultation took place. [SM]

20.332 With respect to (b): Access to a facilitator or an independent third party to record participation or non-participation of the NDIS client or verification at interview that consultation took place. [SM]

Question: To ensure that **a child or young person with ABI** under the age of 18 is involved in decisions about the support they receive, what kind of additional supports could be given to (a) that child or young person and to (b) their parent or guardian?

20.333 Some sort of mentoring perhaps from individuals who have already carried out this role successfully. [FK-M]

20.334 Ask the people that this is more relevant to. [HC]

20.335 The biggest challenge for young people and their parents/guardians is to decide…

a. what supports they want or need and

b. who to go to for provision of these services - especially if consortiums of providers (as in the example of funding for children with ASD) appear in numbers! [VW]

20.336 Providers of services should be registered with the NDIS and comply with criteria decided upon by the NDIS in association with the relevant national organizations (e.g. the Australian Physiotherapy Association; Occupational Therapy Australia Ltd.; Australian Psychological Society; Speech Pathology Australia etc.). [VW]

20.337 Communication aids/devices for children/adolescents with communication difficulties. To ensure they can participate in decision making. [R&L]

20.338 Information is tailored to their age and cognitive level; is accessible and easy to understand; multimodal and relevant to different cultures. [R&L]

20.339 Legal/case management support. [R&L]

20.340 Flexible with the types of supports funded. [R&L]

20.341 Goal directed with child's views taken into account. [R&L]

Question: What do the Rules need to say about how the Agency can best reflect the fact that as children and young people with a disability get older, they may want to have more say in what they do, and the care and support they receive?

20.342 Flexible support and regular reviews of care to under 18s, this will ensure that the child is included and as they mature have more of a say in their support. [LW]

20.343 Regular family reviews will also allow the parents to see how their child is progressing and maturing and may make them more likely to notice the changes in their child than if they were making all of the arrangements. [LW]

20.344 This will be subjective and not objective, based on each individual's state of mind, maturity, ability; disability. [TJ]

20.345 Flexibility must be the key. Not rigid! [TJ]

20.346 This should be covered under the review process with mandatory reviews on reaching age thresholds. [SM]

Question: What do the Rules need to say about how the Agency can best reflect the fact that as **children and young people with an ABI** get older, they may want to have more say in what they do, and the care and support they receive?

20.347 Constant reviews and assessments. [FK-M]

20.348 The regular reviews of the support plan should include the young person; the review could call for qualitative evidence (such as "Quality of Life" questionnaires; the Canadian Occupational Performance Measure) that are often part of allied health services planning discussions with children and their families. [VW]

20.349 Respect for development of young person; that any restrictions are commensurate with age and/or demonstrated abilities/disabilities. [R&L]

20.350 Involvement of children regardless of age in assessment process – increasing involvement with increasing age. [R&L]

20.351 Regular reviews so that there is detection of developmental changes, especially at critical periods of development (i.e. transition to high school; transition to adulthood). [R&L]

20.352 Assessment tools that reflect developmental trajectories (appropriateness of skills at different developmental stages). [R&L]

Question: What do the Rules need to say about the best way to help a child to express their views about the support that they receive?

20.353 Accessible formats. [LW]

20.354 Less formal reviews so the child is more comfortable. Maybe held at the child's home/school. [LW]

20.355 Inclusion of a 'key person' in the child's life, this may not necessarily be a parent/teacher. It would be somebody the child is comfortable to talk to. [LW]

20.356 If the child has the capacity to communicate their wishes directly then they should be considered! Otherwise they should or could be received from the child's Parent(s), Foster Parent(s), Guardian(s); or Carer(s). [TJ]

20.357 This needs to be discussed with an independent third party on hand or in under an interview process to verify the child's opinion has been accurately recorded. [SM]

Question: What do the Rules need to say about the best way to help **a child with ABI** to express their views about the support that they receive?

20.358 Ensure they are aware of what support services are available and given the necessary information to make an informed decision. [FK-M]

20.359 This question should be viewed in context of the Systemic issues re the criteria for recognition of ABI in children. Children in the mainstream education system may find themselves expected to access the educational supports required e.g. Integration Aides within the school, but may find themselves a) ineligible, b) not recognised as needing support c) supported by Educational staff with limited or no knowledge of ABI. [An.]

20.360 Communication devices. [R&L]

20.361 Goal setting tools appropriate for young people/use of diagrams/pictures etc.. [R&L]

20.362 Providing choices. [R&L]

20.363 Involvement of children regardless of age in assessment process – increasing involvement with increasing age. [R&L]

Supporting decision-making

Question: How should the Agency decide what kind of person should (or should not) be appointed as a nominee?

20.364 A nominee should be:

a. Person chosen by client but family needs to be able to have a say in this. Family needs to be defined as parent and or siblings actively involved in supporting client.

b. Person who has the time to follow through.

c. Person who does not have a monetary gain from this arrangement. [GJ]

20.365 A Nominee should not be

a. Person who does not have safety clearance.

b. Who has ties with care agency providing service. [GJ]

20.366 The plan nominee must be an appointed legal guardian if not a parent by birth or adoption. [SM]

Question: How should the Agency decide what kind of person should (or should not) be appointed as a nominee for a **person with ABI**?

20.367 Need to distinguish between legal guardianship/decision making and less formal nominee arrangements. [R&L]

20.368 Formal capacity assessments. [R&L]

20.369 Interview and gathering of collateral evidence e.g. referee reports. [R&L]

20.370 Query: what is the role of the Public Trust and the Office of the AG in the NDIS process, because they typically are the nominee? [G&H]

20.371 Query: is it possible to have a stat health authority SHA (like dis services qld) as nominees? Do people in the NDIS have a SHA? [G&H]

20.372 Consent needs to be provided by the person who they want as a nominee and who they don't. [G&H]

20.373 Does the person have an appointed informal or formal guardian? [G&H]

20.374 1Age (not minor for example). [MD]

20.375 Assessed cognitive ability allows them to make sound decisions. [MD]

20.376 Relationship and history with participant. [MD]

20.377 Clear criminal record check – similar requirements than those required in Aged Care principles. [MD]

20.378 Assessment of how comfortable the participant is around the nominee and displays trust towards the nominee. [MD]

Question: What will the Rules need to say about how a nominee can show that they understand the participant's wishes, goals and life aspirations?

20.379 Able to demonstrate at planning meetings, that they are able to discuss with client the pros and cons of plans laid out and arrive at a decision. Able to communicate this to care support agency and the NDIS agency. [GJ]

20.380 The Nominee should deliver to the Client, their understanding of what the Client's wishes, goals and life aspirations are. Both the Client and the Nominee should, date and sign. In other words, the Nominee and the Client are seen to work together as a team, working on the same page; so that there are no misunderstandings. [TJ]

20.381 The plan nominee if other than a parent will need to provide evidence of continued support in a statutory declaration and references to support their evidence. [SM]

Question: What will the Rules need to say about how a nominee can show that they understand the wishes, goals and life aspirations of a **person with ABI**?

20.382 Interviewing both the participants and the nominees and verifying that they do match and if there are any discrepancies they need to be checked before proceeding. [FK-M]

20.383 Must participate in assessments and reviews. [MD]

20.384 Test participant's level of satisfaction with services and decisions over time and perhaps more often in the early stages. This does not have to be directly with the actual decision but could be monitored through episodes of behaviours of concern for example. [MD]

Question: How can the Agency tell that the decisions of a nominee are reasonably those the person would have made if they had the capacity to do so?

20.385 Assessment information, given by the assessing team, should be the criteria to determine if nominee decisions are reasonable. [GJ]

20.386 Decisions do not put client's well -being at risk. This needs assessment of the decision by qualified personal, e.g monetary decisions verified by social worker or account. Medical decisions verified by pt's GP. [GJ]

20.387 Again, refer back to what a normal prudent person would do in the interests of a Client/Child! [TJ]

20.388 Would the decision be reasonable, given all the circumstances? [TJ]

20.389 Any doubt should rest on whether the decision would have positively influenced the wellbeing and/or circumstances of the Client/Child. [TJ]

20.390 This would require a case worker with an in-depth understanding of the client. The concept of "Greater Good" for the client should be applied where the client does not have the capacity to articulate the decisions they would make. [SM]

Question: How can the Agency tell that the decisions of a nominee are reasonably those the **person with ABI** would have made if they had the capacity to do so?

20.391 By verifying with the participants as best they can. [FK-M]

20.392 If the person has communication problems, then they need to have s plan in place to ensure what their $ being spent on is what they want. [G&H]

20.393 Cultural considerations, if the person's nominee is family what is the families cultural beliefs around money and how money is shared. [G&H]

20.394 Assess outcomes against goals and other parameters determined by the assessment/assessor. [MD]

Question: What will the Agency need to put in place to make sure that the nominee arrangements can change?

20.395 Rules must allow for discharge of Nominees who have proven to be ineffective. [GJ]

20.396 Similarly, there should be a written process/request from the Client to the Nominee of what changes should occur. However, a request is only submitted after a discussion is held between the Client and the Nominee. [TJ]

20.397 If the Client is dissatisfied with potential changes. An Appeal process should be created and actioned, if the changes do not occur. [TJ]

Question: What will the Agency need to put in place to make sure that a **person with ABI's** nominee arrangements can change?

20.398 That the contracts of any with the nominee clearly state this and that there is choice with the nominee as well and they need to be carrying out the wishes of their clients. [FK-M]

20.399 Review document that includes the statement that the nominee arrangements can change if the person wishes or circumstances change. [G&H]

20.400 Regular reviews should be in place to assess the need for this to happen as people with an ABI may not take it upon themselves to ask for it. [MD]

Question: Nominees need to support a participant's decision making personally and give appropriate weight to their views. What other things will nominees need to do?

20.401 Nominee needs to be the advocate to ensure plans laid out, funding and services, match. [GJ]

20.402 Advocate to Agency, if client is not getting the services funded for. [GJ]

20.403 They should seek medical history/treatment/suggestions; and recommendations from Health Care Professionals. [TJ]

20.404 Still concentrate on the team approach between the Client and the Nominee; as mentioned above in the answer to Q.4b. This should be the main focus. [TJ]

20.405 Nominees will need to be trained with respect to the rights, responsibilities and obligations in their role as plan or correspondence nominee. [SM]

Question: A nominee of a **person with ABI** need to support their decision making personally and give appropriate weight to their views. What other things will a nominee of a **person with ABI** need to do?

20.406 To understand what is important to the participant they are representing and ensure that that is what is being delivered. [FK-M]

20.407 Ensure the persons goals and outcomes are met. The person is spending their money how they need to. [G&H]

20.408 Ensure accountability for service provision Is maintained. [G&H]

Question: Do the Rules need to say that the appointment of nominees are for a fixed period? Or would it be better if the appointment was reviewed on a regular basis to make sure the person with disability was satisfied with their nominee?

20.409 Must be reviewed regularly- based on feed- back to case coordinator, by client. [GJ]

20.410 Yes, consider 6 monthly , 12 monthly, two yearly reviews between the Client and the Nominee. As mentioned previously. The main focus is a team approach between the Client and the Nominee. [TJ]

20.411 The second option is preferred with a point that the appointment should be part of the review process. [SM]

Question: Do the Rules need to say that the appointment of a nominee for a **person with ABI** are for a fixed period? Or would it be better if the appointment was reviewed on a regular basis to make sure the **person with ABI** was satisfied with their nominee?

20.412 The latter. [FK-M]

20.413 Would want some flexibility to change nominee – would want it to be reviewed and assessed individually, outcomes and support, have things to be budgeted for in the long term. Constant feedback and constant follow up from the agency responsible. [HC]

20.414 Regular reviews that are driven by person with ABI to make sure person satisfied, and according to outcomes and goals. [G&H]

20.415 Absolutely option 2 would be the smoothest option, with regular pre-planned reviews and a specifically designed process and tool for assessors to pick up on any, initially hidden, issues. [MD]

20.416 Other issues should trigger review; hospitalisation, change of address, etc.. [MD]

Question: What can the Agency do to make sure that the nominee arrangements continue to build the decision-making capacity of people with a disability?

20.417 Nominee should be part of team meetings at initial assessment and review meetings. [GJ]

20.418 The Agency should continue/commence dialogue with the Agencies, NGO's, ensuring that the clients have as much ownership of their treatment; where possible. [TJ]

20.419 The Agency could produce and publish educational material that helps people gain the confidence to take control of their own lives. [SM]

Question: What can the Agency do to make sure that the nominee arrangements continue to build the decision-making capacity of a **person with an ABI**?

20.420 Constantly reviewing that the needs of the person with an ABI are being met by face-to-face contact and without the said nominee being present. [FK-M]

20.421 Include the person in aspects do decision-making. [G&H]

20.422 Actually if decision-making is an area of need, build a therapy plan (could be anything like technology/services of professional) to increase skills. [G&H]

20.423 This should be built into the assessment, review and goals setting process. Assessing that; goals have been achieved, and if not, that reasonable reasons have hindered the progress. [MD]

20.424 Once more, I believe that the detail of this should not be in the rules but be part of the toolkit for assessors and be developed by appropriately qualified people/team probably under the auspices of BIA. [MD]

Compensation

Question: What do the Rules need to say about how compensation payments for care and support are treated in working out how much care and support should be provided by the NDIS?

20.425 Client who does receive a compensation pay out should be required to have a 'administrative order' – to ensure money is spent on needs. [GJ]

20.426 Rules need full disclosure of pay out and terms of pay out. [GJ]

20.427 Rules need to require assessment by a qualified assessment team, if payout is insufficient to meet client's needs. [GJ]

20.428 Rules need to have a position on clients who have received payout but money spent on family home that client, now, is unable to stay in, or requires more support than the current situation can offer. [GJ]

20.429 Clients whose payout has run out should not be excluded by the wording of the rules. [GJ]

20.430 There should be a number of meetings held by the Agency with the Nominees and NGO's, so that an agreement or a MOU be received before the NDIS commences. However, this could take considerable time; but is essential, upon agreement, before the NDIS commences. [TJ]

20.431 The rules need to state:

a. Precedence of distribution

b. Management of the difference. For example: If the payout through compensation is greater than what the NDIS package would provide. If the payout through compensation is equal to what the NDIS package would provide. If the payout through compensation is less than what the NDIS package would provide.

c. How indexation is to be applied and what happens when indexation causes the difference to change from less to more, more to less and more to equal. [SM]

Question: What do the Rules need to say about how compensation payments for the care and support of **a person with ABI** are treated in working out how much care and support should be provided to them by the NDIS?

20.432 That the NDIS provides the support services that the client needs. [FK-M]

20.433 Care might change over time. Care will be needed for things that consistently pop up that a person cannot do. A person may need to be flexible or their needs may remain stable. The bottom line is that not everyone will be able to return to work, but if a persons capacity can return to a stable head space, then that person can contribute to society at large and help other people get to this point who are in a similar situation. [HC]

20.434 Once more, if sufficient time is allocated, and appropriately qualified people develop the assessment tools and principles, then this should all be outlined in the toolkit. The only things that should be in the rules are perhaps a maximum ceiling amount per person and that the assessment tools and assessors determine this. [MD]

20.435 Finally, it is important to note that for the assessment of ABI needs to be truly effective, there needs to be a case management approach where as many stakeholders as possible are involved at initial assessment and review. The decision should not lie solely with the agency assessor as they may have to deal with internal pressures linked directly to costs. There should also be a very clear grievance / appeal process and requirements that the agency must follow including transparency. [MD]