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BACKGROUND PAPER ON THE NDIS / NIIS

1. Eligibility & Assessment

An analysis of the extent to which the Productivity Commission endorsed the recommendations submitted by Brain Injury Australia and its member organisations.

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Abbreviations:

BIA 2010	Brain Injury Australia (prepared by Victoria Schneider), "Submission to the Productivity Commission's Inquiry into Disability Care and Support" (August 2010).
BIA 2011	Brain Injury Australia, "Supplementary Submission to the Productivity Commission's Inquiry into Disability Care and Support" (April 2011).
BINSA 2010	Brain Injury Network Of Sa Inc, "Submission To The Productivity Commission's Inquiry Into Disability Care And Support" (16 August 2010).
FBIC 2011	Friends of Brain Injured Children (ACT) inc., "To the Productivity Commission in consideration of the proposed National Disability Insurance Scheme" (2011)
Headwest 2010	Headwest," Headwest Brain Injury Association WA Inc. Submission to the Productivity Commission Long Term disability Care and Support Inquiry: (2010)
Headwest 2011	Headwest,"Disability Care and Support Productivity Commission Draft Report Submission" (2010)
PC	Productivity Commission, *Inquiry Report – Disability Care and Support*, No. 54 (Australian Government, July 2011).
PWC 2011	"Disability expectations: Investing in a better life, a stronger Australia" (PwC, November 2011)
VCASP/VBIRA 2010	"Submission from VCASP and VBIRA to Productivity Commission Inquiry into Disability Care and Support" (August 2010)

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A | Eligibility

> *"With the level of unmet demand already high, many people find themselves 'defined out' of services despite a very real need for assistance. Rationing has created a 'shadow army' of individuals who exist on the margins and who cannot meet strict eligibility criteria for support despite real and pressing needs."*
>
> — "Shut out", p. 25

In their pre-report submissions to the Productivity Commission, the BIA and its member organisations made a number of recommendations in relation to the eligibility of people with ABI. The following presents these recommendations together with evidence as to whether they were endorsed in the Productivity Commission's report ('the report').

1. The NDIS eligibility criteria must not exclude people with 'mild' to 'moderate' TBI

Over 85% of people who have a 'mild' Traumatic Brain Injury (TBI) will experience "short-term, limited impairments that resolve within three to six months". However, "the remainder will often experience ongoing and debilitating cognitive and behavioural disability, which fundamentally affects their daily life. For this reason, BIA recommended to the Productivity Commission that "any needs-based assessment of eligibility" for a NDIS "must include this group." (BIA 2010, p. 15.)

The report appears to endorse this recommendation. It states that a person will be eligible for Tier 3 of the NDIS only if their functional limitations[1] are both significant and irreversible (or likely to be irreversible), with exceptions considered on a case-by-case basis. So where a person's brain injury is not *physically* significant — such as a 'mild' to 'moderate' TBI – if the *cognitive-behavioural* disabilities that have resulted from this injury involve functional limitations that are both significant and (likely to be) irreversible, then they will be eligible for Tier 3. This will remain the case even if their level of functioning could potentially be improved through early intervention.

> "[A] person in need of tier 3 support would have to meet at least one of the following conditions: [1] have significantly reduced functioning in self-care, communication, mobility or self-management and require significant ongoing support [2] be in an early intervention group. . . . This would encompass people for whom there was good evidence that the intervention would be safe, significantly improve outcomes and would be cost-effective. It would mainly comprise two groups. One group would be those for whom there was a reasonable potential for early interventions that would improve their level of functioning (as in autism, acquired brain injury and sensory impairments)." p. 750-751. (my emphasis)

[1] "A comprehensive component would consider the supports that would allow a person to fulfil a range of *functions*, such as participate in their community. This component would be supports driven, and so would not solely focus on an individual's diagnosis or what they cannot do. . . . Consistent with the ICF framework, the assessment process would identify support needs across a range of life activities, and would take into account the interactive effects of an individual's health condition (and impairment), their desired activity and their context (including environmental and personal factors)." p. 312 (my emphasis)

2. People with ABI who require life-long, but episodic support should be eligible

In its 2010 submission, BIA argued that: "whilst early intervention does bring measurable gains, recovery from a 'severe' or 'profound' ABI may take considerable time and service support needs will be long-term. This is particularly the case with those who experience an ABI early in life: [one study] has shown that service use is high even 20–26 years post-injury, with 85% having used at least one service, such as financial, transport, home support in the previous 12 months." (BIA 2010, p. 21).

The report appears to endorse this view, since it explicitly states that Tier 3 would include people whose needs are permanent *even if episodic*:

> "A person getting funded support from the NDIS would have a disability that is, or is likely to be, permanent. 'Permanent' refers to the irreversible nature of the disability, even though it may be of a chronic episodic nature. For example, this would include people with significant and enduring psychiatric disabilities, who periodically rely exclusively on support from the clinical services of the mental health system, but at other times are able to live in the community provided they have appropriate supports." (PC, p. 14, my emphasis)

Moreover, in a later quote, the report explicitly refers to BIA's 2010 view (quoted above) in the process of arguing that the NDIS must take account of the ongoing episodic nature of some disabilities.

> ". . . the Commission wants to emphasise that ongoing care and support for people with disability is also crucial . . . . As Brain Injury Australia observed . . ." (PC, p. 607)

3. People who are unwilling or unable to disclose their disability should be eligible

The BIA 2010 submission raised a concern that NDIS staff may not be able to identify a person as having ABI because they are "unwilling to disclose or unaware of their disability" (BIA 2010, p. 14). One practical consequence of this — even if unintentional — would be that only those who are both willing and capable of disclosing their disability would be 'eligible' for NDIS funding.

The report appears to acknowledge this issue. It argues that the NDIS should be "based on guaranteed access to supports identified in an objective assessment process" (PC, p. 16, my emphasis). This means that the assessment process will not depend only upon the subjective views or 'self-assessment' of the person with a disability. So, suppose a person with an ABI is either reluctant to admit to (or is not aware of) having a disability, but a carer or health professional nevertheless refers them to the NDIS for an assessment. Assuming that this person (or the person responsible for them) consents to take part in an assessment process, the NDIS could still establish whether or not they meet the NDIS criteria for funding.

4. People with both ABI and a mental illness should not be 'disowned' by the NDIS

In its separate submission, Headwest noted that people who are assessed as having the 'dual diagnosis' of both an ABI and a mental health care issue are currently faced with a 'wrong door' policy: that is, since their issue does not 'belong' to only one system, they are 'disowned' by all (Headwest 2011, p. 5).

Headwest's concern, then, was that this should not be a feature of the NDIS. If people are assessed with both ABI and a mental illness, they should not be 'disowned' by both the NDIS and the mental health system. There needs to be "inter-agency (across health, disability & mental health sectors) care protocols" so that support for *both* issues is provided (Headwest 2010, p. 8).

For instance, if someone is assessed as having both ABI and a mental illness, then "like the mental health care plans currently available through Medicare" they should be "provided with 12 free consultations [per year] with a mental health care provider of their choice as part of their treatment plan" (Headwest 2011, p. 5)

The report would appear to endorse the view that people with a dual diagnosis should not 'fall through the net'. First, it argues that the NDIS should not fund early intervention mental health care, since this kind of assistance is already covered by the existing mental health system.

> "The Commission is of the view that the NDIS should not fund early intervention for mental health conditions for the following reasons: Interventions are largely clinical in nature (involving therapy or pharmacological treatment) and they would thus be reasonably provided for in the mental health system." (PC, p. 635)

It follows that someone assessed as having both ABI and a mental illness could be eligible for 12 free consultations with a mental health care provider. But this would be funded by Medicare, rather than by the NDIS. It would not form part of any NDIS 'treatment plan'.

Second, in cases of dual diagnosis, the report argues that the NDIS should (a) provide appropriate support for the disability in question and (b) refer the person to the mental health system to receive 'early intervention'. The report also recognises the need for interagency formal protocols to make sure this happens:

> "Where a person with disability also has a mental health condition, that person would be referred to the mental health system under tier 2 of the NDIS. (p. 635) . . . people with disability receiving individualised funded support under tier 3 of the NDIS who suffer from co-morbidities such as depression might also be referred to relevant agencies in the mental health sector for early intervention. Such an approach would require the formalisation of links between the NDIS and health, education and other relevant agencies and organisations." (PC, p. 636)

5. Prisoners with an ABI should be identified and supported

In its 2010 submission, BIA recommended that prisoners with an ABI should be correctly identified, provided with early intervention, and more targeted and better funded services. Specifically, there should be "screening specifically for ABI at reception, education of both prisoners and prison workers in ABI and a commitment to in-prison and post-release programs as exercises in crime prevention." (BIA 2010, p. 14)

The report responds to this recommendation as follows. First, it recognises the prevalence of people in prison with an ABI or a mental illness.

> "There is a high proportion of people in the criminal justice system with an acquired brain injury or a mental illness. 37 per cent of prison entrants reported having a mental disorder at some time and 18 per cent reported that they were currently taking medication for a mental health related condition (AIHW 2009b). Similarly, the Department of Justice in Victoria (2007) found that the rate of intellectual disability was 30 per cent higher among the prison population than the general population. These prisoners also had a higher number of prison incidences recorded against them and were assessed as being a higher risk of offending." (PC, p. 950)

Second, the report recommended that the NDIS fund two kinds of programs that "may" result in the reduction of offending in this population: (a) "community supports for people with enduring and significant psychiatric disabilities" and (b) early intervention programs, such as "the NSW Integrated Services Project (ISP)", which "was aimed at people with challenging behaviours" and included clients with "mild intellectual disabilities, acquired brain injuries from alcohol and substance abuse, and multiple psychiatric diagnoses" (PC, p. 950-51). This recommendation appears to be confirmed by the PWC's post-report publication: "Disability expectations: Investing in a better life, a stronger Australia":

> "[J]ust under 30,000 people reside in prisons in Australia at an annual cost of around $100,000 per annum per person. Large proportions of people in prisons have an intellectual disability, an acquired brain injury or a mental health condition. Significant reform in the disability system could lead to reduced incarceration. If the number of prisoners in Australia decreased by 10%, this would result in savings of approximately $300 million per annum to the prison system. The disability support and early intervention programs to achieve these outcomes are able to be provided at far more modest unit costs and will achieve far better outcomes." (PWC 2011, p. 26)

Third, the report suggests that, if the population size is sufficiently large, it should be possible for local area coordinators to deal specifically with particular groups or disabilities — such as ABI and ex-prisoners.

> "In a system as large as the NDIS, there would be greater scope (and grounds) for specialisation, at least in major urban areas. For example, local area coordinators might deal with specific types of disability (like acquired brain injury or other cognitive disabilities) . . . and different backgrounds (for example, ex-prisoners with disabilities). The scope for specialisation would necessarily be less in some regional parts of Australia." (PC, p. 746-7)

It is important to note that none of these recommendations confirm whether or not people *within* the criminal justice system would be eligible for (or able to access) NDIS funding. The only disability services or programs suggested by the report operate either pre- or post-incarceration; and whilst the report implies that Local Area Coordinators ('LACs') *might* provide assistance to ex-prisoners with ABI (and who happen to live in a 'major urban area'), this does not in itself entail the existence of services or programs that are targeted to meet the specific needs of ex-prisoners.

In short, the report does not appear to endorse or even mention BIA's view that (a) all prisoners should be screened for ABI at reception, that (b) prisoners and prison workers should be educated in ABI, or that (b) the NDIS funding arrangements should be capable of supporting the development of ABI services or programs specifically designed for in-prison and post-release contexts.

6. Homeless people with an ABI should be identified and supported

In its 2010 submission, BIA suggested that "training be given to staff working in services to the homeless to help them identify an ABI" (BIA 2010 p. 14).

The report responds in the following way. First, it argues that the NDIS — in collaboration with not-for-profits ('NFPs') and other government agencies — should provide "outreach services" to homeless people with a disability: that is, services that "connect people to support, and educate people about the services available within their community" (PC, p. 233); and the report specifically mentions people with ABI in this context:

> "People with intellectual disability, acquired brain injury and mental illness are over-represented among the homeless, imprisoned and among drug and alcohol service users. There is significant scope to reduce the numbers in this position through the community support funded by the NDIS." (PC, p. 781)

Second, the report suggests that, where the population is sufficiently large, LACs could focus on specific groups and disabilities. Hence, there could be an LAC working specifically to assist homeless people with ABI. (PC, p. 746-7)

Third, once the NDIS provides full funding for the disability services that NFPs currently provide, then NFPs will be able to divert their (non-NDIS funded) resources to engage in activities that could help to reduce homelessness and its impact:

> "Many not-for-profit organisations partly fund their current provision of services through volunteers and philanthropy, and with full funding of NDIS supports, could divert those resources to wider disability concerns. This would include enhancing employment opportunities, increasing community engagement with people with disabilities, research, or resourcing of complementary areas outside the NDIS (such as supports for people who have been in the justice system or who are homeless)." (PC, p. 51-52)

> "Although many not-for-profit disability service providers will remain in their current areas of activity, some will change their activities largely in response to improved funding for tier 3 services and supports that would become available under the NDIS. . . . They might move into other areas of community need like addressing homelessness, child poverty, education and unemployment." (PC, p. 219-220)

In sum, the report clearly recommends that the NDIS provide care and support, in various ways, to homeless people with ABI. Unfortunately, it does not explicitly recommend that staff be trained to identify particular disabilities, such as ABI. On the other hand, it is possible that the Commission viewed this kind of training as a 'given', since it is difficult to see how any of the recommendations listed above could be implemented (effectively) otherwise.

RECOMMENDATIONS:

1. That if a person's 'mild' to 'moderate' TBI results in *cognitive-behavioural* disabilities that are both significant and (likely to be) irreversible, then they will be eligible for Tier 3.

2. That a person with ABI who is unwilling and/or incapable of disclosing their disability would — if they (or the person responsible for them) consents to an assessment — be 'eligible' for NDIS funding.

3. That people who are incarcerated (or who are otherwise sentenced for criminal behaviour) be eligible for NDIS funding.

4. That the NDIS give detailed consideration as to how adequate funding might be provided to develop disability services and programs that are specifically designed to operate effectively in both in-prison and post-release contexts.

5. That protocols be established with the state and territory justice systems to ensure that all prisoners are screened for ABI at reception and that prisoners and prison workers are educated in ABI.

6. That the NDIS ensure that staff working with homeless people are trained to be able to identify the presence of ABI.

B | Assessment

In pre-report submissions, BIA and its members recommended that any **assessment tool** should have a range of features. The tool should be:

- inclusive of both the physical and cognitive-behavioural aspects of a disability;
- developed by those who have specific expertise in the disability being assessed;
- early and ongoing,
- equitable (i.e. affordable and nationally accessible);
- scientifically verifiable; and
- culturally appropriate and sensitive.

BIA and its members also made recommendations relating to the assessment process. This process should be:

- made available locally;
- carried out by a panel that consists of at least one person with ABI expertise and one who can act as a representative of the person with ABI; and
- open and transparent to ensure that the outcomes are readily understandable to the person with a disability.

The following will examine whether the report endorses these recommendations.

1. Tools should assess both physical and cognitive-behavioural aspects of disability

If the NDIS employed an assessment tool that focused primarily on the functional limitations caused by the *physical* aspect of a disability, then it is likely that this tool would overlook or at least discount the impact of cognitive-behavioural deficits — particularly if these emerge some time after the initial physical injury. Since this is a common occurrence for people with ABI, there is a high risk that any assessment tool that focuses on or prioritises physical disability will exclude or underestimate the care and support needs of many people with ABI. For example:

> "Assessment requires an understanding of the person, their environment and the activities that they are wishing to engage in every day. VCASP and VBIRA believe that currently there is an over reliance on neuropsychological or medical assessments in isolation from information about how people manage in their specific context. There is a need with the NDIS to develop or endorse appropriate clinical and whole of life assessment tools." (VCASP/VBIRA 2010, p. 15).

> "[M]any people with an ABI [are diagnosed as having an] "mild to medium disability". Many are not diagnosed as having an ABI at all. But the injury progressively leads to cognitive-behavioural impairments "which may significantly impair their enjoyment of life and ability to fulfil their potential. These people would struggle if they were required to try and access support under the scheme(s) in a period of time after the initial diagnosis." (Headwest 2011, p. 3)

> "[25% of] 'mild' TBIs . . . will often experience ongoing and debilitating cognitive and behavioural disability, which fundamentally affects their daily life. Brain Injury Australia believes that any needs-based assessment of eligibility for a 'national disability scheme' must include this group." (BIA 2010 p. 15)

The report appears to endorse this recommendation. First, it acknowledges that any assessment tool must be able to capture the core features of specific disabilities.

> "Applicability refers to whether the tool can be applied to a particular target group. Some tools for example, target particular disabilities such as intellectual disability, while others target people of certain ages, such as children. Given the target population of the NDIS (chapter 3), the assessment tools will need to be applicable for individuals of different ages and with a wide range of levels, types and combinations of disabilities." (PC, p. 316)

Second, this would require the creation of assessment tools that are designed with particular disability groups in mind.

> "The Commission considers that the NDIS should only use a tool to assess the needs of particular groups where its reliability and validity have been established for that group. Recognising the importance of applicability, key groups have already been working with the developers of assessment tools. For instance, the Royal Society for the Blind is currently working with the University of Adelaide on the D-Start Assessment Trial." (PC, p. 317)

In practice, this will mean that the NDIS will not employ a single tool, but rather an internally consistent and non-overlapping suite of tools or 'toolbox':

> "[M]any current assessment tools tend to be developed on the basis of a single disability type (such as intellectual disability) or service type (such as attendant care or home modifications) and so lack the flexibility or breadth of coverage required by the NDIS. A simple and common response to this problem is to employ a toolbox rather than a single tool. In order for this model to work effectively, a thorough benchmarking and mapping process would be required . . . to ensure that all relevant activities were covered, that there was no overlap, and that where individuals were assessed for the same support using different tools, the outcome was equitable. . . . In the lead up to the implementation of the scheme, the implementation taskforce and the NDIA should progress work on the toolbox and ideally identify tools that are valid and reliable across the full spectrum of disabilities." (PC, p. 323, p. 338)

2. Tools should be developed by professionals with specialist expertise

A second concern — not unrelated to the first — is that the NDIS assessment tools may not include substantial input from ABI experts. Again, this is likely to entail that people with ABI are unfairly excluded from the scheme or that any assessment of their actual level of care and support needs will be unreliable.

For this reason, BIA and its members have argued that "ABI clinical and rehabilitation units" should be involved in the development of any assessment tool (SA 2012, p. 2). Since neuropsychological assessments are currently the 'gold star' standard for ABI, it

has also been recommended that this type of assessment "be included in the scheme(s) to ensure that people are comprehensively assessed" (Headwest 2010, p.2)

The report seems to have taken this particular concern on board. First, it argues that one way of measuring the validity of an assessment tool is to show it meets "a gold standard measure which has been used and accepted in the field." (PC, p. 316) This would entail that any NDIS assessment of someone with ABI would only be regarded as valid if it included a neuropsychological assessment.

Second, the report recognises that new tools may need to be developed to ensure that they capture the kinds of care and support needs that the NDIS is designed to fund.

> "[O]ver the longer-term, the NDIS should oversee the development of its tools (and ideally hold copyright), since such tools effectively determine resource allocation . . . ." (PC, p. 319)

In the meantime, the report proposes that the scheme use "the best available tools . . . with the later development of better tools." (PC, p. 338-39).

3. Assessments should be made by a panel including ABI experts and representatives

BIA and its members have argued that, whilst most assessments are likely to be "straightforward", there will be complex cases that require specialist input — including health professional(s) with specialist expertise and independent ABI service providers or a representative of persons with ABI.

> "The assessment should be made by a panel or using a methodology with input from at least one person with ABI expertise and one consumer representative." (BIA 2010, p. 15)

> "Notwithstanding the need to develop a national assessment process, our experience shows that the vast majority of assessment decisions of this kind are straightforward and non controversial based on available information, context and functional assessments. It is the complex and 'by exception' situations which require a more resource intensive process. An assessment panel with the option to draw on specialists is suggested. When further assessment needs to be undertaken it should be by professionals knowledgeable about ABI and independent service providers. The MACNI (multiple and complex needs initiative) model from Victoria for people with complex needs is a relevant example." (VCASP/VIBRA 2010, p. 15; also quoted in PC, p. 327-28)

The report responds to this concern in the following ways. First, it acknowledges that "[m]any participants were supportive of assessments being undertaken by an approved pool of allied health professionals" (PC, p. 327) and referred to VCASP/VIBRA's view (quoted above). However, the report does not make any direct comment on this view, and appears not to endorse a panel-based model of assessment.

Second, the report does, however, propose an alternative model that approximates the features that BIA and its members are recommending. This model would allow

specialists (or specialist assessment tools) to be employed to assist in the assessment process. It would also allow a 'circle of support' to be 'involved' in the assessment process. This 'circle' may include family members, friends, a representative of the person with a disability and/or a disability service organisation.

These additional parties would not be *making* the assessment: that role would belong to an individual 'assessor'. Rather they would 'assist with' the assessment process, in the sense that the assessor would draw upon information that they provide.[2]

> "The assessment process should . . . draw on multiple sources of information, including:
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> - information provided by the individual with a disability, including their aspirations and requirements for supports
> - information provided by an individual's circle of support, including family members, carers and direct support professionals
> - information on the current support provided both formally and informally
> - current medical information on the person with a disability" (PC, p. 338)

The report's rationale for this model is as follows. First, it will limit the number and training of staff required to administer the assessment:

> "The skills required by staff that implement the tool also affect practicability [i.e. "the ability of a tool to be applied in a given situation or context"]. A tool that is easier to administer and requires less training of staff, while still producing reliable results, may be preferred to one which requires extensive training of assessors by accredited trainers." (PC, p. 318)

Second, this staffing limitation could be upheld even in complex cases, given that it would be possible for an assessor to draw upon more complex assessment tools and/or to spend more time and effort for such cases.

> "In the first instance, a tool that is quick and easy to administer might be preferred. In the second, given the complexity of the task and the need for the outcome to be highly valid and reliable, it would be appropriate for the scheme to invest relatively more time and/or effort in undertaking the assessment. This suggests a role for either a hierarchical tool or multiple tools (section 7.6)." (PC, p. 318)

Third, one concern with an 'assessment panel' that includes a specialist or 'consumer representative' is that it is likely to consist of parties that have (or previously had) "treatment and support responsibilities" for the person with a disability. If that were the case, then it would be less likely that the assessment would be objective. For this reason, the report recommends that any 'assessor' should be independent:

[2] Elsewhere the report uses the concept of a "panel", but only in the context of "arriving at and approving a support package", and it seems clear that this is a 'post-assessment' process: "While many people may be involved in bringing a support plan into fruition (for example a panel may be involved in arriving at and approving a support package), there should be one clearly defined person [i.e. the local area coordinator] with ultimate responsibility to ensure that clients are receiving the supports they are eligible for, that support services are of an adequate quality, and to monitor their wellbeing over time" (PC, p. 485)

> "In order to promote independent outcomes, assessors should be drawn from an approved pool of allied health professionals. Assessors should also be independent of the person being assessed to reduce the potential for 'sympathy' bias. This means that health professionals — GPs and others — with past treatment and support responsibilities for the person, would not undertake assessments." (PC, p. 327)

Fourth, the report recognises the importance of involving 'interested parties' in the assessment process. Hence, the report recommends that a 'circle of support' be included as a key resource of information for the assessor to draw upon.

> "[W]hile the individual undertaking assessments would be independent, it would important to involve other interested parties (a so called circle of support) in the assessment process. Ideally, these would be people who were familiar with the care and support needs of the individual, they might include family members, carers and direct support professionals. ["Individuals could also elect to involve DSOs" p. 334] Moreover, the assessment process would draw upon existing medical reports." (PC, p. 327)

Finally, the report recommends that, to ensure the independence and quality of assessors, they would all be:

- "mentored in their first six months of assessments . . .
- regularly assessed to ensure comparability of outcomes . . . [which] would prevent assessors from developing their own criteria for assessment, and avoid outcomes such as 'sympathetic bracket creep' . . .
- approved or appointed by the NDIA for the purpose of conducting NDIS assessments . . .
- [required to align] their approaches to assessment . . . with the objectives of the NDIS (which is another reason why a person's general practitioner would not be a suitable assessor) . . .
- properly trained in the use of the tools and in listening to the input of participants" (PC, p. 327).

There are several problems with this model, especially for people with ABI. First, it is unclear whether anyone other than an accredited neuropsychologist would be able to understand and use existing neuropsychological assessment tools effectively. But this tool is the 'best available' for assessing the functional limitations of people with ABI. So unless 'assessors' are able to employ neuropsychologists to conduct this aspect of the assessment — rather than merely 'clarify' or 'advise' — it follows that the report's preferred model will be not optimal for people with ABI.

One response that might be made to this objection is this: the report makes it clear that "in the context of an NDIS, the assessment tool is not intended to measure needs per se, but needs that must be funded by the scheme" (PC, p. 316). It may be the case, then, that (a) a neuropsychological assessment (which measures "needs per se") is conducted by an accredited neuropsychologist; but then (b) a NDIS 'assessor' conducts their own assessment (i.e. which measures "needs that must be funded by the scheme"). This

second assessment draws upon the findings of the first, but the two assessments are not (and are not required to be) identical — even if there may turn out to be cases where a person's 'needs per se' correspond exactly with the 'needs that must be funded by the scheme'.

It remains the case, however, that a neuropsychological assessment is the 'gold standard' for assessing the care and support needs of a person with ABI — even if it turns out that only a subset of these needs can be funded by the scheme. Hence, assessors will still need to be able to employ specialist assessors if their assessments are to be, as the report recommends, 'valid and reliable'.

Second, it is unclear how the 'circle of support' will be 'involved in' the assessment. For instance, will there be any obligation — legal or organisational — for the 'assessor' to ensure that (a) a 'circle of support' has been organised; (b) that the person with a disability or their representative has nominated and/or consented to the membership of this circle; (c) that the circle includes at least one 'specialist expert' and one 'consumer representative'; and (d) that both the person with a disability and the members of the circle are properly consulted on both the process and content of the assessment (e.g. using realistic time-frames)?

Finally, the report recommends that, if a person disagrees with the outcome of an assessment then "there should be some scope for minor adjustments to be made, without necessitating a full reappraisal. Failing this, individuals could ask for a review." (PC, p. 337) However, to ensure that this process is fair, the assessor should be obligated to present the person with a disability and all parties in their 'circle of support' with a formal opportunity to review and, if necessary, request corrections to the assessment before it is finalised.

4. Assessments need to be early and ongoing

There are several concerns here. First, there is the issue of timing. Many persons with ABI can benefit significantly from early intervention. So any assessment should be conducted *as soon as possible after the injury*. The NDIS should, in other words, address the current situation, in which persons with ABI can wait for "six months" or even "up to two years" for a neurological assessment (Headwest 2010, p. 7); and this is partly due to the uncertainty of funding, or at least the protracted length of time devoted to legal and administrative processes. For this reason, Jennifer Cullen has suggested that one outcome measure for the NIIS should be that people with a catastrophic injury have received NIIS funding "within a particular period of time" after the injury (Jennifer, Synapse, email April 2012).

Again, assessments need to be *ongoing*, given the variable, emergent or progressive nature of ABI and its cognitive-behavioural consequences. In a supplementary submission, BIA recommended that, given "the episodic needs often associated with ABI", the needs of a person with ABI should be "regularly re-assessed over time" (BIA 2011, p. 6).

It would appear that the report has endorsed these concerns about timing. First, the report argues that care and support should be provided to applicants as soon as possible, and on an interim basis in cases where the time taken to conduct the assessment has been excessive.

> "Individuals should not have to wait excessive periods for their care and support package to be finalised. Where possible, streamlined processes should apply. The NDIA should report annually on this metric." (PC, p. 334)

> "Where it becomes clear that the time required to complete an assessment of care and support needs will substantially exceed the norm, there should be scope for the NDIS to provide services on an interim basis. This might be the case where say an individual with complex needs disagrees with an initial assessment outcome." (PC, p. 337)

Second, the report explicitly recognises that the needs of a person with a disability changes over time — and so, it states, "the NDIS would periodically re-assess people's needs" (p. 305). The timing of each re-assessment would depend upon a range of factors, such as "the nature of the disability, the age of the person and any major life transitions" (p. 328). These transitions include "leaving school, getting a job, moving out of home, or losing a natural support" (p. 305). Reassessment might also be warranted "when individual circumstances have changed, or are about to change . . . [e.g.] following a period of ill health." (PC, p. 328)

These concerns are also addressed in the report's recommendations for the NIIS. First, the problem of delayed funding is fully recognised:

> "[C]ompensation [after a catastrophic injury] is often delayed and, particularly if liability is disputed, access to early treatments and appropriate discharge from hospital to medical and social rehabilitation can be delayed and poorly coordinated" (PC, p. 798)

The report's response is that the NIIS will be inherently quicker primarily because it is a no-fault scheme:

> "[N]o-fault insurance schemes directly seek to achieve better health and functioning by explicitly managing cases and consumption of services and supports to get better outcomes as fast as possible. At a broader level, no-fault schemes regularly survey their clients, are developing tools to measure and better understand how to improve client outcomes and progress. These are not the priority concerns of fault-based systems." (PC, p. 824)

In terms of ongoing assessment, the report argues that the NIIS should use a two-staged assessment process so as to ensure that the full extent of the injury can be determined:

> "As the NIIS would only include catastrophic-level injuries, the Commission sees merit in the use of a two-staged assessment to distinguish between a participant's interim (say, up to two years post accident) and long-term participation in the NIIS. This . . . [would] limit the potential adverse consequences from any classification errors in determining a catastrophic injury, especially for suspected moderate to severe brain injury where the extent of injury and scope for recovery is initially uncertain" (PC, p. 912)

Finally, the report argues that the NIIS must ensure that transitions, rehabilitation, early intervention, and ongoing care — especially in specialist areas such as ABI — are properly funded and planned for.

> "The NIIS would also need to involve the following:
>
> - Transitions through the health system would need to be as seamless as possible, and care and supports coordinated over a person's duration of need.
> - Rehabilitation and early interventions should be appropriately timed (informed by rigorous data analysis) and, where necessary, supported by clinicians and allied health professionals.
> - The stream of funding provided would also help develop specialist health services necessary for rehabilitation, which tend to be under-developed and under-funded in the health system (such as specialised brain injury centres).
> - Key life transition points would be anticipated and planned for, to facilitate independence and participation goals — including, where appropriate, by connecting with community groups (as under the NDIS (chapter 4))." (PC, p. 853)

5. Assessments need to be equitable (i.e. affordable and nationally accessible)

There are two concerns about the equitability of assessments. First, the situation at present is that whilst "some assessments are free, others cost $200 or more. For many people this is not affordable" (Headwest 2010, p. 7). Second, medical evidence is often difficult to obtain, given the lack of portability across jurisdictions in Australia. Moreover, people with cognitive disabilities can find it very difficult to retain or readily locate their medical records:

> "As an aspect of cognitive disability is an incapacity to organise daily affairs, medical evidence required for an assessment is frequently lost by people with acquired brain injuries." (Headwest 2010, p. 8)

The report appears to address both of these issues. First, it recommends that the NDIS pay for assessments *if they are relevant to determining whether an applicant is eligible for NDIS funding*. It is very likely that any 'gold star standard' assessments of the care and support needs of persons with ABI *will* be relevant in this way — although it remains to be seen which particular assessment tools will be 'approved' (and so funded) by the NDIA. For instance, the report indicates that, whilst an 'approved' tool need not be free (i.e. not under copyright), it is likely that, for budgetary reasons, there will be a preference either for tools that are in the public domain or that have been developed over time by the NDIS.

> "The Commission agrees that an assessment tool need not be in the public domain. But considers that, over the longer-term, the NDIS should oversee the development of its tools (and ideally hold copyright), since such tools effectively determine resource allocation and because the NDIS would have the best evidence for their ongoing development. The tools should also be made available at no cost to researchers wanting to develop them further." (PC, p. 318)

Second, the report is clear that both assessment tools and their results should be made nationally accessible. For this to occur, assessments would also need to be held on national databases, which would mean that people with a disability would not be excluded or delayed if they were unable to provide their own medical records.

> "[A]ssessments should be portable across the system — subject to protection of privacy — so that people do not have to repeat information for different providers or government agencies. Where there is extensive overlap in the nature of information being provided, the NDIS should reach agreement with other departments or agencies to either act as the sole assessment point, act as a point of referral or to share information, subject to strict privacy safeguards." (PC, p. 314)

> "The Commission favours [a 'toolbox' that would be employed nationally], since it would ensure more equitable access to nationally funded support services and allow portability of funding across borders when people move." (PC, p. 320)

6. Assessment tools need to be reliable

BIA and its members expressed a concern that assessments be based on "scientifically verifiable tools" (BIA 2010, p. 2), which includes not only self-assessment, but also "contemporary cognitive function assessments and medical evidence" (Headwest 2010, p. 8).

The report addresses this concern in two ways. First, it acknowledges the limitations of self-assessment, particularly with respect to accuracy and objectivity (PC, p. 324-26). But it also insists that the views of the person with a disability are a vital component of any assessment (see 8 below). Second, the report recommends that any NDIS assessment tool must be "valid" and "reliable" (PC, p. 315-16). These attributes are defined as follows:

> "Validity is measured in a number of ways, including by reference to a gold standard measure which has been used and accepted in the field. . . . A reliable measure is one that measures a construct consistently across time, individuals, [assessors] and situations." (PC, p. 316)

7. Assessment tools need to classify by diagnosis and/or functional ability

BIA and its members argued that the NDIS assessment process should not be limited to medical or neuropsychological diagnosis, but should include — or, in some cases, focus entirely upon — functional ability.

> "Brain Injury Australia understands that there exist a number of nationally available, scientifically verifiable tools that are currently used which could be appropriate for the assessment process. These include tools that classify by diagnosis and/or functional ability." (BIA 2010, p. 15)

> "VCASP and VBIRA believe that currently there is an over reliance on neuropsychological or medical assessments in isolation from information about how people manage in their specific context. There is a need with the NDIS to develop or endorse appropriate clinical and whole of life assessment tools." (VCASP/VBIRA, p. 15)

The issue of diagnosis vs. functional ability was also raised in relation to the NDIS's eligibility criteria; and it seemed clear that, in this respect, the report endorses the view of BIA and its members. But the report also recommends that, once a person has met the eligibility criteria, the NDIS assessment tools "would not solely focus on an individual's diagnosis", but would instead aim to identify supports that are needed to enable a person to carry out "a range of life activities . . . in keeping with [their] personal goals and aspirations." (PRC, p. 312, 306)

In other words, the assessment process would "take into account the interactive effects of an individual's health condition (and impairment), their desired activity and their context (including environmental and personal factors)." (PC, p. 312) This approach would seem to be entirely consistent with the view of BIA and its members.

8. Assessment tools need to be culturally appropriate and sensitive

BIA and its members have argued that any NDIS assessment process should have a range of culturally sensitive features, including (NDIS-funded) "culturally secure formats", "translated versions" and "interpreter services" for applicants "from non-English speaking backgrounds" (Headwest 2010, p. 4). Again, since indigenous communities "would not label themselves as disabled and in need of support", any NDIS assessment tool would need to find culturally appropriate ways of garnering evidence of disability. (BIA 2010, p. 14)

The report appears to agree, in principle, with these recommendations. But it is short on detail and makes no formal recommendations on the matter.

> "It is important that any tool not unfairly discriminate against people from Indigenous or ethnic communities. As noted by The Victorian Equal Opportunity and Human Rights Commission, 'assessment tools and processes must be culturally robust' (sub. DR885, p.3)." (PC, 317-18)

This may be due to the fact that the report's authors were not aware of any assessment tools that could be described as 'culturally appropriate and sensitive'. However, the report does suggest, at least by implication, that the NDIS will seek to create such tools, in conversation with indigenous and other cultural communities.

> "[I]t is clear that there is a lot to learn in order for the NDIS to effectively deliver supports to Indigenous Australians. There is relatively little literature about this — as stated by the First People's Disability Network 'in many ways 'disability' is a new conversation in Aboriginal and Torres Strait Islander communities' (sub. 1047, p. 14). Encouraging new or innovative approaches, trials and local experimentation will be important in improving service delivery. Similarly, directed research, transparent evaluation, independent review and active dissemination of the knowledge base will also play a central role. At times, this

may uncover failures or areas with a frustrating lack of progress. However, the commitment to honest appraisal of what works and what doesn't will critically determine the success of NDIS in providing a greater level of support to Indigenous people with a disability. Systemic advocacy, such as Aboriginal Disability Networks in New South Wales, Queensland, Victoria, South Australia and Western Australia, will also play an important role in uncovering issues, suggesting solutions and working with service providers and the NDIA to improve the cultural appropriateness of disability services." (PC, p. 560)

9. The assessment should be open and transparent for persons with a disability

BIA and its members have argued that the assessment process and its outcomes must be readily accessible and understood by persons with a disability (BIA 2010 p. 15). The report appears to endorse this view insofar as it advocates that the assessment process should be "collaborative": that is, it should be conducted in such a way that the person with a disability is able to:

- "gain a better understanding of the purpose of assessment and its implications for their situation
- actively participate in the process
- identify and articulate the outcomes they wish to achieve (a support plan will also be key here)
- identify the options that are available to meet these outcomes and to support their independence and well being
- understand the basis on which decisions are reached." (PC, p. 326).

10. Neuropsychological and other assessments should be made available locally

In many cases, neuropsychological (and other) assessments are not conducted locally. So if someone with an ABI lives in a rural location, they can be suffering from "fatigue due to travel requirements" when they undertake these assessments. This can have severe impact on their performance, resulting in poor quality assessments (BIA 2011 p. 8).

The report doesn't appear to address this issue directly. The only mention of how assessment might work in practice is given in a flow chart (see below). There is one stage in which the suggestion is made that an assessor and local coordinator will "visit the person to better understand their circumstances" (PC, p. 336). But all other assessments refer only to "meetings", leaving open the question of location.

Figure 1 **Suggested initial assessment process** (PC, p. 335)

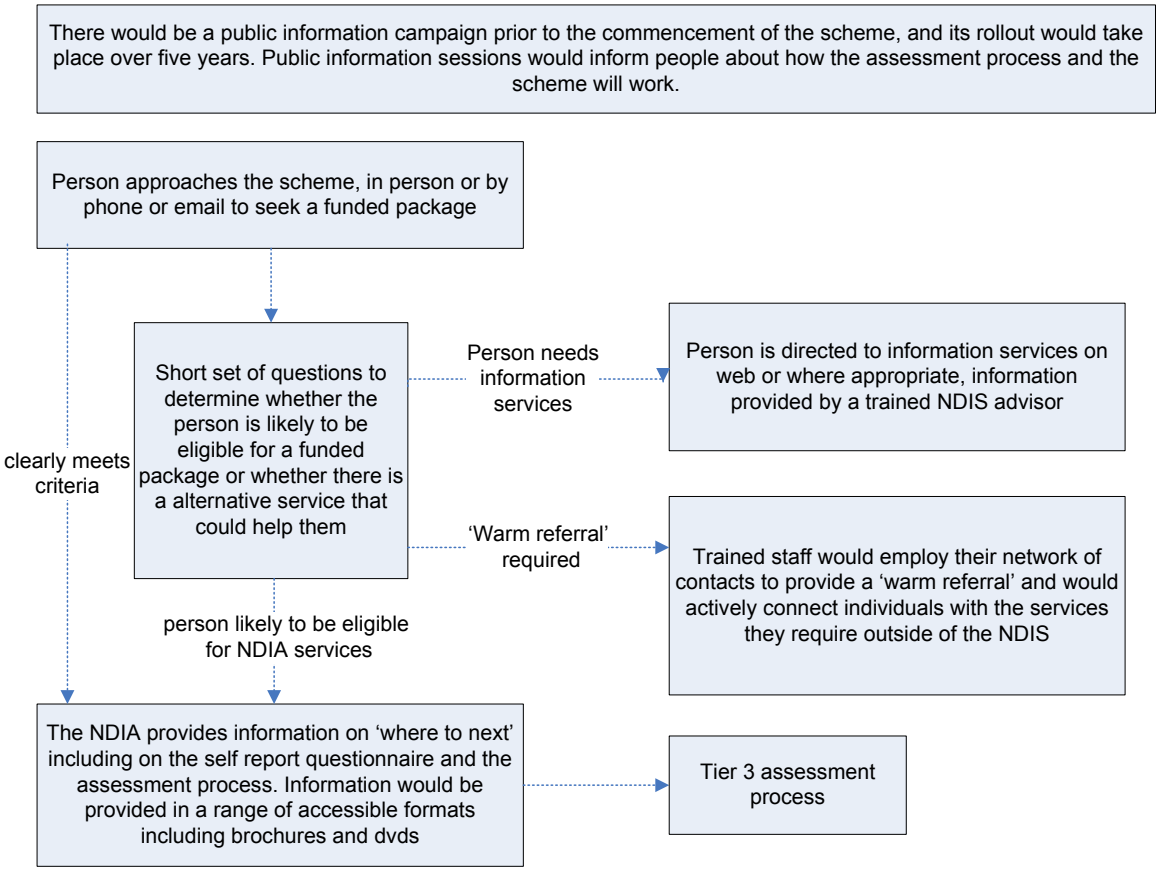
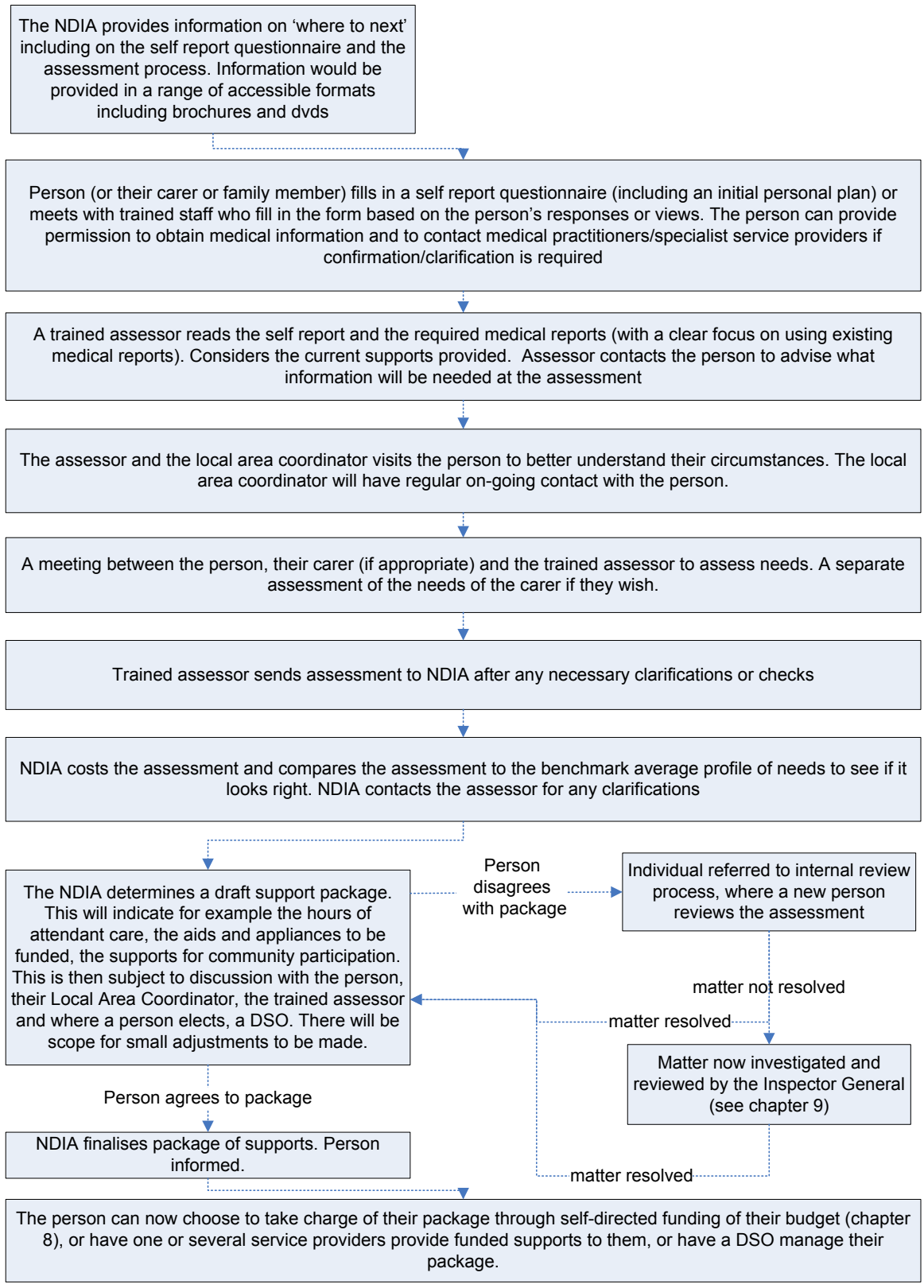


Figure 2 **Suggested assessment process for tier 3** (PC, p. 336)

Following on from figure 7.2



RECOMMENDATIONS:

1. That the NDIS National Assessment Tool Project (NATP) identify or create valid and reliable assessment tool(s) that are applicable to the specific disabilities — both physical and cognitive-behavioural — associated with ABI.

2. That the NATP developers take into account the fact that neuropsychological assessments are the 'best available' tools for people with ABI, which includes ensuring that they are culturally specific.

3. That the NDIS should pay for medical or neuropsychological assessments, even if they are only partly relevant to determining whether an applicant is eligible for NDIS funding (e.g. where they do not constitute an 'NDIS assessment tool' as such, by are instead used as one source of information that the NDIS 'assessor' draw upon in making their assessment).

4. That NDIS 'assessors' should be obligated to employ specialists (e.g. neuropsychologists) to conduct any component of or source for their assessment that requires specialist expertise.

5. That the NDIS provide greater clarity on the obligations of the assessor in relation to the person with disability's 'circle of support'.

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BACKGROUND PAPER ON THE NDIS / NIIS

2. Choice & Control

An analysis of the extent to which the Productivity Commission endorsed the recommendations submitted by Brain Injury Australia and its member organisations.

Prepared by Dr. Derek Brookes
Policy Officer, Brain Injury Australia

May 2012

Abbreviations:

BIA 2010	Brain Injury Australia (prepared by Victoria Schneider), "Submission to the Productivity Commission's Inquiry into Disability Care and Support" (August 2010).
BIA 2011	Brain Injury Australia, "Supplementary Submission to the Productivity Commission's Inquiry into Disability Care and Support" (April 2011).
BINSA 2010	Brain Injury Network Of Sa Inc, "Submission To The Productivity Commission's Inquiry Into Disability Care And Support" (16 August 2010).
FBIC 2011	Friends of Brain Injured Children (ACT) inc., "To the Productivity Commission in consideration of the proposed National Disability Insurance Scheme" (2011)
Headwest 2010	Headwest," Headwest Brain Injury Association WA Inc. Submission to the Productivity Commission Long Term disability Care and Support Inquiry: (2010)
Headwest 2011	Headwest,"Disability Care and Support Productivity Commission Draft Report Submission" (2010)
PC	Productivity Commission, *Inquiry Report – Disability Care and Support*, No. 54 (Australian Government, July 2011).
PWC 2011	"Disability expectations: Investing in a better life, a stronger Australia" (PwC, November 2011)
VCASP/VBIRA 2010	"Submission from VCASP and VBIRA to Productivity Commission Inquiry into Disability Care and Support" (August 2010)

Contents

A | Portability

> *"Our son would like to move north but because he is funded by another state this is almost impossible. We approached the authorities and were told that he could apply but would not be considered until he actually lived in the specific state. Even though his funding would be transferred across to his new state, it only lasts one year and then reassessment would occur, leaving us wondering what that would lead to, all in all it is far too difficult and risky for him to move."*
>
> — Shut out, p. 21

1. The NDIS should enable portability across jurisdictions

In its submissions to the Productivity Commission, BIA and its members argued that there is one systemic factor that would provide a significantly higher degree of choice to people with a disability: namely, the capacity to "readily move between jurisdictions but also access services in adjacent States or Territories where they live closer to borders than regional or metropolitan centres" (BIA 2011, p. 11). In other words, disability funding, care and support should be portable and consistent across all jurisdictions.

The report endorsed this view, and argued that the most effective way of ensuring portability would be to implement a national scheme, rather than a scheme that is run independently by each state and territory or a scheme that is federated.

Specifically, the report "strongly" recommends that there should be a single agency — which it calls the "National Disability Insurance Agency" (NDIA) — that will "oversee a coherent system for all Australians, regardless of their jurisdiction." (PCR, p. 37) The NDIA would be "a new federal social and economic institution that would be independent from all governments in operational matters." (PCR, p. 42) This infrastructure will have the following advantages:

First, a single agency is more likely to implement "the same national eligibility criteria, assessment toolbox, arrangements for assessors, and access to the full range of necessary supports. That would mean that regardless of location, people with equal disability status and traits/natural supports would receive the same entitlements based on need certainty of future resourcing." (PCR, p. 36) Second, a single new agency is more likely to bring about much needed "rapid and uniform" innovations in disability care and support than "the current nationally fragmented disability system" (PCR, p. 38) Third, a single agency would ensure that "expectations about, and measurement of, the performance" of services that will complement the NDIS (i.e. "disability employment services, income support, education, public transport, housing and health") is more likely to be "nationally consistent and equitable." (PCR, p. 38)

The report contrasts these advantages with the other two possible approaches.

First, suppose the scheme operated by rolling "out the NDIS to those states and territories that saw the advantages of a better-funded and coherent system, with other jurisdictions joining later if they wished to gain the advantages of that system." (PCR, p. 37) The report acknowledges that there would be one advantage to this approach: the logistics of creating *nationally consistent* reforms would be considerably less if each state/territory were given responsibility for devising its own reforms. However, this only takes into account the logistical burden of *the bureaucracies involved*. It does not take into account the more important logistical burden of non-portability that would remain under this model *for people with a disability*.

Second, suppose the scheme operated by "the Australian Government provid[ing] additional disability funding to state and territory governments and stipulat[ing] some common national features, but . . . otherwise leav[ing] state and territory governments in control of their own systems." (PCR, p. 37)

The problem with this federated model is that the NDIS would only perpetuate the incoherency that makes the current system so "dysfunctional and unfair". (PCR, p. 37) in particular, it is very likely that jurisdictions would adopt "their own unique assessment tools and eligibility criteria over time" (PCR, p. 37). This level of inconsistency will mean that people with disability are likely to continue suffering from a lack of portability.

2. The NIIS should enable portability across jurisdictions

The report recommends that the NIIS, by contrast with NDIS, should "structured as a federation of separate, state-based injury insurance schemes." (PC, p. 854) — which is precisely the model that the report argued *against* in relation to how the NDIS should be structured. Hence, it would appear that the NIIS is unlikely to have the same degree of portability as the NDIS. However, there are a few points made in the report that may be read as an attempt to ameliorate this problem.

First, the report argues that the NIIS and NDIS may — some time after a review in 2020 — combine under the NDIA. In that case, presumably, the problem of portability for the NIIS would be resolved.

> "Over time, separate state and territory schemes might well coalesce to form a single Australian system." (PC, p. 861) "An independent review in 2020 should examine the advantages and disadvantages of: . . . merging the NIIS and the NDIS." (PC, p. 89)

Second, in the meantime, the report notes that work is being undertaken to improve the Interstate Portability Protocol, which, presumably, will have an impact on the degree to which NIIS funding becomes portable.

> "The Interstate Portability Protocol: In 2000, the Disability Services Ministers endorsed a national policy framework regarding the interstate transfer of people with a disability. This framework or Protocol establishes a mechanism to assist people with a disability

> transferring between jurisdictions to negotiate programs and services to achieve a comparable level of support. Work is currently underway to improve the implementation of the Protocol across jurisdictions. Source: NSW Government (sub. 536, pp. 49–50)." (PC, p. 923)

Third, the report recommends that "people with injuries acquired before the establishment of the NIIS . . . be covered by the NDIS" (PC, p. 13). If this is accepted, then at least that category of people with injuries will have the benefits of portability provided by the NDIS model.

Finally, even though the NIIS is a federated model, there would still be national minimum benchmarks for the level or benefits and the standards of care. This would not in itself entail portability, but it would theoretically make it easier to transfer funding packages across jurisdictions. It would also mean that the level and quality of care is not a 'postcode lottery'.

> "The purpose of federation membership [for the NIIS] should be to ensure consistency in assessments and to provide certainty around a benchmark minimum standard of care. Benchmarking would need to be transparent and agreed." (PC, p. 46)

> **"**A coordinated federated approach would be critical, however, to ensure that the level of benefits and the standard of care provided by individual schemes were subject to minimum reasonable benchmarks." (PC, p. 854)

RECOMMENDATIONS:

1. That the NDIS should be implemented as a National Scheme.

2. That, if the NDIS is implemented as an Independent State/Territory Scheme or a Federated Scheme, then measures must be put in place that will guarantee portability — e.g. by creating a national database that held "an electronic record of each client's assessed need and financial entitlement applicable throughout Australia." (PC, p. 488)

3. That serious attention be given to the matter of how best to ensure interstate portability for the NIIS: for example, by (a) implementing the NIIS as an independent national scheme, (b) incorporating the NIIS into the NDIS immediately, or as soon as is practically feasible, (c) including within the NIIS scheme legislation and protocols that will guarantee interstate portability.

B | Self-directed funding

> *"Managing my own [support] package has given me the flexibility to alter the assistance I need as my circumstances change. I have also found it to be quite empowering to know I am able to buy services from other agencies when, and if, the need arises. I am extremely conscious of creating a life for myself so that I am not reliant on family and friends. I want to keep them just as that — family and friends — not as carers."*
>
> — "Shut out", p. 22

> *"If people are not enabled to make meaningful choices and provided with information and resources with which to make them, then the notion of 'choice' becomes empty rhetoric and the [NDIS] system will fail to live up to its transformative potential. . . .*
>
> — "Disability expectations", p. 30

1. People with disability should be able to self-manage funding

BIA and its members argued that people with a disability should be given the option to "manage their own funding" (BIA 2011, p. 10). The report endorses this view insofar as it recommends that the NDIS employ "self-directed funding".

This approach entails two features: First, people with a disability will be able to "shift the cash value of one component of their individual support package to another component". For example, "they might decide to forgo some hours of personal care for a greater amount of community access." (PC, p. 346)

Second, people with a disability will be able to shape "the supports that suit their individual and evolving needs" (subject to certain conditions). For example, they could "employ the support workers they wanted (and when), at wages they jointly determined with the worker, rather than having to purchase personal support services through specialised disability providers." (PC, p. 346)

The report also recommends that the NIIS include the capacity for self-directed funding, although it does not provide any detail as to how this will be managed.

> "Opportunities for self-directed funding . . . would be part of the [NIIS] scheme design to enable greater flexibility, where that is appropriate and consistent with the scheme's objectives and improves outcomes for participants." (PC, p. 853)

> "The NIIS would include a greater role for self-directed funding and self-determination of care and support to facilitate increased autonomy and choice where that would deliver better outcomes for participants." (PC, p. 856)

2. People with disability should be able to use an intermediary to manage their funds

BIA and its members recommended that people with a disability should be given the option to "appoint – and for them to choose – someone to manage funding" (BIA, 2011, p. 10). Again, the report endorses this suggestion.

The concept of 'self-directed funding', as defined in the report, does not entail that people with a disability should be *compelled* to manage or put together their own support package. Hence, 'self-directed funding' would include the following cases:

- A person with a disability chooses to enlist the support of intermediaries (e.g. disability support organisations [or 'DSOs') to plan their supports and manage the administrative aspects of their funding (e.g. "workers' compensation coverage for employees"). (PC, p. 346)
- A person with a disability chooses to pay a service provider for a complete package of supports. This might be an attractive option where "the provider was able to provide a cheaper or better suite of supports than that obtained by a person assembling their own suite from many suppliers." (PC, p. 346-47)

3. The capacity to self-manage funding should be assessed fairly and equitably

BIA and its members wanted to ensure that the report took into account people with disabilities who lack the capacity (or find it too difficult) to self-manage funding. This issue was explicitly noted in the report.

> "Some people with disabilities have to address addictions and substance abuse problems that may make it difficult for them to handle money directly (though other parties could act on their behalf). For example, there is empirical evidence that 68 per cent of people who experience traumatic brain injury have a history of substance abuse (Headwest Brain Injury Association of Western Australia, sub. 448, p. 6)." (PC, p. 389)

However, BIA and its members raised a concern about whether the NDIS would identify people who were unable to self-manage funding in a way that is "fair and equitable" (BIA 2011, p. 10). And the report seems to be aware of the grounds for this concern. For example, without a fair and objective assessment of their own capacity to choose, a person with disability could easily be left at the mercy of someone who is incompetent, abusive or corrupt:

> "[S]ome people with disabilities are not able to make all of their own decisions (as is the case with profound intellectual disability). In that case, decisions about their well-being will often be made jointly with or by their primary carers, who are usually familiar with the strengths, goals and other preferences of the person with a disability. However, while such carers will usually have the best interests of the person with a disability at heart, that will not always be the case. Like all people, carers (and people with disabilities) are not perfect, and sometimes will act in a way contrary to the interests of the person they are supporting . . . ." (PC, p. 356)

The report is also aware that the existing system has severely restrained and even damaged people's capacity for choice; and that it cannot therefore be assumed, from someone's past record, that they are incapable of choosing for themselves. Any assessment must be preceded (or accompanied) by a serious attempt to enable a person to realise any latent or supressed ability to decide for themselves:

> "A lot of people with disabilities and families are coming from a background of being disadvantaged, poor, powerless, not used to actually making those decisions. So to expect that people might just jump into a system is, I think, a bit silly. There has to be some of those capacity-building things in place. (Samantha Jenkinson, trans., p. 982)" (PC, p. 385)

For these reasons, the report agrees that, before anyone elected to use self-directed funding, they would need to be assessed to ensure that they had the capacity "to handle their funds" (PC, p. 393). Unfortunately, the report does not stipulate precisely *how* this assessment will be made. However, it does mention "Risk Enablement Panels" (as used in the UK) as a possible model.[1] It also recommends that Local Area Coordinators provide a role in assessing people's ongoing capacity to choose.

> "Some local authorities have explicitly assessed the risks for individuals using Risk Enablement Panels, and these have generally received strong support by care coordinators (Glendinning et al. 2008, p. 177). If a person is perceived as high risk, then management of the funding could be the responsibility of an intermediary, but the person could still determine the decisions about the allocation of funds in accordance with their approved personal plans. DSOs could play such a role in Australia. Local area coordinators would also assess whether a person was coping with self-directed funding." (PC, p. 394)

Nevertheless, until the procedure for assessing the 'capacity for choice' has been made explicit, it will not be possible to determine the extent to which it is "fair and equitable".

4. People with disability should be able to pool funding with others

BIA and its members argued that the NDIS should "afford opportunities to pool or share funding". This issue was of particular concern to members in remote or very remote areas, such as Alice Springs and Mutitjulu. (BIA 2011, p. 10)

The report does not discuss the concept of 'pooled' or 'shared funding' in any depth, but the option is endorsed by way of an example related to housing:

> "The Commission . . . considers that the NDIA should encourage the development of an accommodation model that gives people the capacity to unbundle the provision of the 'bricks and mortar' and the provision of services. . . . people could separate out their housing support and pool their funds with others to form a group home, or request that a DSO organise other potential co-occupants." (PC, p. 232)

[1] For an example of a Risk Assessment Panel form and criteria, see here: http://goo.gl/tC78Z, and procedures: http://goo.gl/7PXZR.

5. Self-directed funding should be accountable

BIA and its members have argued that there should be "appropriate levels of accountability in keeping with the scale of packages" (VCASP / VBIRA 2010, p. 23). The report acknowledges that there is a risk that the self-directed funding might be abused, and gives, as an example, people who have substance abuse problems.

> "Some people with disabilities have to address addictions and substance abuse problems that may make it difficult for them to handle money directly (though other parties could act on their behalf). For example, there is empirical evidence that 68 per cent of people who experience traumatic brain injury have a history of substance abuse (Headwest Brain Injury Association of Western Australia, sub. 448, p. 6)." (PC, p. 389)

On the other hand, the report also argues that the likelihood of abuse should not be over-stated, given the evidence of comparatively low levels of abuse:

> "[W]hile anecdotes indicate that abuse occurs, the systematic evidence suggests that . . . people with disabilities . . . are less vulnerable under consumer-directed care arrangements than through those organised by specialised services." PC, p. 391

Nevertheless, the report endorses the need for accountability by recommending that "risk mitigation" could be achieved by:

- "assessing the capacity of people to handle their funds before agreeing to direct payments. . . .
- providing information, training and support to people using self-directed funding where it is needed, and clear guidance on appropriate usage of funds, including an understanding that penalties may be applied for misuse . . .
- providing avenues for people using self-directed funding to complain to the NDIA about any inappropriate behaviour by providers and to have these investigated . . .
- ensuring reasonable accountability for funding, with acquittal periods determined on a risk basis . . .
- ensuring that people with a disability and their carers have easy and cheap access to police checks of employees who provide personal services . . .
- improving community engagement with people with disabilities . . . " (PC, p. 393-4)

A more systemic kind of risk could occur if a DSO places it own financial interest above the interests of a person with disability. The report argues that this kind of risk could be "minimised" by:

- monitoring the effectiveness of DSOs over time and assessing them against clearly specified, person-specific objectives
- ensuring (where possible) that helping people to develop planning and organisation skills are themselves a feature of DSO activity." (PC, p. 419)

Finally, the report acknowledges that, whilst accountability is necessary, it must not be so onerous that people are dissuaded from taking up the self-directed funding:

> "If consumers take full control of funding, they would be responsible for hiring any staff they want . . . ; ensuring that they have adequate public liability or other insurance; overseeing service provision; and accounting for spending. The costs and uncertainty associated with these responsibilities act as a barrier to take-up of self-directed funding. . . . [so the system should] reduce compliance burdens where they do not undermine public accountability or the safety of people with disabilities or support workers." (PC, p. 384)

As one example of reducing the burden of compliance, the report recommends an approach to accountability measures that takes account of the level of risk involved:

> "In offering self-directed funding, the NDIA should ensure that: it adopts a risk-management approach for receipting and other accountability requirements, which:
>
> – requires less accountability for people with low risks or who have demonstrated a capacity to manage their funds well
> – takes into account the compliance costs of excessive accountability measures
> – allows a small component of the individual budget to be free of any receipting requirements" (PC, p. 395-6)

6. There should be criteria for delegated decision-making

BIA and its members recommended that there should be a framework "outlining who should be an alternative decision maker on someone's behalf and on what basis, if someone is deemed to not be competent to self manage their funds, and where guardianship is not needed". (VCASP / VBIRA 2010, p. 24)

The report does not list a detailed set of criteria, but rather makes the basic assumption that the best delegated decision-makers will be those who have been intimately or regularly involved in the daily life of person with a disability, rather than someone more 'removed'.

> "[S]ome people with disabilities are not able to make all of their own decisions (as is the case with profound intellectual disability). In that case, decisions about their well-being will often be made jointly with or by their primary carers, who are usually familiar with the strengths, goals and other preferences of the person with a disability." (PC, p. 356)

This approach is based on the report's understanding of how to arrive at the most economically efficient decision:

> "People have different, complex and changing preferences about their lives — their food, clothes, jobs, education, hobbies, friends and partners — that are not cheaply or easily observable by others. This is true for even the most apparently simple products. A social worker might observe that a person likes tea. But they are less likely to be able to remember what type they like, or whether they like it strong, sugared, with milk, in a mug, very hot, after or before breakfast or both. Nor would an external agent know how,

> given a finite budget, a person might trade off one preference against another. So, individuals know a lot more than others about how to meet their own preferences, and in turn, this is likely to lead to better outcomes for them (greater economic 'efficiency'). This is why in most cases, a large degree of weight is appropriately given to the power of people to make their own decisions. The same principles hold for people with disabilities or their families." (PC, p. 355-6)

But the report also argues that there are important qualifications to the 'we know best' principle. First, not all of our preferences are in our best interests; or, put another way, what we *want* is not always the same as what we *reasonably need*:

> "[S]ome vulnerable people may have preferences that lead to harm for themselves or others. (Examples among the general public would include driving dangerously, illicit drug taking and excessive alcohol consumption.)" (PC, p. 356)

> "[T]here are potentially strong ethical and economic arguments for the person with a disability (or people acting on their behalf) to control how it is used. However, it does not imply that it is efficient for taxpayers to meet *all* of a person's preferences, regardless of the cost. . . . the funding of the NDIS is based on people's reasonable needs, not wants." (PC, p. 359)

> "[T]here would be a strong presumption that people would not be able to trade-off funding for essential aids and appliances and building and motor vehicle modifications against other spending options. However, people could direct some non-recurrent funding to other purposes if they could provide persuasive reasons for this as part of their funding proposal. The discipline of an approved funding proposal (described below) would prevent the practical dilemmas and risks of completely free choices about these high-cost non-recurrent spending items." (PC, p. 374)

Second, no matter how confident or resourceful we might be, we are not always in a position to know *how best to satisfy certain preferences*. In such cases, the best outcome for the least cost will require 'third-party screening' or 'expert gatekeepers':

> "[T]he choices people make to meet a given preference may be based on inadequate or false information, or on faulty cognitions. For instance, people may want to treat a debilitating cancer by using a well-marketed, but ineffective therapy, when a cheaper and more effective one is available. Further, consumer knowledge may be sufficiently limited for some specialised, highly complex services that experts need to act as gatekeepers to ensure that people get the services that genuinely meet their needs ('credence' goods). This may apply to some complex health/early intervention services used in conjunction with disability services. Notably, no health system allows people to choose any therapeutic substance they want without some controls. That said, the bulk of disability services would not require third-party screening" (PC, p. 356)

These two qualifications help to fill out how alternative decision-makers are likely to be selected and/or monitored: when it comes to purchasing (a) specialised, highly complex services, (b) inadequately tested or expensive therapies, then the 'alternative decision-makers' should be (or at least should be overseen by) the relevant technical experts; and all purchases made by delegated decision-makers should be screened for anything that is illegal or might harm the individual concerned.

> "[S]ometimes others may need to provide advice or even override the preferences of people with disabilities or their carers (as, for example, occurs with regulations about drug use in the community as a whole)." (PC, p. 356-7)

Third, the report seems to indicate that the NDIS will rely upon existing legislation to ensure that (legal) guardians fulfil their obligation "to take into account, to the extent practicable, the wishes of the represented person.[2]" (PC, p. 364)

Finally, the report recommends that any funding proposal would need to be approved by the NDIA or possibly a panel, ideally using a set of national guidelines. This process will act as a deterrent against the misuse of delegated decision-making power; but it will also serve as a filter for any decisions that, whilst well intentioned, are not in the best interests of the person with a disability.

> "A plan would get approval [by the NDIA or a panel] if it met some clearly specified criteria relating to outcomes for the person and for appropriateness. The guidelines used in various Australian and overseas jurisdictions could be adapted to create a national approach under the NDIS, such as the guidelines used in the Florida self-directed care program (Hendry 2008)." (PC, p. 374)

7. Delegated decision-making arrangements should undergo periodic review

BIA and its members have argued that "[s]ome people's ability to make good decisions will improve, so any arrangements for delegated decision making need to be reviewed over time". (VCASP/VBIRA 2010, p. 24)

Whilst the report does not mention the need for this kind of review explicitly, it does endorse the principles of 'flexibility' and 'need-dependent arrangements' that lies behind this kind of review. For instance, in another context, the report appears to support the view that "people with episodic disability — such as those with mental health problems or certain chronic diseases — may benefit from more flexible arrangements that allow them to access a 'support bank' when their needs are greatest" (PC, p. 371).

In addition, it also recognises that, for personal or cultural reasons, people's capacity to decide for themselves can improve over time. The implication seems to be that, even if people delegate to begin with, they (and their delegated decision-makers) should receive ongoing support, so that their capacity to choose can reach its full potential.

> "Inertia, uncertainty and lack of confidence may also affect people's willingness to take up self-directed funding. For example, one participant thought that a short-run cultural obstacle was the learned passivity of some people with disabilities, who were too long accustomed to command and control services (PC, p. 383) . . . [T]ake-up can be improved through better support of people using self-directed funding, and training and commitment by front-line staff in government and other disability agencies" (PC, p. 385)

[2] "For example, see Section 28 of the *Guardianship and Administration Act 1986*, Victoria."

8. Training to manage financial aspects of self-directed funding should be available

Jennifer Cullen (Synapse, Qld) has suggested that the NDIS will "need to consider if education/training will be required for any financial obligations associated with receipting of funds for self-directed individuals." (Email correspondence, 11/04/12) The report endorses this suggestion, and recommends two ways in which such education or training could be made available. First, the NDIA would provide "videos, written material and other guidance" (PC, p. 31) to persons with disability on how to administer self-directed funding. For example, it might adapt and make available existing software:

> "[T]here is already a free, open source, software tool (the CDM or Consumer Direction Module from the US National Resource Center for Participant-directed Services) for administering self-directed funding, which could be adapted for Australian use (and which could be made freely available on the NDIA's website). . . . Among other things, the CDM allows the overseeing agency to keep track of participants in a self-directed funding arrangement (brokers/counsellors, fiscal agents, employees, medical providers, representatives/guardians); maintain case notes; generate spending plans; track participant expenditures; coordinate approvals, denials and appeals; and communicate with all participants." (PC, p. 387, n. 25)

Again, the report recommends that the NDIA should use training models that have been shown to be effective elsewhere. For example:

> "[A] small-scale pilot of self-directed funding in the UK among young people found that practice budgets helped people understand how to set budgets, and that shared experiences among families about self-directed funding plans helped people to realise what was possible and how to set up practical plans (Crosby and Fulton 2007, p. 35)."

Second, NDIA should provide training to "local area coordinators, [service providers] and other front-line government agencies in implementing self-directed funding — why [self-directed funding] exists, how a plan is drawn up, knowledge about the supports for people with disabilities, and the risks" (PC, p. 386 [387]).

Third, the report suggests that, whilst DSOs and DSPs could be employed by the person with disability to handle all (or some) of their financial obligations, they could also provide them with training so that they can manage their funds independently:

> "Disability support organisations (or indeed service providers) . . . might also develop short training sessions in people skills and confidence to self-direct, especially as so many people with a disability have been used to a system in which they only had a passive role." (PC, p. 31)

RECOMMENDATIONS:

1. That greater clarity be provided on how self-directed funding will be managed within the NIIS.

2. That greater clarity be provided on the procedure that will be used to assess the capacity for choice; and that this assessment procedure must be fair and equitable, so as to minimise the risk to people with disability.

3. That greater clarity be provided on (a) the conditions under which pooled funding might be possible, and (b) what kind of safeguards will be put in place.

4. That greater clarity be provided on both (a) the criteria for assessing when delegated decision-making is necessary and to what extent; and (b) the process by which delegated decision-making will be periodically reviewed.

brain injury AUSTRALIA
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BACKGROUND PAPER ON THE NDIS / NIIS

3. Quality Safeguards & Standards

An analysis of the extent to which the Productivity Commission endorsed the recommendations submitted by Brain Injury Australia and its member organisations.

Prepared by Dr. Derek Brookes
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May 2012

Abbreviations:

BIA 2010	Brain Injury Australia (prepared by Victoria Schneider), "Submission to the Productivity Commission's Inquiry into Disability Care and Support" (August 2010).
BIA 2011	Brain Injury Australia, "Supplementary Submission to the Productivity Commission's Inquiry into Disability Care and Support" (April 2011).
BINSA 2010	Brain Injury Network Of Sa Inc, "Submission To The Productivity Commission's Inquiry Into Disability Care And Support" (16 August 2010).
FBIC 2011	Friends of Brain Injured Children (ACT) inc., "To the Productivity Commission in consideration of the proposed National Disability Insurance Scheme" (2011)
Headwest 2010	Headwest," Headwest Brain Injury Association WA Inc. Submission to the Productivity Commission Long Term disability Care and Support Inquiry: (2010)
Headwest 2011	Headwest,"Disability Care and Support Productivity Commission Draft Report Submission" (2010)
PC	Productivity Commission, *Inquiry Report – Disability Care and Support*, No. 54 (Australian Government, July 2011).
PWC 2011	"Disability expectations: Investing in a better life, a stronger Australia" (PwC, November 2011)
VCASP/VBIRA 2010	"Submission from VCASP and VBIRA to Productivity Commission Inquiry into Disability Care and Support" (August 2010)

Contents

A | Quality Safeguards

> *"Participants expressed concern about the quality of disability services in some locations. They also noted there was little or no monitoring of service quality, with manifestly poor services appearing to not only have their funding renewed, but increased."*
>
> — BIA 2011, p. 11

BIA and its members argued that disability service providers should be closely monitored so as to ensure that (a) their service standards are of the highest quality possible, and (b) they are held accountable for their performance. BIA and members also suggested a number of features that would make it more likely that these two objectives would be met:

1. The monitoring process should be independent in two senses: (a) it should be "independently audited" (BINSA 2010, p. 4) and (b) it should be "independent of government and the [NDIA]" (Headwest 2010 p. 6).
2. It should make use of "individual client feedback evaluation mechanisms" (BINSA 2010, p. 4), in a way that places "the experience of clients and their families at their centre" (BIA, 2011, p. 11).
3. It should be "comprehensive" (BIA 2010, p. 23), "ongoing" (BIA 2011, p. 11) and "nationally consistent." (BIA 2010, p. 23).
4. It should include "a taskforce and watchdog committee in each state made up of 'official visitors' with representatives from the major agencies and stakeholders including consumers and carers . . . ." (Headwest 2010 p. 6).
5. It should include advocacy agencies assisting people with disability, who, by "providing independent advice in selecting the most appropriate services . . . would then . . . be in a position to monitor service providers and ensure individuals' right to the best possible care and support." (Headwest 2010 p. 7).
6. It should evaluate the "cost effectiveness" of services or the programs they deliver, by considering whether (or to what extent) they are able to deliver "outcomes [that are clearly] defined in objective and consumer centred (self-determination) terms." (BINSA 2010, p. 4)
7. It should evaluate whether "service providers . . . have the skills to enable people with ABI and their families to set the goals of support programs as far as is possible." (VCASP/VBIRA 2010, p. 22-23)

Rather than assess the report's response to each of these suggestions one by one, the following will instead present the full range of quality safeguards and standards that have been recommended by the report. By the end, it should be clear that the report endorses every one of the suggestions made by BIA and its members — and a great deal more besides. Hence, there is less need to make any recommendations in response to the report, other than to affirm, in general, the report's own position on these issues.

Monitoring the Service Providers

1. People with Disability and their Carers

The report recognises that people with a disability and/or their carers will have the most interest in and knowledge about the quality of 'day-to-day' service delivery.

> "Consumers have a strong personal interest in the quality of goods and services they receive, can observe actual quality first hand (rather than through an audit, for example) and are able to change providers if they are dissatisfied. This directly links service provider's viability with their capacity to satisfy consumers' needs, rather than their ability to fulfil the administrative requirements issued by their funding body." (PC, p. 498)

However, the report also accepts that, even if the mechanism of self-directed funding will eventually have an impact on the quality of service delivery, it is not enough in itself. Many people with a disability will not be "equipped to make good informed decisions about the support services they wish to use, to demand high quality services and to complain or switch providers when their expectations are not met (if given the opportunity to do so)". In other words: "the vulnerability of many people with a disability increases the risks of harm or poor outcomes, even when consumer choice is greatly enhanced under the NDIS" (PC, p. 498). Hence, the report recommends that the NDIA provide education and support to help people with a disability both (a) to evaluate the quality of services for themselves and (b) to effect change by using their consumer power "to discipline and *reward* service providers" (PC, p. 493):

> "[A] public education campaign should accompany the introduction of the scheme, including how to seek help, people's rights as consumers and how to make complaints. Direct assistance will also be provided to people with a disability through better advice and support from local area coordinators. . . . NDIS clients will also be allowed to use their entitlement to purchase additional support from DSOs if they wish . . . The national online database of service providers will be a valuable source of information to [all concerned]." (PC, p. 498)

2. Local area coordinators

The report argues that Local Area Coordinators (LACs)[1] would also provide a means of monitoring delivery of services at the 'ground level'.

> "The primary role of LACs would be to oversight the delivery of services to people in the NDIS, and their ongoing interaction with the NDIS, and provide some links to the community. But they would also assist in monitoring other aspects of the scheme — for example, by helping to independently assess the quality of service providers (through [confidential] feedback from people with disabilities and carers). . . . ." (PC, p. 411 [413])

[1] "Several participants proposed that the NDIA use the term 'local area coordinators', as used in Western Australia, rather than 'case managers', when identifying staff who would have the front line role of assisting people with disabilities. A common concern was that people not be seen as 'cases' . . ." (PC, p. 413)

More specifically, LACs would carry out the following types of regulatory oversight: (a) they would perform "[p]eriodic checks on people, (according to degree of vulnerability)"; they would be the "[c]ontact point for complaints and breach of standards (as LACs would be the major source of information for NDIS participants about service providers)"; and they would be "[a]ble to initiate investigation against service providers, or pass to Office of Inspector–General". (PC, p. 421).

One important restriction is placed on this role: to avoid conflicts of interest, the LACs must be independent of *both* service providers *and* persons with a disability. That is, if a LAC is overseeing the services being delivered to a particular person with a disability, then that LAC should not be, at the same time, employed by any of those service providers; and, since LACs will also oversee the use of funds, people with a disability should not be able to hire them.

> "While LACs would generally be employed by the NDIA, some may be employed under contract. To avoid any conflict of interest, they could not be employed by a provider that is also providing supports to the person. And as LACs would serve a regulatory function for the NDIS, concerns about potential conflict of interest suggest that people with disability should not hire LACs." (PC, p. 411)

3. Disability Service Organisations

The report suggests that Disability Service Organisation (DSOs) would have a monitoring role to play, although in a capacity that is more 'complementary' to the LACs. First, DSOs could be hired by people with a disability to carry out certain administrative tasks.[2] As with the role of LACs, this might include finding DSPs that are of the highest quality; and, of course, this task could not be performed effectively unless the DSOs were closely monitoring the DSPs.

> "DSOs may advise people with disabilities about the quality and choice of specific support services available, and act as brokers by assembling 'packages' of supports for them. There are several potential benefits from this approach: . . . DSOs will face lower 'search costs' (that is, finding services and obtaining information about the availability and quality of products and services will be easier, due to their knowledge and experience) than for some people with a disability, who may have little experience with the sector or may have functional limitations that make research and organisation difficult." (PC, p. 415)

Second, the report suggests that another "possible role" that the DSOs could play is to "[inform] the NDIA about breaches of service standards by providers" (PC, p. 417-8), which would add another valuable 'ground-level' monitoring arm to the system.

[2] "The LAC could inform the person about DSOs in the local area, their services and any specialisation or skills they have, which DSO services the NDIS would pay for and which the person would have to pay for themselves out of their NDIS package." (PC, p. 413 – see p. 420 for more detail)

Third, DSOs could themselves fail to provide a service that is in the best interests of people with a disability (e.g. rather than enable people to manage their own funds, DSOs could 'engineer' a relationship of dependency). So the report recommends that DSOs also be monitored, presumably by the NDIA:

> "In some cases, there may be a risk that DSOs have a financial interest in the ongoing provision of services to people with a disability that runs counter to the interest of the individual's personal development. Such risks arise may be minimised by . . . monitoring the effectiveness of DSOs over time and assessing them against clearly specified, person-specific objectives." (PC, p. 419)

4. Individual and Systemic Advocacy

The report argues that advocacy would play a key quality assurance role under the NDIS. First, individual advocacy organisations could be used to help people "express concern or make a complaint about the quality of service provision, either to service providers themselves, or to local area coordinators as well as the NDIA directly" (PC, p. 507). Second, individual advocates would ensure that "assessment processes properly recognise people's needs", and act as "a safeguard when dealing with DSOs and local area coordinators" (PC, p. 507). Third, systemic advocacy organisations will be needed as an independent means of promoting a higher quality of service provision throughout the system — that is, by performing the following roles:

> "[U]ncovering system failures; petitioning for widespread change; disseminating information of best practice to service providers; promoting public awareness of disability issues; and promoting the interests of particular groups such as CALD, indigenous and women with a disability." (PC, p. 507)

5. State and territory statutory bodies

State and Territory statutory bodies (e.g. Offices of Public Advocates, ombudsmen and disability commissioners) typically engage in tasks that contribute to the promotion of service quality. These include:

- "facilitating communication and helping [people with a disability] to understand their rights
- speaking for and negotiating on their behalf
- providing and alternative avenue of complaint
- investigating and seeking to resolve disputes
- making recommendation for operational and legislative change
- monitoring residential facilities through community visitor programs" (PC, p. 507).

The report argues that, under the NDIS, these bodies should continue to play these 'broader roles' as well as being an "additional and independent source of support to people with a disability" (PC, p. 507).

6. Community Visitor Schemes

The report recommends that community visitor schemes "should be implemented in states where they do not currently exist under the appropriate state and territory statutory bodies, potentially with funding assistance from the NDIS", preferably replicating "features of the Victorian model, including the publication of annual reports and the use of volunteers" (PC, p. 509).

The reason why community visitors are essential, the report suggests, is that (a) they are able to monitor the care of people who are in situations where the failure of standards is likely to "go undetected"; and (b) their legal powers (to make unannounced and random inspections, talk privately with anyone, inspect documents and make reports on the services provided) "strengthens industry wide incentives to comply with service standards as well as other laws and regulations" (PC, p. 508). In addition:

- "they can draw issues to the attention of service providers
- when serious issues are detected, they can instigate further investigation by the NSW Ombudsman, the Office of the People's Advocate or police
- in Victoria, the publication of the annual report provides information to consumers about ongoing issues with certain providers and to government about broader industry challenges and trends in service delivery." (PC, p. 508)

7. Members of the community

The report argues that other community members — particularly health professionals — can also provide an important monitoring role. If they become aware that a person with disability is not receiving adequate care and support (e.g. repeated admission into hospital for bed sores or infections), then the NDIS should ensure that they "have avenues to express concern to local area coordinators or directly to the NDIA itself" (PC, p. 509-10)

8. Disability Service Providers (self-assessments)

The report argues that there are several key drawbacks with using service self-assessment to monitor DSP compliance with standards. First, verifying the accuracy of self-assessments (e.g. with direct observation and interviews with consumers) would be "expensive". Second, the time required for staff to complete self-assessment forms and compile supporting evidence could be a "significant cost burden". This would be especially true for smaller DSPs "offering niche service products", who may exit the market (or reduce their capacity to deliver a service) if the cost of self-assessment is too high (PC, p. 505). Third, the satisfactory completion of self-assessment forms can merely indicate that a DSP has a well-resourced administration, rather than that it is delivering a high quality service:

> "[S]elf-assessment and auditing tends to focus on the existence (or non-existence) of documented policies and procedures, which are a poor proxy for quality of service. Compliant providers may actually deliver lower quality services (for example, nicely completed forms, but unempathic staff), and non-compliant ones may be more responsive and effective at meeting people's actual needs." (PC, p. 505).

For all these reasons, the report suggests that the self-assessment requirements for certified DSPs should be "concise and aimed at informing providers of their obligations (in terms of standards and other laws and regulation) and the explicit policy or procedures they must have in place to meet them." (PC, p. 505)

9. NDIA audits of service providers

The report argues that DSPs should be audited by the NDIA (with auditors reporting to the Inspector General – see below).[3] Over time, for reasons of cost-effectiveness, the NDIA should move toward a "graduated auditing regime". In other words, audits should move away from universal application, and begin instead to incorporate a "random component". They should also focus more on areas where there is a higher level of risk: for example, they might target DSPs that have a history of non-compliance, or where there has been "new information indicating a serious problem (such as a complaint or report of a serious incident)", or where the risks are generally greater for a particular "consumer group or service type", and so on. (PC, p. 505)

These audits might include monitoring the electronic disability record. This could either be proactive or rules or triggers could automatically alert the NDIA to problems. The NDIA might also use the record as a source of evidence in any investigation as to whether "a specific complaint is indicative of more widespread problems with a particular service provider and if intensive auditing is warranted" (PC, p. 511).

10. Consumers surveys

The report argues that consumer surveys could be used — as they are already in a number of states — to gain a 'big picture' assessment of the quality of service provision from the perspective of persons with a disability and carers. To be reliable, ethical and cost-effective, however, surveys would need the following features: "appropriate sampling, careful targeting of questions, and surveying methods that protect the privacy of respondents" (PC, p. 505).

[3] "While organisations should be subject to self-assessment and audits, where people with a disability hire individuals directly (for example within their self-directed funding budget), such measures would not be required (though they would still have to undergo a basic approval process). Nevertheless, local area coordinators would still provider a degree of oversight and regular checks that appropriate care was being delivered." (PC, p. 505)

Monitoring the NDIS and the NDIA

1. An independent commercial board

In terms of overseeing the NDIS and the NDIA, the report argues that an independent commercial board be appointed.

> "Primary roles of the board would be to appoint the CEO, provide strategic direction and oversight of the scheme's success in meeting the objectives laid down in its Act, to ensure financial sustainability and to manage the relationship with governments. The board would need to ensure that the scheme, and the NDIA, was run professionally and efficiently, and that structures and procedures were in place to ensure that costs and the associated future liabilities were monitored and controlled." (PC, p. 424)

The board should, the report argues, include members that have "a mix of skills and commercial expertise" in relevant disciplines, such as "finance, management, and insurance". In particular, the board should include members that have "knowledge about the prudential management of a large and complex commercial corporation with long-term liabilities of the kind envisaged here." (PC, p. 425)

To avoid the problem (or perception) of 'politically friendly' appointments', the report recommends that the board be selected by an "independent appointment panel". The membership of this panel would need to have (a) the same range of skills and experience as the board, and (b) the approval of *all* Australian governments. Once formed, the panel would recommend a chair of the board and nominate at least two candidates for each of the other board positions. The final appointments in each case would be based on the majority vote of all Australian governments. If the votes were tied, then a minister (e.g. the Treasurer) in the Australian Government would make the ultimate decision. The Australian Government would also have the power to dissolve the board or replace the chair (using the appointment process above) if the board or chair performed badly. (See PC, p. 426-7)

One question raised in the consultation phase was whether the board membership should include people with disability. The report responds to this issue in the following way: It begins by acknowledging the concern that such an important body should represent the 'voice' of people with disability. However, it argues that, for the members of a board to govern in a way that is objective, fair and effective, they need to be situated 'at arms length' from *all* 'interested parties' or 'stakeholders'. This means that the board should not include persons who are (or who represent the interests of) any government, employees of the NDIA, service provider, or users of the system—namely, people with disabilities. This is not to say that the board should not include people "who also have experience and understanding of disability"—but only if doing so is consistent with the principle that the board's role is to 'keep the scheme on track and within funding limits', not to represent the special interests of stakeholders (see PC, p. 427-8).

> "This approach is not peculiar to disability, but are principles generally adopted in corporate governance. . . . [e.g.] Medicare is independent of the chronically ill and medical practitioners who are the biggest users and producers of its services." (PC, p. 428)

2. An Independent Advisory Council

The report recognises that the activities and decisions of the board would benefit from the advice of key stakeholders, such as people with disabilities, their carers, and service providers. Hence, it recommends that "an independent disability advisory council" should be created to fulfil this role. This council should be made up of individuals who can represent the perspectives of "people with disabilities, carers, suppliers of equipment and services, and state and territory service providers" (PC, p. 429).

The council would thus function as a conduit through which people with disability and others can report problems to the board (and, in an annual report, to the public):

> "An advisory council would help identify problems at the coal face on how the NDIS was operating. As hypothetical examples, it might reveal faults in the way self-directed funding was working, inadequate training of LACs, excessive compliance burdens, or poor IT links between suppliers and the NDIA. The board and the CEO would then consider this advice when determining how they ran the NDIA. The advisory council would provide an annual public report on their principal advice." (PC, p. 429)

3. Other advisory councils/groups

The report recognises that there are specific issues that may require a specialist or more focused advisory input. For instance, the board may need advice on "voucher pricing", "aids and equipment", "particular service standards", and so on. So the board may request that separate groups or councils be set up to advise them on such matters, whether in a short-term or standing capacity.

In addition to the other advisory groups, the report recommends that there should be a 'red-tape' group that is responsible for monitoring "all aspects of compliance costs", so that it can advise the board on "ways to keep this to a minimum" (PC, p. 430):

> "There should be a red-tape advisory group for the NDIA that includes key stakeholders—people with disabilities, carers, service providers and disability support organisations. It should advise the NDIA on ways of controlling compliance burdens on providers, people with disabilities and carers, and to ensure plain English forms, letters and emails." (PC, p. 431)

4. Independent audits of any changes to NDIS legislation

One major concern with setting up the NDIS is that it remain financially sustainable over the long term. For this to be the case, it will need to be able to resist efforts either to 'widen' or 'reduce' the scope of who or what is covered by the scheme. The report argues that this objective requires that the scheme have its own Commonwealth legislation ("constructed with the agreement of the states and territories") so that the NDIA management team and board can "plan with assurance". This legislation — which the report calls the 'NDIA Act' — would enshrine "the roles, objectives [one of which would be 'financial sustainability'] and powers of NDIA and the NDIS, and the critical

features that would affect the costs and operation of the scheme . . . such as "an entitlement to reasonable support, together with details about people's eligibility for services and the range of services to be offered." (PC, p. 432)

Legislation can, of course, be changed by successive governments. So the report recommends that any changes to the NDIA Act be done transparently and "accompanied by" an independent review to determine how the changes might effect the financial sustainability of the system. This assessment "should be made publicly available" (PC, p. 433).

> "Future changes to the legislation should be implemented in accordance with a protocol to ensure good governance and transparency, in consultation with the states and territories, and with full parliamentary scrutiny. Such changes would be independently assessed and audited for their financial implications. Periodical widening and narrowing of eligibility and generosity, such as happened in New Zealand with successive changes of government, exemplifies the problems that can happen. In that case, the financial sustainability of the ACC was put at risk." (PC, p. 433)

5. Independent external reviews

The report recommends that the NDIA Act enshrine the requirement that the system receive regular, independent and external assessments and audits. The report suggests six different types of reviews:

First, there should be an annual audit of the scheme's financial statements (checking "accuracy and compliance with appropriate accounting standards"). (PC, p. 435)

Second, there should be "(monthly) reporting of trends in usage and costs — and 'red flags' for significant departures from expected outcomes" (PC, p. 435).

Third, the NDIA Act should (a) enshrine the requirement that there be an "independent professional actuarial assessment of the NDIA on a quarterly and annual basis" (PC, p. 435); and (b) define the obligations of these actuarial assessments—for instance, they should be required to:

- "monitor and report on outcomes for scheme participants
- identify the likely capacity of NDIA funding arrangements . . . to meet the future expected liabilities of the scheme
- identify the main factors leading to the costs of the scheme and service utilisation, with that analysis undertaken for different groups of people with disability, by location and by support type
- consider the magnitude and sources of any emerging risks for the scheme, including risks to solvency. A major objective of the report would be to separately consider the impacts on long term liabilities of:
    - internal factors under the control of the NDIA, such as: improving or declining rehabilitation rates; changes in key transition rates (including outcomes); changes in the patterns of assessment of eligibility and entitlements to supports; trends in service use; and over-servicing in allied professional services

  - external factors, such as the impacts of changes in input costs (like wage increases) on overall costs, and the effects of asset rates of return on the NDIA reserve

- examine the quality of the strategies being used by the management of the NDIA to address those risks, and any recommendations for improved processes
- make recommendations about the suitability of data collected to monitor the scheme
- recommend any additional (or changes to) performance measures that could usefully indicate the performance of the NDIA." (PC, p. 436)

These actuarial assessments would be provided to the NDIA board, the minister and the external 'regulator' (see later). The states and territory governments would be informed about the scheme's actuarial performance by the Secretary of the federal Treasury reporting regularly to Heads of Treasury meetings on this matter. (PC, p. 436)

Fourth, the "Australian National Audit Office should also conduct periodic performance audits of the processes used by the NDIA, including its reporting functions, but with a clear focus on appropriate, cost effective risk management, scheme accountability and sustainability" (PC, p. 436).

Fifth, "a small specialist unit in Treasury should provide external monitoring of the activities of the NDIS." This unit would:

- "consider the performance of the NDIA across a range of other indicators (for example, client satisfaction and benchmarked performance against other insurers in areas such as claims processing efficiency and overheads)
- analyse the reports made to the board and the annual actuarial report (seeking the advice of the Government Actuary if necessary), seek clarification if needed and provide advice to the relevant minister if the scheme's performance was falling below expectations
- assess whether the NDIA was managing costs and claims efficiently, and had the right processes for doing so. . . .
- prepare an annual statement on the performance of the NDIS and the NDIA, to be provided to all governments and made public. . . .
- advise the Australian Government of any necessary legislative changes that, if agreed, would then be put to state and territory governments as part of the consultation process." (PC, p. 437)
- initiate "benchmarking studies" that would assess the cost efficiency of the NDIA's various functions (e.g. "claims processing, research, IT and data management, accounts and personnel departments") relative to other "comparable corporate entities" (e.g. New Zealand's ACC, and, "over time", the NIIS) (PC, p. 439)

Finally, the NDIA Act should stipulate that (after the first 3 years and every 5 years thereafter) "the NDIS and NDIA should be independently reviewed . . . with the outcomes publicly and promptly released." The report also suggests that this periodic review should focus specifically on the extent to which the scheme has met the needs of people with disabilities and their carers. (PC, p. 438)

B | Standards

1. Service charters and standards

The report recommends that the NDIS should put in place complaint and dispute resolution arrangements. These arrangements should (a) enable persons with disability and carers to register their complaints about the decisions and conduct of the NDIA and service providers; as well as (b) give them confidence that they will be "treated fairly", that "reasonable complaints will be investigated" (PC, p. 451), and that "[i]f the NDIA corroborated a complaint against a provider, then the NDIA [will] make a determination" and adjust that provider's 'star rating' accordingly. (PC, p. 452)

In order to "underpin" these arrangements, the report argues that the NDIA establish two separate "service charters" — "one for the NDIA and the other for specialist providers and DSOs" (PC, p. 451). These charters should specify the "appropriate conduct" of each service, so that there is agreement and clarity for all concerned about what people can reasonably expect.

> "Without general agreement among producers and consumers about the interpretation of standards, and a competent third party that can reasonably assess whether a breach has occurred, the capacity for standards to serve a useful regulatory function is significantly weakened." (PC, p. 501)

Hence, the NDIA will — in consultation with all stakeholders[4] — develop a set of objective, consistent and nationally agreed upon standards that can be referred to whenever a complaint is made.

> "These standards should be complete rather than augmented on a state-by-state basis — essentially replacing state and territory equivalents for the purposes of the NDIS. A period of mutual recognition of state and national accreditation would be required to minimise the transitional impact on service providers." (PC, p. 501-2)

It would need to be clear to both consumers and providers about (a) "what compliance with a standard would actually mean for service quality" (PC, p. 502), and (b) what would, in practice, count as a breach. This is even more important for the more aspirational standards, where genuine evidence of compliance will be complex, and so there can be a tendency to resort to superficial indictors:

> "[F]or there to be useful standards in this area they would have to: (a) clearly identify the threshold for compliance and (b) avoid over-emphasising visible indicators of compliance (such as a membership card to a club) at the expense of more intangible but valuable outcomes (such as developing real social networks). This may be difficult to achieve in practice." (PC, p. 501)

[4] "These standards could be developed by the National Quality Framework Working Group. Alternatively, the NDIA could request Standards Australia to design the national standards as well as seek input from other peak bodies such as the Attendant Care Industry Association (sub. DR642). In either case, development of standards should consult with service providers, advocacy groups and consumers, as well as drawing upon the jurisdictional experience from evaluating the effectiveness of existing regimes." (PC, p. 502)

The report acknowledges the standards would need to be carefully designed to ensure that they are not too complex to understand, too costly to assess or too onerous to keep — yet without watering them down to the point where they become pointless.

> "[M]ore onerous compliance burdens for industry will result in fewer services to people with disability . . . Overly complex standards potentially undermine the capacity for effective oversight [e.g. where the NDIA cannot "cost effectively assess compliance"], and therefore the main objectives of the quality assurance system in first place" (PC, p. 502)

With such standards in place, people can "complain to the NDIA about any breach of the service charter by a provider (for example, rude staff or erroneous records)" or "the conduct of the NDIA, its employees and contract staff" (PC, p. 452). The charter should make it clear that (a) "the quality of its day-today interactions with people with disabilities" and (b) "the quality of the claims decision-making process [e.g. "how well it is handled by staff"] can determine whether a matter goes to dispute or not" (PC, p. 451-2).

In relation to the NIIS, the report argues that one of the most important reasons for setting up this federated scheme is that it will ensure that each state/territory's service provision will be subject to national minimum benchmarks.

> "The NIIS would be structured as a federation of separate, state-based injury insurance schemes. The purpose of federation membership should be to ensure consistency in assessments and to provide certainty around a benchmark minimum standard of care. Benchmarking would need to be transparent and agreed." PC, p. 46

> "A coordinated federated approach would be critical, however, to ensure that the level of benefits and the standard of care provided by individual schemes were subject to minimum reasonable benchmarks." (PC, p. 854)

In terms of what the minimum benchmarks might be, the report suggests that the NIIS could, at least initially, learn from existing schemes that are running well.

> "A nucleus of existing, well-functioning no-fault schemes already exists in some jurisdictions, like those run by the Tasmanian Motor Accident Insurance Board, the Transport Accident Commission and the NSW Lifetime Care and Support Authority. These can provide a valuable platform for learning and dissemination of skills and expertise in other jurisdictions. Such schemes and expertise can help to guide early determination of an appropriate minimum benchmark of care and support across jurisdictions." (PC, p. 867-8)

The report also suggests that the NDIS and might learn from the NIIS in terms of best practice — particularly in terms of the health sector's responses to ABI.

> "The NDIS can benefit from the NIIS experiences in determining the way it coordinates its activities with the health sector. For example, the lessons from appropriate rehabilitation for acquired brain injuries from motor vehicle accidents would be relevant to people experiencing major strokes. The MOU between the NDIS and the health system would need to reflect the importance of coordination between the two systems, and incorporate best practice knowledge from the NIIS." (PC, p. 866)

2. Complaints process

In terms of the process, it would be expected that people would, initially, take their complaints to the source of the problem directly — whether this is the NDIA or a service provider. If, however, they felt "too vulnerable or uncomfortable" to make a complaint themselves, they could ask their LAC, a DSO or an advocacy organization to support them, or "act on their behalf" (PC, p. 453, p. 507).

Each service would use its own internal complaints process to respond.[5] If people are not satisfied with this response, then they could take their complaint to the NDIA's "internal complaints office" (which would be set up to "hear complaints about the NDIA and service providers, or disputes about its decisions", PC, p. 453).

To ensure that this office acts fairly and gains the confidence of those concerned, the report recommends two features: first, the office should operate separately from other parts of the NDIA; second, it should be headed by an "Inspector-General, an independent statutory officer appointed by government" (PC, p. 453).

> "The NDIA legislation should create this role and specify that the Inspector-General would be independent, would act fairly and impartially, basing their decisions on the available evidence, and could not be directed in their decision-making." (PC, p. 453)

The NDIA would then take the following progressive steps:

1. "[I]nvestigate the issue through discussion with clients, their local area coordinator and the service provider, as well as through visiting their facility." (PC, p. 509)
2. "If this process revealed non-compliance with service standards, the service provider would be given a time frame to improve their operations, and if necessary, advice on how to do so. Such service providers would be subjected to greater oversight (including more frequent auditing against service standards) for a period afterwards." (PC, p. 509)

In terms of sanctions for non-compliance, the report suggests the following penalties:

1. "Incidents of substantiated non-compliance would also have a commercial consequence for service providers through the information being made available to consumers [optimally online[6]] and DSOs on the database of service providers . . . ." (PC, p. 509)
2. "For serious or repeated breaches of service standards, the NDIA could impose sanctions (such as fines) on service providers, or remove them as a registered provider, which would mean that people would no longer be able to use public funds to purchase disability supports from them." (PC, p. 509)

[5] And so, "[u]nder the disability service standards, providers would continue to be required to demonstrate effective complaints policies and procedures" (PC, p. 507).

[6] "The most appropriate central access point for consumers would be the national internet database of service providers described in section 10.2. This database could contain information about simple quantitative indicators, could link to more detailed qualitative indicators and, over time a summarising indicator could be developed by some combination of these, as well as from the personal level data contained in the electronic disability record. . . . Local area coordinators and DSOs would be available to assist consumers in interpreting these measures." (PC, p. 512)

If there is evidence of "criminal wrongdoing", or "breaches of other legislation", then the report recommends that these be "recorded by the NDIA and passed on to the relevant authority." (PC, p. 509)

3. Merits review process

One major concern is that the NDIS will become financially unsustainable if (a) disputes about claims are resolved in a way that widens eligibility or entitlement unnecessarily; or if (b) the dispute process is unable to identify 'unreasonable' or 'ill-founded' claims (presumably *before* they consume excessive time and funds).

> "The key concern here is that appeals processes that are unduly 'soft' can create costly precedents, leading to an unplanned and problematical redrawing of the rules and boundaries of the scheme. This can lead to additional unanticipated costs, and demands on revenue, over the long-term. Such outcomes may also undermine the motivation for assessors or other NDIA staff to continue to make hard-headed objective decisions. . . . Moreover, appeals and complaints processes can be very costly to provide, and there is the reality that not all people make well-founded complaints." (PC, p. 454)

The report suggests several monitoring mechanisms to prevent the likelihood that these risks will take hold:

> "It will be important for review mechanisms to have not only a broad 'reasonable person' criterion, but to be supported by legislative requirements to:
>
> - have thorough and robust formal initial assessments and processes for calibrating them
> - assess reasonableness by balancing the costs of some support against the benefits that these supports have for the person
> - assess the appropriateness of the service and of its provider
> - take account of any threats to the long run sustainability of the scheme from the review outcome and
> - take into account the obligation of people with disability or their families to avoid decisions that unreasonably impose costs on the scheme (such as moving to a dwelling that is very costly to modify)." (PC, p. 456-7)
> - "as much as possible, attempt to provide clarity about specific entitlements . . .
> - amend the legislation defensively, as loopholes and problems emerge and also, in some cases because more not less supports should be provided. . . .
> - seek to avoid large increases in benefits that are associated with small changes in context or circumstances, especially where there is ambiguity about the severity of a person's functional limitation." (PC, p. 457)

One important question considered by the report is whether the merits of any particular dispute (that an individual or service provider has with the NDIA) should be

reviewed by the NDIA itself or by an external body. The report takes the view that the merits-based review should be conducted by the NDIA.[7] It gives the following reasons:

First, if a person affected by a decision wants a review to take place, then they already have the right to take the matter to an external body, namely, the court — although this will only be worthwhile if there is a prima facie case that the original decision-maker breached their legal obligations (presumably as set out in the NDIA Act). (PC, p. 459)

Second, "there is no legal requirement for external *merit-based* review" (PC, p. 459) — although presumably this requirement could included in the NDIA Act

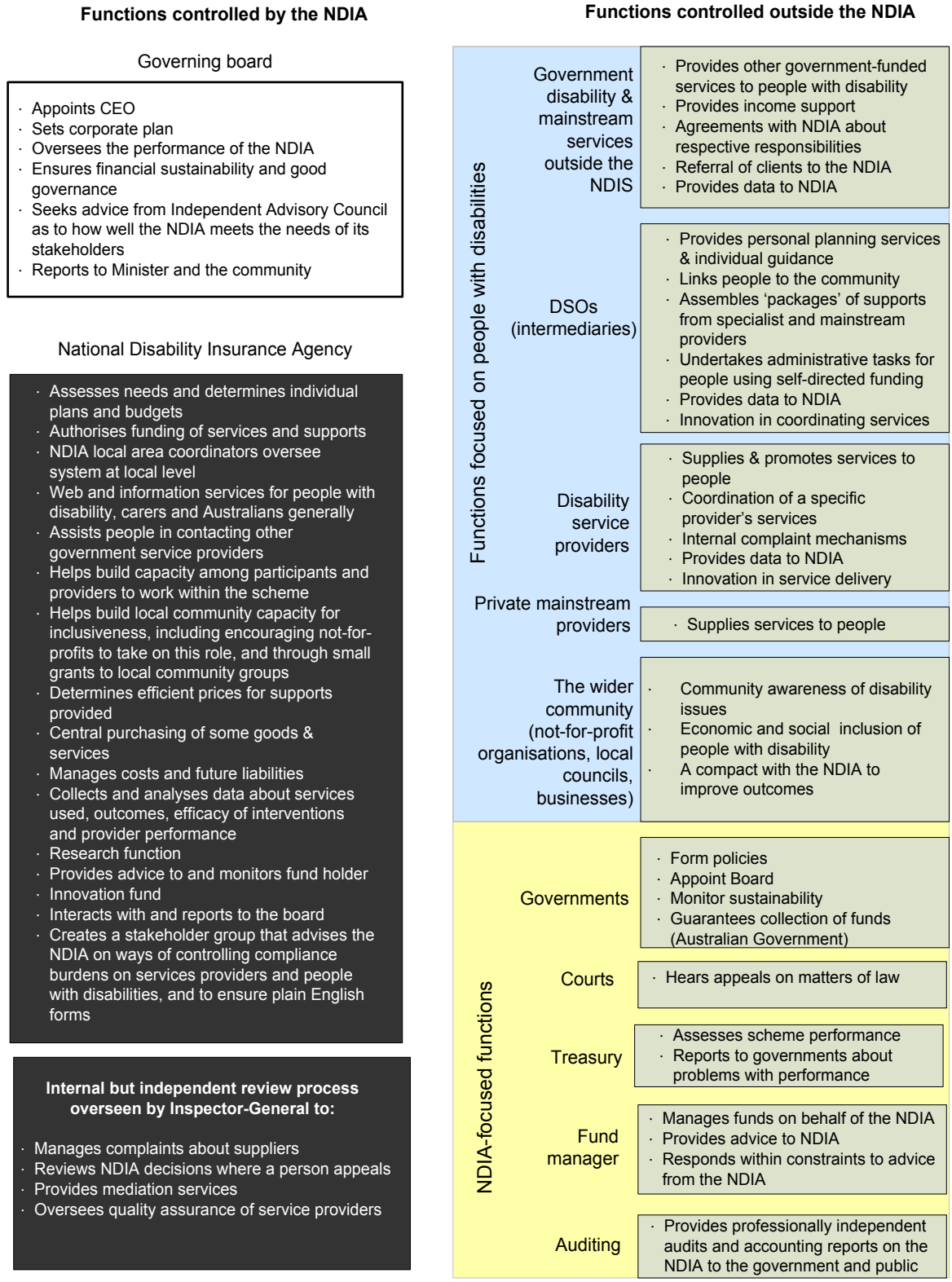
Third, "external complaints-handling mechanisms" cannot be easily constrained and so are more likely to set precedents that have the effect of extending the scheme's eligibility criteria and entitlements in a way that could "undermine the financial integrity of the NDIA". But it is far more important to "people with disabilities and their families" that the NDIS be "financially sustainable over the long term". For this reason, having an external review would pose "a much greater threat to the interests of people with disability than having dispute-handling mechanisms handled within the NDIA by the independent statutory officer — the Inspector-General." (PC, p. 461)

Finally, to ensure that the NDIA merit-based review is as independent, reliable, transparent and (legally) challengeable as possible, the NDIA Act would place a number of legal obligations upon the office of the Inspector-General, requiring it:

- "to be separate from the other parts of the NDIA dealing with people with disabilities and service providers" (PC, p. 462)
- "[to] act fairly and impartially, basing their decisions on the available evidence . . . and not be directed in their decision-making" (PC, p. 463)
- "to independently review appeals against decisions of the NDIA (where they had been through internal NDIA review processes but a dispute remained) . . . [but with appeals on matters of law being heard by courts in the usual way]" (PC, p. 462)
- "to undertake its own investigations and, if need be, direct the NDIA to alter contested decisions" (PC, p. 462)
- "[to] regularly advise the NDIA board on issues arising from its independent investigations" (PC, p. 463)
- "to independently review disputes and complaints about the quality of services provided, and breaches of service standards, including auditing and appeals" (PC, p. 462)
- "to report to Parliament, and publicly, on the number and nature of complaints and appeals, the reasons for its decisions, and on the activities of the office more generally" (PC, p. 462)

[7] The report also suggests "two other less preferred options", should its recommendation not be accepted by the Australian Government: "[a] the NDIA should use the Inspector–General as an interim arrangement during the setup and establishment years of the NDIS, and then revisit the appropriateness of external administrative tribunals; [b] the Australian Government should create a specialist arm of the Administrative Appeals Tribunal to hear appeals on merit about the NDIA's decisions subject to the constraints of recommendation 9.13. In this instance, the Australian Government should set aside significant additional resources to fund this specialist arm and should include a larger reserve for the NDIS, calculated to take account of the higher risks of this approach." (Rec. 9.15 PC, p. 466).

Appendix: Long-run structure of the NDIS (PC, p. 439)



brain injury AUSTRALIA
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BACKGROUND PAPER ON THE NDIS / NIIS

4. Disability Workforce & Sector Capacity

An analysis of the extent to which the Productivity Commission endorsed the recommendations submitted by Brain Injury Australia and its member organisations.

Prepared by Dr. Derek Brookes
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May 2012

Abbreviations:

BIA 2010	Brain Injury Australia (prepared by Victoria Schneider), "Submission to the Productivity Commission's Inquiry into Disability Care and Support" (August 2010).
BIA 2011	Brain Injury Australia, "Supplementary Submission to the Productivity Commission's Inquiry into Disability Care and Support" (April 2011).
BINSA 2010	Brain Injury Network Of Sa Inc, "Submission To The Productivity Commission's Inquiry Into Disability Care And Support" (16 August 2010).
FBIC 2011	Friends of Brain Injured Children (ACT) inc., "To the Productivity Commission in consideration of the proposed National Disability Insurance Scheme" (2011)
Headwest 2010	Headwest," Headwest Brain Injury Association WA Inc. Submission to the Productivity Commission Long Term disability Care and Support Inquiry: (2010)
Headwest 2011	Headwest,"Disability Care and Support Productivity Commission Draft Report Submission" (2010)
PC	Productivity Commission, *Inquiry Report – Disability Care and Support*, No. 54 (Australian Government, July 2011).
PWC 2011	"Disability expectations: Investing in a better life, a stronger Australia" (PwC, November 2011)
VCASP/VBIRA 2010	"Submission from VCASP and VBIRA to Productivity Commission Inquiry into Disability Care and Support" (August 2010)

Contents

4 | Disability Workforce

There are a range of generic issues involved in creating and supporting the kind of workforce that will be required by a NDIS/NIIS. But there are two basic concerns that are specific to ABI: first, support workers and health professionals within the NDIS/NIIS system need to be trained to meet the specific needs of people with ABI; second, (informal) carers of people with ABI need to be adequately supported by the NDIS/NIIS.

1. Carers of PWD should receive recognition, information, support and direction

BIA and its members argued that the NDIS should recognise "that carers' needs are very important, especially given the significant financial and social cost to the community of a higher than usual incidence of family breakdown following brain injury". It should also provide carers with "greater information, support and direction"(BINSA 2012, p. 3).

The report appears to endorse this recommendation. First, the report does acknowledge the critical role of carers to the disability system — and that, whilst this is likely to continue under an NDIS, it is unsustainable under current conditions:

> "Informal care, usually provided by family members, is the main source of support for people with disabilities. While this informal support will continue to be fundamental to the disability system in the future, one of the key goals of the NDIS is to relieve the excessive stress that is currently felt by some carers." (PC, p. 704)

Second, the report refers to the Australian Government's national carer strategy as the primary source of 'recognition' for carers.[1]

> "The Australian Government is pursuing a national carer strategy. Some parts of that strategy would lie mainly outside the NDIS — such as better recognition of carers . . ." (PC, p. 727)

Third, the report indicates that the NDIS would be "partly" responsible for providing carers with counselling and respite care: that is, the NDIS would assess the needs of carers along with those of the people they are caring for; if the carers required counselling, then there would be three options: the NDIS could refer them to (a) the National Carers Counselling Program[2]; to (b) the 'Carer Support Centres', if and when these are implemented; or, if carers prefer, to (c) other sources of NDIS-funded counselling. (PC, p. 725, p. 728)

Finally, BIA and its members suggested that information, support and guidance come by way of "assigning an advocate or support worker to the family" (BINSA 2010, p. 3). The report's response here would be this: first, information and guidance would be provided

[1] See: <http://www.fahcsia.gov.au/sa/carers/pubs/national_carer_strategy/Pages/default.aspx>
[2] See: <http://www.carersqld.asn.au/_literature_82990/Talking_it_over>

by an assigned Local Area Coordinator, perhaps supplemented by a DSO; second, any support worker(s) would be paid for and arranged as part of the NDIS 'package'; finally, individual advocacy would need to be arranged independently, given that funding for advocacy would fall outside the remit of the NDIS.

2. Carers' allowances should be tied to the NDIS assessment outcome

BIA and its members argued that NDIS should "make carers allowances tied to the assessment outcome of the individual who is approved for an NDIS — so there is not the need for constant reviewing of eligibility as there is at present". (BINSA 2010, p. 3)

There are several aspects to the report's response to this suggestion. First, the report argues that there are a number of reasons for keeping the Carer Allowance independent of the NDIS:

> "Carer Payment, Carer Supplement, Carer Allowance and the Child Disability Assistance Payment . . . apply to a broader population than that covered by the NDIS (particularly care for the aged). In theory, these payments could be transferred to the NDIS and directed more flexibly to people's support needs, while reducing the poverty traps that sometimes apply to carers from such payments. However, the issue is complex. The gains may be small relative to the disruption created by the change, especially if carers viewed the change as undermining or diminishing recognition of their critical role." (PC, p. 256)

Second, the report argues that the NDIS should ensure that any assessment of needs (which can include the needs of the carer as well the person with a disability[3]) 'takes into account' these payments.

> "[T]he NDIS should share information about carer payments [such as Carer Allowance] with Centrelink and take into account the receipt of such payments when assessing people's needs." (PC, p. 256)

Now, theoretically, this could entail that both (a) the dollar value of the payments, and even (b) the carer's eligibility for a Carer's Allowance would be linked to the NDIS assessment outcome. But in fact the report does not suggest that the linkage would be two-way: in other words, the idea seems to be that the dollar value of any NDIS package may increase (or decrease) depending upon the dollar value (if any) of the carer's allowance — but not vice versa.

This is confirmed by the following quote, which suggests that eligibility for the Carers Allowance, understood as 'income support', would remain dependent upon the 'means and assets' of carers, rather than on the outcome of the NDIS assessment.[4]

[3] "[T]he assessment process should gauge a person's appropriate natural supports — those which could be reasonably and willingly provided by unpaid family carers and the community. When it becomes apparent, as part of that process, that an informal carer will provide a substantial share of the care package, the Commission considers that carers should receive their own assessment if they wish." (PC, p. 331)

[4] The report does recommend that NDIS-funded 'supports' for carers—such as specialist assistance—should be linked to the assessed need. But again, as indicated by the quote above, the report clearly distinguishes between these 'supports' and 'income support': "Responses to family needs should be tiered, with referrals to local support groups for those with less significant needs, and access to NDIS-funded specialist assistance where the needs were high." (PC, p. 332)

> "Income support payments act as a safety net for people on low income, rather than as a means for buying specific types of supports. The income is means and asset tested (unlike NDIS packages); is not aimed at purchasing support services, therapies or complex equipment; subject to relatively low ceilings; and, by virtue of the size of the payments must mostly be spent on basic needs, like food, clothing and accommodation." (PC, p. 365, n. 11)

On the face of it, then, it would seem that the report does not endorse the idea of basing a carer's eligibility for the Carers Allowance (and/or its dollar value) on the outcome of a NDIS assessment. However, one of the reasons given for this suggestion was to avoid "the need for constant reviewing of eligibility as there is at present" (BINSA 2010, p. 3). In this respect, the report mentions one possible solution that could perhaps be explored. The idea is this: to avoid the duplication of assessments across specialist and mainstream services, agreement should be reached so as to ensure that assessments are, to whatever extent possible, portable.

> "[T]he care and support needs of people with a disability are broad-ranging, and the NDIS is not intended to address all of them. There are good reasons for the scheme to focus on disability specific needs, with mainstream services such as education and employment remaining outside its scope . . . . But the ongoing distinction between specialist and mainstream services should not make for an overly complex system in which assessment effort is duplicated. Rather, assessments should be portable across the system—subject to protection of privacy—so that people do not have to repeat information for different providers or government agencies. Where there is extensive overlap in the nature of information being provided, the NDIS should reach agreement with other departments or agencies to either act as the sole assessment point, act as a point of referral or to share information, subject to strict privacy safeguards. . . . The NDIA and mainstream providers should identify opportunities to employ these and other models for information sharing, in order to reduce the paperwork burden on people with disabilities." (PC, p. 314-15)

So if the NDIS assessments were able to establish that a carer was eligible for a Carers Allowance, then the NDIS could, for instance, provide the relevant authority with the necessary details so that it could proceed to provide the Allowance.

3. Carers of people with ABI should receive specialist training

BIA and members argued that the NDIS should provide "training for support workers and family members: to address the systemic lack of knowledge of how to work effectively with people with an ABI" (BINSA 2010, p. 4). This suggestion is strongly endorsed by the report.

First, the NDIS assessment process would determine whether (and what kind of training) the carer might need.

> "The role of a carer assessment would be to consider the sustainability of the caring role and whether the carer would benefit from their own supports, such as counselling or training (for example, a carer may request training in relation to safe lifting or dealing with challenging behaviours)." (PC, p. 331)

Second, the NDIS would then not only fund training for carers, but also provide its own (local or remote) training. It would also refer cases to the (as yet to be implemented) Carer Support Centres.

> "[T]here are strong grounds for the NDIS to provide and fund training to interested carers across Australia in a coherent way . . . The NDIS website could provide some training remotely. . . . The Commission recommends that the NDIA would also refer carers to [Carer Support Centres to address the training and skills development needs of carers] where that was appropriate" (PC, p. 726)

Third, the report appears to endorse the training role that a number of other disability organisations and groups already play, so presumably this would continue.

> "Peak bodies often provide some assistance [in training carers], as do informal support groups. . . . Disability Support Organisations may also play a role in this area." p. 726

Fourth, the report does not explicitly recommend 'specialist' training for carers of people with brain injury. But this seems to be implied insofar as it does suggest that training should be designed to ensure that the carer has the specific skills and knowledge to meet the particular needs of the person for whom they are caring. This means, in part, that the training design should include input from actual carers.

> "By providing an additional source of funding, the NDIS and carers could determine where training would best meet people's training needs. Furthermore, as part of its research and data collection function, the NDIS should assess the best training options for carers of people with a disability. . . . There is sound evidence for carer interventions (box 15.5), which would inform the nature of training and other assistance to carers." (PC, p. 726)

4. Support workers and health professionals should receive specialist ABI training

The report is somewhat more explicit about the need to fund and provide specialist training for support workers and health professionals (See PC, Chapter 15.6). First, it recognises that there are (at least) five kinds of skills and knowledge that would be required—from the most generic to the most individual:

a) "**practical generic skills** (such as cooking, cleaning, driving, and general communication skills)"

b) "**critical intangible skills**" ("such as the capacity to treat people with dignity, respect, compassion and patience")

c) "**[skills] specific to the disability sector**" (such as "lifting safely, bathing, protocols for providing care in different settings, supporting people who have challenging behaviours, such as self-harm, providing disability support appropriate for specific groups, such as Indigenous people or those from cultural and ethnic backgrounds with different social attitudes to disability")

d) "**specialized expertise about specific conditions** to understand their client's care needs better and the most effective way to support them"

e) "**knowledge and skills that are specific to a single client**" (such as "the diverse life circumstances of their clients, how their personality and preferences influence their care and support needs, the unique ways in which disability manifests itself, the fact that many conditions underlying disability are rare, so that particular knowledge learned with one client may never be used again, the service-based nature of the industry that, like all services, should be as responsive to the individual needs of clients as possible") (PC, p. 736-7) [my emphases]

Second, the report is clear that the NDIS must provide the funds to ensure that disability support workers and health professionals can access the training that they require — and presumably this would include the specialist training needed to work effectively with people who have ABI.

> "With such a wide variety of skills within the sector, the challenge is to ensure training, and associated funding is available to those who need it, while not forcing people to undertake training when it is not required." (PC, p. 737)

5. Informal care should be sustainable

BIA and its members argued that informal care should be made sustainable through providing appropriate carer and family support.

> "A 2009 Access Economics report estimated $25.1 million in 'total lifetime carer costs' for a 'moderate' TBI and $28.5 million for a 'severe' TBI. The incidence of family breakdown following ABI is high and could lead to significant 'replacement costs' from the formal care sector. Further, without adequate community support and services people have a 'carer life' of around five years before the demands of the role cause 'burnout'. Therefore, there are potentially significant savings to the cost of a 'nationally disability scheme' if informal care is made sustainable through providing appropriate carer and family support . . . [which includes] social supports, financial assistance, and respite." (BIA 2012, p. 16)

Some of the support that the report recommends for carers and family members will have been mentioned above. However, there are several outstanding important issues dealt with by the report.

5.1 Informal care must be reasonable and willing

First, the report recommends that unpaid family members should not be expected to provide care that is either (a) unreasonable or (b) against their will.

> "[I]nformal care arrangements need to move to a more equitable and sustainable footing. The pressure on carers should be lessened by more and better services. . . . Under the NDIS, the focus would be on supports that could be reasonably and willingly provided by unpaid family carers and the community." (PC, p. 313)

Hence, any existing informal care (or 'natural supports') will not simply be taken for granted, but rather will be a matter for assessment by the NDIS — and this will include asking whether the care provided by family members is both reasonable and willing.

> "In gauging a person's appropriate natural supports, the assessment process should have regard to:
>
> - how much unpaid support is currently being provided or is likely to be provided
> - the impact on family members, including young carers and other current or potential carers providing support
> - the level of care and support (if any) current or potential carers want to provide." (PC, p. 313)

So, to take (what the report calls) a "simple example" of how this assessment might work in terms of determining an individual's budget:

> "[W]ere a person assessed as needing 10 hours of attendant care per week, but their partner was happy to provide two hours, and the cost of attendant care was $30 per hour, their budget would be $240 per week (8 hours x $30 per hour)." (PC, p. 314-14)

5.2 It should be possible to pay family members for care

The report recommends that, in the initial phase of the NDIS, there should be a trial that involves the person with a disability using their 'package' to pay family members for their work as carers.[5] The report is cautious about this approach, and so recommends a number of safeguards (e.g. a preliminary assessment of carers and administrative oversight, see PC, p. 382). But it also recommends three additional qualifications designed to minimize the inherent risks — each of which would be subject to evaluation. First, it suggests that the optimal approach would be to restrict payments to the intermittent care of non-resident family members:

> "The arguments about the risks from paying family carers relate to ongoing employment of resident family members. They apply less clearly to non-resident family carers and even less so to intermittent or one-off employment contracts. Accordingly, there are strong grounds for at least intermittent (rather than just recurrent) payments to non-resident family members, with less stringent accountability, for activities like respite and holiday care. . . . [T]he NDIS should conduct a trial of payments to resident and non-resident family members to test its risks, advantages, disadvantages and optimal design." (PC, p. 381)

Second, payment of family members should be discounted, relative to the normal wages of non-family support workers:

> "[T]he part of any self-directed funding package relating to payments to family members should be discounted (for instance, by 20 per cent). This recognises that once self-directed

[5] The report does not appear to suggest that this would replace the Carers Allowance. So, presumably, both types of payment could co-exist: "Carer Payment (and to a lesser extent, Carer Allowance) is already a payment to a family member (or others close to the person with a disability). These (or similar) payments should continue . . . ." (PC, p. 381)

> funding allows family members to be paid, it creates stronger incentives to maximise these wages by understating the availability of natural supports or by overstating needs. A discount would reduce such cost-padding incentives . . . the evaluation of the trial could reassess the risks in this area in determining any appropriate future discount" (PC, p. 381-2)

Third, there should be a probationary period to ensure that the arrangement is sustainable, both psychologically and relationally:

> "[P]aid family care would initially be limited in duration (say 6 months), with continuation based on assessment of 'burn out' or psychological distress for carers, and the consequences of the arrangements for the independence of the person with a disability" (PC, p. 382)

5.3 Flexible leave for employed family members should be permitted

The report recognises that family members caring for a person with a disability would be better able to find employment if they had access to flexible leave. Hence, the report has argued that legislation be changed to enable this to happen:

> "The Australian Government should amend s. 65(1) of the Fair Work Act 2009 to permit parents to request flexible leave from their employer if their child is over 18 years old, but subject to an NDIS assessment indicating that parents are providing a high level of care." (PC, p. 729)

5.4 Carer assessments should consider the need to support family relationships

The report recommends that a separate carer assessment should consider how best "to support the relationship as well as the carer". This might include the following:

First, the assessment should take account of the "need for respite services" (which the NDIS would provide — see PC, p. 23); second, it should consider how best to provide "assistance with long-term/ life-long planning, particularly for adults with intellectual disabilities living at home with elderly parents"; finally, it should look at the need for "family/sibling counselling where there are high levels of carer stress." (PC, p. 331-32)

RECOMMENDATIONS:

1. That if the Carer Allowance is kept independent of the NDIS, then — to avoid unnecessary duplication — if an NDIS assessment establishes that a carer is eligible for a Carers Allowance, then the NDIS should provide the relevant authority with the necessary details so that it can proceed to provide the Allowance without undergoing any further assessment.

2. That the NDIS should assess which training options will ensure that carers, support workers or health professionals involved with a person with an ABI are equipped with the specific skills and knowledge required to meet their particular needs; and then fund and/or deliver that specialist training, where needed and desired.

3. That informal care should be made sustainable through providing appropriate carer and family support, including (a) assessments as to whether the level of care is reasonable and willingly provided, (b) financial assistance from the NDIS, (c) legislation that permits flexible employment leave, (d) relationship support, such as respite and counselling.

4 | Disability Sector Capacity

BIA and its members raised four related concerns about whether the disability sector has the capacity to operate effectively within the new NDIS/NIIS system: that is, if the NDIS/NIIS is to depend entirely upon self-directed funding, how will it be possible to maintain or promote diversity, reform, sustainability and advocacy within the sector?

1. Sector diversity should not depend upon self-directed funding alone

BIA and its members argued that self-managed funding should be accompanied by genuine "choice in service provision"; otherwise it would be "meaningless" (BIA, 2011, p. 10). The report agrees that the "benefits of self-directed funding can be improved substantially if there are a . . . reasonable number of competing service providers in the local area (or the prospect of their entry)" (PC, p. 400). However, it is important to recognise that the primary 'benefit' that the report has in mind is *quality assurance*: that is, if service providers are faced with the "genuine threat" that people will move "to another supplier" (PC, p. 400), then this will motivate them to improve their quality of service.[6]

> "Consumers have a strong personal interest in the quality of goods and services they receive, can observe actual quality first hand (rather than through an audit, for example) and are able to change providers if they are dissatisfied. This directly links service provider's viability with their capacity to satisfy consumers' needs, rather than their ability to fulfil the administrative requirements issued by their funding body." (PC, p. 498)

The problem here is that the ultimate goal for any 'player' in a market place is not merely to triumph over the competition, but to destroy it; and thereby to exploit a monopoly of the market — a result that invariably *reduces* the number and range of services available to consumers. The report responds to this issue in six ways:

First, it seems clear that the report acknowledges the problem (and the likelihood) of emerging monopolies:

> "[T]he scope for full competition may not always be present when suppliers have market power . . . " (PC, p. 357)

> "The most important source of economies of scale in specialist disability services are likely to arise because larger suppliers can spread the fixed costs of regulatory burdens over a greater client base (and more diverse services), and as they have more scope to provide services during awkward times." (PC Appendix E, p. E.23)

[6] It is worth noting that the report envisages that any contract between persons with a disability and a service provider will be governed by relevant 'mainstream' legislation: "[People with a disability could] shift from one specialist supplier to another if they were unhappy with their services. Clearly such mobility would need to balance the reasonable commercial certainty for suppliers writing any longer-term contracts with people with disability and the need to avoid onerous exit terms if services were inadequate (noting that the Australian Government has introduced unfair contract legislation that would address this risk — *Trade Practices Amendment (Australian Consumer Law) Act (No. 2) 2010)*)." (PC, p. 468.)

Second, the report recommends that measures should be put in place to ensure 'robust competition' — in other words, to prevent services from monopolising the market.

> "In conjunction with measures to promote robust competition and targeted consumer protection mechanisms, [self-directed funding] represents a powerful incentive to deliver high value and high quality goods and services." (PC, p. 498)

> "The NDIS would be structured so that, as much as feasible, competition was strong between service providers" (PC, p. 951)

> "[P]rices should only be constrained by the pressures of competition and the usual safeguards against the abuse of market power and anticompetitive practices." (PC, p. 520)

Unfortunately, the report provides no detail on precisely what these 'measures' or 'safeguards' will be; and it would surely be an error for the NDIS to rely upon existing mainstream 'safeguards', given their apparent failure to prevent thriving monopolies across a number of Australian markets (e.g. Woolies/Coles, News Limited/Fairfax, etc.)

Third, the report argues that self-directed funding — together with the increased funding made available through the NDIS — will increase the level of competition simply because it will encourage new service providers to enter the system:

> "The point is that competition is not just about achieving the lowest price, but also encouraging the entry of new suppliers, quality service and the creation of new products that match people's preferences." (PC, p. 357)

> "[T]he additional funding to disability services after the introduction of the NDIS . . . will take place in market conditions where demand already significantly exceeds supply. This means that, in general, services will tend to be expanding rather than contracting and consumers will likely have more service options rather than less." (PC, p. 519)

Similarly, self-directed funding will give people with a disability the flexibility to employ a mainstream service or informal non-agency care. This will increase competition to the extent that disability-specific services will be unable to monopolise the market entirely:

> "[C]hoice gives people with disabilities or their families a greater capacity to buy mainstream services (for example, to go to a film, rather than a specially organised event for people with a disability). That . . . provides more pressure for responsive service by specialised agencies because it broadens the scope for competition. . . . [although] the role of mainstream services [in providing services to people with a disability] should not be overstated." (PC, p. 357-58)

> "[M]icro-suppliers [of attendant care]— friends, neighbours and family members — are ideally placed to provide [a more] flexible service [than larger scale services], despite being single employee 'enterprises'." (PC Appendix E, p. E.23)

> "[A]s a funding and purchasing agency, NDIA should give no preferences to suppliers based on their ownership (whether that be government, for profit or NFP), giving consumers the ultimate power about where to buy the services and supports they want." (PC, p. 528)[7]

[7] This response appears to endorse BINSA's recommendation that there be "a mix of public and private as well as NFP so that there

Fourth, the report suggests that, even if the results of a market-based model are 'imperfect', it is still likely to be better than the current system:

> "[C]hoice among specialist disability services may often still produce better outcomes even where markets are imperfect" (PC, p. 357)

This, the report argues, appears to be confirmed by the evidence from other jurisdictions where self-directed funding has been implemented:

> "Self-directed funding is now a common feature of international disability systems, and has grown in importance where governments have implemented it. There are few indications of major problems in areas where people perceive significant risks." (PC, p. 361)

> "There is good evidence from many studies that self-directed funding has significant overall positive benefits for people with disability and their families. It is typically associated with greater satisfaction levels, perceptions of greater power and control over life decisions, without adverse effects on health." (PC Appendix E, p. E.1)

Fifth, the report argues that "people would not have to take up self-directed funding, so [even if there were limited options for purchasing services] they would not be worse off." (PC, p. 376) However, the purpose of the NDIS is not to achieve equity between the past and the present, but rather equity between all persons with disability, no matter where they happen to be located.

One might argue that the point of the argument is not that they would be worse off *than they were prior to the NDIS*, but rather that they would not be worse off than *any other person who has not taken up self-directed funding*. But someone who lives in an area where the number of services is so small that they have no real choice between services is clearly 'worse off' than someone who is surrounded by an abundance of services but nevertheless decides not to take up self-directed funding.

On the other hand, it is important to distinguish between (a) having a choice between *service providers* and (b) having a choice between *particular supports* that are delivered by the same service provider (e.g. choice of support workers, equipment, times of service, type of support, and so on). Even if there were a limited number of service providers, self-directed funding would still enable persons with a disability to make significant choices about the particular supports they receive.

Put another way, competition can occur *both* between service providers *and* between 'products'. So, for instance, a person with a disability might use their purchasing power to select one support worker over another: it would be the individual support workers, then, who would be compelled to improve their quality of service—given the 'threat' that they might otherwise be fired or not selected.[8]

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was choice and also more available and accessible services . . . ." (BINSA 2012, p. 4).

[8] Concerns have been expressed about the negative impact of this kind of 'consumer power' on disability support workers. But the report argues that "In general, the best empirical evidence suggests that fears about the overall wellbeing of employees are misplaced. . . . [For example:] The most comprehensive study . . . found generally positive outcomes for consumer-directed

Sixth, the report attempts to show that, even where there is a lack of 'meaningful' choice, self-directed funding remains the better long-term option: first, it will motivate competitors to enter the market; second, it will enable people with disability to use mainstream services wherever possible.

> "Even if there were only one provider, the potential for self-directed funding would at least encourage entry by a new provider or the use of mainstream services as replacements for specialist services." (PC, p. 376)

To support this argument, the report presents evidence that, when self-directed funding is available, people with disabilities living in the country do not appear to be much worse off than people in metropolitan areas. This is due to the flexibility of self-directed funding: people in the country can make more use of mainstream services, non-agency workers or hiring family members.

> "The evidence suggests that many of the patterns of spending by people with access to self-directed funding between country and metropolitan areas were similar in that state, suggesting comparable spending options were available. For example, Perth Home Care Services noted that the spending shares for aids and appliances, leisure support and personal care were very close between these two areas (sub. 520)." (PC, p. 376)

> "People in rural communities were much more likely than urban dwellers to spend their voucher on non-agency workers compared with agency workers (Meng et al. 2010). Some of the reasons for this were shortages of agency workers in rural locations and the preferences of rural people for hiring workers they knew, rather than receiving services through formal agencies." (PC, p. 377)

> "A potentially important aspect of self-directed funding relevant to regional Australia is the capacity to hire family members. . . . it appears that this flexibility can be a further way of reducing shortages of formal support workers in regional areas." (PC, p. 377)

However, whilst this kind of equity between country and metropolitan areas might be true for certain basic services (e.g. aids and appliances, leisure support and personal care), it will not be true for more complex, specialist or technical services. In addition, there will inevitably be people in rural areas who are unable to hire family members, or who need the kind of care that, for whatever reason, cannot be provided by non-agency workers. Indeed, the report itself acknowledges the limited role of mainstream services.

> "[T]he role of mainstream services should not be overstated. . . . they may play a limited role for many people with disabilities. Many people will mainly acquire services from specialist disability providers." (PC, p. 356)

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employees. Considering only workers who were unrelated to the person with disability, the results suggest that compared with agency workers, hourly wages were higher (by around 15 per cent across the three states); people were much more satisfied with the wages they got (42.5 per cent compared with 21.3 per cent); and they had equivalent satisfaction with working conditions. People employed under self-directed funding tended to work more unpaid hours (seven hours a week compared with two for agency workers), but clearly without this affecting their positive attitude to their employment conditions." Again: "[T]he evaluation of the NSW Attendant Care (Direct Funding) pilot found that: 'All direct funding participants report an increase in attendant carer satisfaction. They state that attendant carers are happier for reasons discussed above, including pay and conditions and the quality of the relationship.' (Fisher and Campbell-McLean 2008, p. 29)." (PC Appendix E, p. E.27-28)

In this respect, the report argues that access to specialists in rural areas could be improved by using the following strategies.

(a) The actual cost of accessing specialists in remote areas (including their travel time) should be included when individualised budgets are determined.

(b) There could be a "coordinated and periodic visitation of remote towns with teams of specialists", which would make it easier for people who need to see "multiple specialists"; and it "could potentially allow travel costs to be split between specialists travelling together, and the patients commuting to see them".

(c) There could be something like a 'flying doctor service' consisting of specialists that "follow a published circuit through remote areas" (PC, p. 529).

(d) The NDIS should "actively promote" the use of remote health-related IT by (i) "conducting research into their efficacy" and (ii), "where demonstrable benefits arise, funding them" (e.g. "telehealth technology to monitor health conditions", "telerehabilitation to deliver specialist advice", "skype with a GP or allied health professional . . . for advice or referral", "remote interpreting services", etc.)

(e) "For people with very complex needs" the scheme would assist with relocation if that is "necessary to take advantage of highly specialised services". (PC, p. 529)

2. Sector reform should not depend self-directed funding alone

BIA and its members have argued that the mechanism of self-directed or individualised funding, on its own, will not be sufficient to produce much needed system-wide reform and development.

> "Systemic and organisational level reforms will not flourish in a system driven solely by individualised funding. All effort and creativity will be directed to making as many people as possible satisfy the eligibility requirements for direct funding. . . . [There should be] deliberate system development and cross-sectoral coordination roles for the NDIS, which . . . are beyond direct funding mechanisms for individual recipients" (VCASP / VBIRA 2010, p. 10, 12)

The report responds to this issue in the following ways:

First, it argues that the systemic impact of self-directed funding should not be underestimated. The model of self-directed funding enables persons with a disability either to manage their own funds or to enlist the assistance of disability organisations or carers to manage their funds on their behalf. Either way, most jurisdictions will require significant systemic and organisational reform to accommodate this new approach.

> "Under a NDIS, the sector will face significant structural changes over the medium run — in particular, increased funding, changes in the design of disability system, the adoption of consumer choice (including self-directed funding) and new governance arrangements." (PC, p. 472)

Second, self-directed funding will create an immediate need for a new kind of organisation in the disability sector: that is, 'disability support organisations' (DSOs). The purpose of a DSO will be to act as a "compliment"[9] to local area coordinators, insofar as they can provide people with a disability, if they wish, with separate assistance in managing certain aspects of self-directed funding more effectively.

> "[DSOs] would offer people brokering services; management services (such as dealing with the administrative aspects of self-directed funding, were a person to go down that route); assistance in developing the skills and confidence to practically exercise choice; personal planning services; and orientation supports for people who are suddenly faced with the unfamiliar world of severe disability." (PC, p. 414)

It might be argued that disability service providers (DSPs) could just as easily play these roles, and so no new organisations would be required. But the report argues that this would — with some exceptions — invariably lead to a conflict of interest:

> "[DSOs] should not be permitted to act as disability service providers (although exemptions might be made where it can be shown that no conflict exists — such as for service providers that also offer services that reduce the administrative burden of self-directed funding). For example, it would not be appropriate for a DSO to provide the supports to which they might refer people as part of a brokering role. Similarly, DSOs should not be able to accept commissions (either in the form of direct payment or through brokers 'keeping the change' on any discount they negotiate) from the service providers." (PC, p. 419)

The point here is that self-directed funding, by virtue of creating the need for DSOs, will facilitate greater innovation in the provision and coordination of services to people with disabilities. Hence, self-directed funding will, in this way, instigate sector reform that is likely to be of considerable benefit to persons with a disability.

Third, the report does not suggest that self-directed funding should be implemented without regard to its consequences. "Self-directed funding", it states, "is not an objective in its own right". If it turns out that this funding model is not meeting people's needs *as they perceive them*, then other mechanisms should be used:

> "If people make informed choices in favour of other arrangements then it should not be a policy goal to persuade them otherwise." (PC, p. 383)

By implication, the report even suggests the possibility of retaining one of the most important features of the NDIS — namely, person-centred planning — without employing the mechanism of self-directed funding (although, in the report's view, these two elements work best together).

[9] "[T]he principal role of a DSO would be to act as an agent for a person with a disability on a range of matters, including in relation to the implementation of that person's package of services from the NDIA. It is a role separate to that of a LAC . . . but complementary to it." (PC, p. 414)

> "Person-centred planning (PCP) is a collaborative process that helps people with disability to outline their needs and life goals as the basis for support, rather than the professional judgments of specialist providers. PCP is typically an essential component of self-directed funding, though it is possible to have one without the other. For example, a person may collaboratively formulate a life plan, but a service provider may ultimately determine which elements to implement (unlike direct payments)." (PC Appendix E, p. E.29-30)

> "Overall, the evidence (as limited as it is) implies that PCP is likely to be one contributor to the success of self-directed funding, suggesting that PCP should be a key aspect of implementing self-directed funding." (PC Appendix E, p. E.31)

3. Sector sustainability should not depend self-directed funding alone

One concern with the mechanism of self-directed funding is that, on its own, it will not be capable of ensuring that the sector is financially sustainable. The report agrees, and so responds in the following way.

First, the report makes it clear that, even with the NDIS, the formal roles, agencies and organisations involved in the 'disability system' will be funded by a range of sources, under different funding arrangements:

A. Direct funding from the National Disability Insurance Agency (NDIA):
- NDIA administration
- Assessors
- Local Area Coordinators (LAC)

B. Self-directed funding and/or direct funding from the NDIA:
- Persons with disability
- Carers of persons with disability
- Disability Service Organisations (DSO)
- Disability Service Providers (DSP) — private, NFP and government-run

C. Not funded by the NDIA:
- Systemic and Individual Disability Advocacy
- Education
- Disability Support Pension
- Public Housing
- Hospitals

In other words, there are system-wide organisations — such as Centerlink — that will remain separate from the NDIS, and so will not be subject to self-directed funding.

> "[T]he NDIS cannot be a complete 'one-stop-shop' that facilitates the full range of government services that people with a disability are eligible for (for example, income support through Centrelink, the provision of public housing, education etc)." (PC, p. 482)

Hence, the NDIS's use of self-directed funding cannot be held *directly* responsible for whether or not *these* agencies or organisations are financially sustainable.[10] Having said that, it is very likely that the use of self-directed funding (coupled with person-centred planning) will have beneficial *cultural or attitudinal effects* that reach far beyond the NDIS. Moreover, the additional funding provided by the NDIS (together with the efficiencies made possible by self-directed funding) will result in significant savings elsewhere (e.g. "fiscal gains from reductions in DSP beneficiaries and an increase in part-rate DSP payments" PC, p. 941).

Second, the report argues that, at certain times and for particular supports, the NDIA should be able to "issue tenders and form contracts" with service providers (PC, p. 413) — and this, of course, is not in itself a self-directed funding mechanism. However, self-directed funding still plays a role insofar as the report argues that the following conditions would need to apply to such tenders or contracts:

- there would need to be "a given per-unit price for a given tender period";
- for bids to be clear-cut, the quality would need to be specified in advance by the NDIA—so there would need to be "regulated quality guidelines for all supports";
- the service provider would not be given "a guaranteed market" — which presumably means that, even if the NDIA agrees to pay a "given per-unit" production cost, "consumers might not choose to go to [the service] in question", and so the service would not receive the unit's *retail* value (PC, p. 413-14).

Third, one concern that has been raised about self-directed funding is this: if service providers were entirely dependent upon the choice of individual 'consumers', this would make it impossible for them to operate over the long-term with sufficient funding certainty — especially those services that have large capital costs.

The report responds to this concern in the following way. First, it argues that the sustainability of a consumer-based model is hardly 'untested', given that the ordinary market operates successfully enough on precisely the same basis.

> "In general, the Commission does not support the proposition that reducing service provider uncertainty is a legitimate justification for block funding. Uncertainty about future levels of demand and revenue is common in other sectors of the economy and has been accepted as a necessary cost of doing business. Indeed, this 'uncertainty' functions as powerful motivation to understand and fulfil customer needs and drives competition between providers — to the benefit of consumers." (PC, p. 519)

Second, the NDIA would not be entirely 'hands off'. One of its main roles will be to "reimburse service providers" for items that are purchased by persons with disability as

[10] This not to suggest that there will not be linkages between the NDIS and these other organisations and agencies, especially with respect to information sharing: "Over time, there is also the potential scope to develop linkages with other government agencies (such as Centrelink) whereby required information relating to someone's disability could also be accessed (with the individual's permission)." (PC, p. 487-8)

part of their "package". But if service providers are to be "efficient and sustainable" over the long term, then, at least initially, this reimbursement will have to be carefully calibrated by the NDIA. As with any other consumer-based market, unit prices will have to take into account such 'fixed' expenditures as capital costs, funding for training staff, wages that will retain and attract new workers into the sector, and so on.

> "Another potential risk of withdrawing block funding in favour of a consumer choice model is that it might undermine providers' ability to service their fixed costs (such as rent, capital maintenance administration and other overheads) or make capital investments (including human capital such as training) to expand or improve the quality of their services. . . . These problems are not unique to disability service providers and have been widely demonstrated to be surmountable in other industries. The core issue is not the method of payment, but the price paid. Failure to properly reflect fixed costs under the proposed price setting model would be problematic for both producers and consumers — but no more so than is the case under current arrangements." (PC, p. 519-20)

It is important to note, however, that — if the consumer-based approach is to work over the long term — this price-regulating role of the NDIA would need eventually to yield to market forces.

> "The necessity of such price regulation may diminish over time with the development of a mature competitive market. In this case fixed costs would be driven by consumer preferences and reflect a variety of service models." (PC, p. 520)

> "[I]n some situations, there may be a role for governments in setting prices . . . . However, ideally, prices should only be constrained by the pressures of competition and the usual safeguards against the abuse of market power and anticompetitive practices." (PC, p. 521)

Fourth, the report argues that, "given the shortcomings of the block funding model" the NDIS should, over time, be aiming to make consumer-based funding the "industry norm". However, it acknowledges that there are "very specific circumstances" in which the 'market' alone will not be able to support key services — and so block funding may be required in the following areas (PC, p. 523):

- to ensure that specialist disability providers have the capacity and equipment to offer people with disability the required type of "crisis care (or for crisis care as service type in its own right)" — even taking into account the fact that (a) "interim provisions could be put in place that allowed people to draw upon an anticipated future entitlement" and that (b) "additional support usually could be obtained with the assistance of local area coordinators and through reassessment (if necessary)" (PC, p. 517-8)
- where "the potential market . . . may be too small to support . . . a consumer choice model", e.g. "rural areas" and "people with very complex needs or very challenging behaviours" — especially where "specialist health support services, therapy and centre based respite" are needed (PC, p. 521-22);

- to promote activities such as "community awareness and capacity building" since this "type of activity [is] necessary for a more inclusive society" and "the market is unlikely to deliver [this kind of] 'public good' activity" (PC, p. 521)
- some individual capacity building;
- DSPs that are directly working to redress "the combination of remoteness and cultural aversion to traditional models of service provision dramatically increases the risks of exclusion and harm for Indigenous Australians" PC, p. 521); and
- the promotion of innovation, experimentation and research. (PC, p, 471, 521)

Even in such cases, the report recommends key changes in the way that block funding is implemented and monitored[11]:

- "the NDIA should develop standardised tendering, contracting, reporting and acquittal requirements in order to reduce compliance cost" (PC, p. 523)
- there should be "a collaborative approach between the NDIA and service providers that: includes both parties in the design of programs; embeds and funds agreed evaluation processes; regularly reviews and revises service delivery approaches in light of finding from evaluations and changing demands or environmental conditions" (PC, p. 523)
- "the length of service agreements and contracts should reflect the length or the period required to achieve agreed outcomes, rather than having arbitrary or standard contract periods." (PC, p. 523)

Fifth, the report accepts that the transition to self-directed funding will be very disruptive and challenging for DSPs who have operated for many years on the block-funding model. Hence, it recommends that the NDIA "may" provide:

- "assistance establishing payment systems that interface easily with NDIA
- advice on governance structures or expectations about standards and how to best meet them as well as industry best practice in service delivery
- support in implementing software associated with the electronic disability record . . .
- an innovation fund that service providers could access on a competitive basis . . . . [the intention being that this fund will] contribute to innovation in service quality in the disability sector" (PC, p. 499)

4. Sector advocacy should not depend self-directed funding alone

One question that has been raised is whether the mechanism of self-directed funding could provide sufficient funds to support effective individual and systemic advocacy within the disability sector.

[11] These are based upon Productivity Commission 2010a, *Contribution of the Not-for-Profit Sector*, Research Report, Commonwealth of Australia, Canberra, available at www.pc.gov.au/projects/study/not-for-profit.

The report responds to this concern in the following way. **First**, it accepts that self-directed funding is unlikely to be sufficient to support either kind of advocacy, and so argues that advocacy should remain block funded:

> "Neither advocacy, nor individual advocacy are well-suited to a user pays system. This is because systemic advocacy has characteristics of a public good (in some ways similar to research and development), meaning it would be under-provided in the absence of dedicated public funding. In the case of individual advocacy, it is problematic attempting to predict individual need for it during assessment processes. Relying on individual's capacity to privately pay for advocacy is likely to render it unobtainable to those who need it most. For these reasons, it is important that advocacy should continue to be block funded." (PC, p. 524)

Second, the report argues that, in the context of a NDIS/NIIS, advocacy organisations will be most effective if they are financially independent of the very bodies that they are most likely to be calling into question: namely, the NDIA, service providers and DSOs:

> "[T]he NDIA should not *directly* fund advocacy. The role of allocating funding for advocacy should continue under the National Disability Advocacy Program administered by FaHCSIA as well as from State and Territory governments. . . . organisations funded to provide advocacy services . . . should not be eligible for NDIS funding for either disability service provision or intermediary services as a DSO. . . . . funds specifically allocated to providing individual advocacy for people dealing with the service providers or DSOs should go to organisations with no financial interest in these industries." (PC, p. 525-6)

The report does give two important qualifications to this position. First, it suggests that "there may be merit in the NDIA contributing additional funds to [the National Disability Advocacy Program]", although it makes clear that, in such cases there should be "no associated directive [from the NDIA] as to how [these additional funds] should be used" (PC, p. 525). Second, in arguing that advocacy organisations should be independent of DSPs and DSOs, the report is not suggesting that DPSs and DSOs will (or should) never 'advocate' on behalf of their clients.

> "This is likely to occur frequently of their own volition and in some cases as an essential part of their business (for example, a DSO offering brokerage service may act on behalf a person with a disability when a service package they have negotiated is not being effectively implemented)." (PC, p. 525)

But DSPs and DSOs will be 'businesses'; and so, given their financial self-interest, they are less likely to 'call into question' their own practices — at least not with the 'vigour' of an organisation that is dedicated to advocacy; hence, the need for independence.

RECOMMENDATIONS:

1. That the NDIA clarify what measures and safeguards will be used to ensure that large disability service monopolies will not emerge, thereby reducing the range of service options available.

2. That the NDIA put in place measures to ensure that people with disability in remote or rural areas are able to access a range of service options — especially specialist services that cannot be delivered by mainstream and informal/non-agency support workers.

3. That the NDIA ensure that, where the market alone will not be able to support key services, block funding is provided: for example, specialist crisis care, rural areas, Indigenous Australians, people who have very complex needs or very challenging behaviours, specialist health support services, therapy and centre based respite, community awareness, capacity building, and the promotion of innovation, experimentation and research.

4. That the NDIA provide financial and other kinds of assistance to DPSs to transition from block-funding to self-directed funding, including assistance with new payment systems, governance structures, standards, software for the electronic disability record, and innovation.

5. That individual and systemic advocacy should continue to be funded under the National Disability Advocacy Program administered by FaHCSIA as well as from State and Territory governments; and if any funds for advocacy are provided by the NDIA, then — to ensure independence — they should be accompanied by no specific directive from the NDIA.