BRIGHTwater

Submission in Response to the Disability Care and Support Productivity Commission Draft Report

Submitted by Brightwater Care Group (Inc)

28 April 2011

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1. INTRODUCTION

Brightwater would first like to acknowledge the remarkable effort made by the Productivity Commission in pulling together the vast amount of information it received while formulating its Disability Care and Support Productivity Commission Draft Report. The Commission attempted to provide a workable solution to a system that is terminally fractured, and that it has successfully provided such a framework cannot be overstated.

The Draft Report clearly shows that the Commission has understood the complexity of the disability sector, both for those who are consumers as well as those who provide a myriad of services. Brightwater unequivocally supports the framework that the Draft Report provides and is excited by both the scope and the vision of the Draft Recommendations.

In particular, Brightwater applauds the soundness of the overarching framework. The recommendation of a national system will allow people living with disability to move in and out of the system according to their changing needs and geographical location. It also means that the disabled population of a number of Australia states, including Western Australia, will no longer be hampered by the idiosyncrasies and inefficiencies of some of the existing state-based systems.

The Draft Report's willingness to encourage innovation among disability sector providers is also encouraging. When a system is not working, merely doing "more of the same" is not a helpful solution, and the Draft Report's financial acknowledgment of the absolute need to provide innovative solutions to service delivery is refreshing and exciting.

As always, however, the devil lies in the details and the Draft Report is no exception. Brightwater does have some areas of concern that it hopes will be addressed in the final report, and these are detailed below in the section titled "Responses to Specific Draft Recommendations".

Of the concerns raised below, there are two that Brightwater would like to reemphasise here. One is the difference between the impact of congenital

disability and acquired disability. It is essential that this is more clearly differentiated at all points throughout the final report. This matter goes far beyond mere semantics, for until it is truly understood and accepted by all people involved in the disability sector that the presentation and provision of support for people with an acquired disability is not synonymous with that of intellectual disability, the needs of that group of people will not be fully met.

The second concern is around the implementation of the trial phase of the scheme. Rather than rolling out the (trial) scheme in one region (page 17.12), Brightwater strongly recommends holding simultaneous trials in each state. State-based differences in the disability sector are substantial, and meaningful data that will usefully inform the final rollout will only be gathered if the scheme is trialled in the same states in which it will be actually implemented. In other words, what works in a trial in Tasmania may be different to what works in Perth, which will be different to what works in the Northern Territory, etc.

Brightwater fully understands that no single scheme can be the panacea of all the ills that currently befuddle the disability sector in Australia. In the Disability Care and Support Productivity Commission Draft Report, however, the Productivity Commission has provided an achievable and sustainable framework that will provide (to paraphrase the Draft Report's Preamble) an equitable, properly funded, cohesive and efficient system that will give people with disability real choice. While there is still work to be done on fine tuning the final recommendations there is no doubt that the National Insurance Disability Scheme and the National Injury Insurance Scheme will benefit both people with disability and the Australian community as a whole.

2. RESPONSES TO SPECIFIC DRAFT RECOMMENDATIONS

2.1 DRAFT RECOMMENDATION 3.2

In relation to who is eligible for the National Disability Insurance Scheme (NDIS), Brightwater believes that it is important for the final report to:

- Clearly **differentiate between cognitive disability and intellectual disability** and recognise the differences in presentation and differing support requirements between the two. Current systems (such as benefits related to MBS Items 718/719) perpetuate the misconception that cognitive disability is synonymous with intellectual disability. This makes it difficult for people with a cognitive disability and also service providers to determine whether an individual is eligible for certain services.
- Provide more detail about the Draft Report's expectations around **early intervention**. It is not clear what groups are being targeted and what is meant by "early intervention" – a term that has different meanings for different groups of clinicians and lay people.
- **More clearly identify people** with stroke, neurodegenerative disability, tumour related disability, other neurological disorders and sensory disabilities. These groups are largely "hidden" in the Draft Report.

While Brightwater recognizes that the scheme needs to clearly **determine eligibility** in order to determine economic viability going into the future, it is also important to recognize that often intervention to address what on the surface may appear to be a minor issue may in fact reduce the risk of this becoming a major issue in the future.

- Sometimes, what can appear to be a relatively mild disability (such as impaired awareness of time) can have a profound impact on an individual's home life, work life and engagement with their community if they are not supported to learn ways to manage this issue.
- By providing all people with permanent disabilities early access to either learned or supported capacity to meet essential baseline

needs (e.g. to be showered and dressed every day), many will be able to move on to do other things (community access, work, etc) without the need for ongoing paid support. Others may need supported access to enable community engagement.

This concept fits neatly with the concept of early intervention as mentioned in Draft Recommendation 3.2 and would support people to move out of the scheme once issues that impact on their functional abilities have been resolved.

2.2 DRAFT RECOMMENDATIONS 3.5 AND 4.3

Brightwater agrees with the Draft Report that the issues around co-payments and contributions are indeed "vexed ones" and suggests that:

- Concepts of **co-contribution** (payment for those who are over the aged pension age), **co-payments** (paying an annual "excess" for a service) and **assessed contribution by family** to the individuals support are certainly contentious and must be explored rigorously before being implemented.
- There is a risk that both co-contribution and co-payment could discriminate against those who acquire disability later in life, in particular those who have not consolidated their assets before of the acquisition of disability. **Family obligations** (i.e. age of dependent children or spousal support) need to be considered when determining what payments a person may be required to make.

2.3 DRAFT RECOMMENDATION 4.5

Brightwater believes that there is great benefit to the NDIS funding and overseeing the provision of **specialized housing,** as this will:

- Enable the exploration of a variety of different housing models. This will offer people with disabilities choice of housing within the scope of their funding arrangements.
- Support research into design of housing for people with disabilities as well as establish realistic cost frameworks for the building and maintenance of adapted housing.
- Allow additional costs that are often not contributed to in the mainstream State housing markets, such as air conditioning for those with poor temperature regulation, to be identified and included.

However:

- How this model will fit with the existing Public Housing systems will require further exploration.

2.4 DRAFT RECOMMENDATION 5.5

BW supports the need to **reassess people's funding and service requirements** periodically, in particular at key transition points. Specifically:

- It is important that the scheme recognizes the capacity for people's levels of independence to change due to changes to their level of impairment.
- It is vital to understand that for some people (for example, those with an acquired brain injury), this change may be an <u>improvement</u> in functionality. It is essential that both improvement and deterioration are accommodated and that the scheme is responsive to those changes.
- Provision of a continuum of care would also support people to move seamlessly across levels of service provision depending on their requirements.

A CONTINUUM OF CARE FOR PEOPLE WITH HUNTINGTON'S DISEASE

Brightwater Cannington is a small 6 bed community house in a residential suburb of Perth. It is a temporary home for its residents while a purpose built duplex (two three-bed houses) is being constructed in the suburb of Belmont. All clients living there are in the early stage of Huntington's Disease and are unable to manage to live independently in a sole occupancy arrangement. Each client is funded by the Disability Services Commission.

Brightwater Ellison House is situated in a nearby suburb and is a 12 bed triplex (spread over 3 houses) special care facility for clients with mid to advanced stage Huntington's Disease. People living at Ellison House can choose to remain there to end of life and are supported through the palliative process. Again, all funding comes from the Disabilities Service Commission.

Both Brightwater Cannington and Brightwater Ellison House are part of a continuum of care for people with Huntington's Disease. This continuum also supports people to live in their own homes using HACC and EACH funding while others are given the option to live in a Brightwater residential aged care facility if they so choose. The aim is to provide people with a choice of accommodation options, enable them to plan for the future degeneration associated with the progressive nature of the disease and to be provided with support commensurate to their needs - i.e. not over or under serviced.

It is important to note that in our experience providing care for this diagnostic group in a specialised facility is far preferable to providing the same care in an aged care facility or a group home where there are clients with different neurological disabilities. Staff at both Brightwater Cannington and Ellison House are specifically trained in providing support and outcomes relevant to people with Huntington's Disease including facilitating independent self management, dysphagia and dietary support and end of life planning.

Such a structure also facilitates the staff to cope with the ebb and flow of the disease progression. It is a cost effective model in that a dip in care requirements demonstrated by one individual helps to dilute the high peaks of care provision required for a person who is experiencing challenging behaviour or needing additional support associated with palliative care.

However, we cannot overemphasise the importance of working continually, consistently and openly with our colleagues in the health, mental health and palliative care sectors. Without their input we would struggle to achieve the excellent outcomes for our clients that we do.

5 DRAFT RECOMMENDATIONS 6.1 – 6.9

It is commendable that the Draft Report has attempted to demonstrate the checks and balances necessary for the method of **self directed funding**. However, more detail is required on the concept of self directed funding. Brightwater trusts that the final report will recognise that:

- This is potentially a high risk area, in particular for people who, by the very nature of their disability, display poor insight into their level of impairment and its impact on their skill base - including their financial management skills.
- It is important that all people with disabilities are able to have choice over who provides services for them. It is equally important that it is informed choice. Regardless of an individual's capacity to make decisions and influence their own personal plan, it is vital that they are first provided with the information that will enable them to make sound and informed choice.
- It is also essential that the information is presented to them in a format that is meaningful to them and recognizes the impact of their disability on their ability to receive and process information.
- It will therefore be essential that the Disability Service Organisations (DSOs) are able to make a full and accurate assessment of a person's decision making capacity and tailor development of the personal plan in accordance with that capacity. This will ensure that the individual's potential for input into their own plan is maximized.
- The importance of families to people with disabilities must be recognised. However, it is also important to understand that many people with an acquired disability had already reached a stage in life before acquiring their disability where they had achieved personal independence outside of the primary family unit. This status needs to be recognized and the level of involvement and influence of key family members explored during the establishment of the decision-making structure. To put it bluntly, while some people with an acquired disability value their family members for

their roles in their life, they object to them making decisions for them.

2.6 DRAFT RECOMMENDATION 7.1

Brightwater supports the establishment of the **National Disability Insurance Agency (NDIA)** as the **overarching federal body** that will be responsible for administering the scheme. This body will ensure that:

- Processes and assessments are consistent
- Funds are portable across states
- Funds are effectively utilized
- Economic sustainability, legislative accountability and the principles of good governance are maintained, especially as the Board members will be unrelated to delivery of the scheme
- The scheme is not reliant on management capacity at state level, as this may be varied and put some states at risk
- The scheme is not reliant on the revenue generation capacity of individual states

The NDIA will also have the capacity to:

- Influence policy direction at an all-of-Australia level
- Influence general infrastructure codes and guidelines to be more disability sympathetic

2.7 DRAFT RECOMMENDATION 7.3

In addition the need for a **National Disability Insurance Agency,** Brightwater believes that it is also vitally important for each state to maintain a **strong State-based branch of the NDIA.** The role of this branch would be to:

- Develop closer contact with Service Providers and DSOs, especially in the early years where each state will have different structure and historical ways of working

- Advocate for state differences (especially in rural and remote areas) while still working within national guidelines
- Develop evidence-based guidelines regarding the true cost of service delivery. This is especially important for regional and remote areas, as these differ markedly from state to state. A strong example of this is the high cost of service delivery in both the Kimberly and Pilbara areas of Western Australia. The differences are due to factors such as the need to spread specialized resources across a large geographical area as well as the additional cost of items such as fuel, travel, equipment, accommodation and wages.
- Support the deconstruction of existing State systems if they are not compatible with the new Federal system or are unable to meet the challenges that the scheme will bring.

2.8 DRAFT RECOMMENDATION 8.3

A robust quality framework must be an integral part of any group or organisation that provides services to others. Brightwater therefore welcomes the concept of Australia wide **regulation of services**, with the proviso that:

- The development of the regulatory system will include safeguards against it becoming the central focus of service provision.
- The regulatory system is sensitive to the nature of service delivery in the disability sector, including the vast variety of services provided and the often complex and diverse nature of its consumers.
- The regulatory system allows room for the exploration of innovations in service delivery (as referred to throughout the Draft Report), not only to manage a diminishing workforce but also to deliver outcomes specific to the individual consumer.

Brightwater applauds the Commission's recognition for the need of **innovation** in service delivery including developing a fund that supports services to trial "novel" approaches to service delivery. Specifically, the freedom to innovate will:

- Become particularly important as the sector continues to experience workforce challenges.
- Enable organizations to consider models of service that provide effective and safe supports to consumers without the sole reliance on human resources.
- Auger well for supporting consumers in developing a level of functional independence that is commensurate with their abilities, rather than providing hours of care to reinforce their disability.

2.9 DRAFT RECOMMENDATION 9.1

Provision of services for **people from indigenous background** is touched upon in the Draft Report but is obviously an area that requires more thorough investigation.

- It is Brightwater's experience that even when living in a large metropolitan area, people from an indigenous background have specific accommodation, service delivery and relationship requirements that are currently unmet.
- For those living in rural and remote areas there is often a large amount of expertise in cultural and regional requirements but a dearth of expertise in disability-specific issues.
- Opportunities to connect both areas of knowledge so that individualized outcomes can be provided need to be explored.

2.10 DRAFT RECOMMENDATION 13.2

Brightwater is concerned that the Draft Recommendations regarding police checks are not rigorous enough. Specifically:

- The Draft Report bases the need for **police checks** on the level of client vulnerability and level of risk to the client. The question of who assess these levels, how frequently and how changes in these levels are managed are challenging and not addressed in the Draft Report.

Brightwater submits that police checks are easily available in all states and are not an onerous or expensive security measure.

- We strongly advocate that all paid workers providing services to people with a disability must have a National Police Certificate and that it is **renewed every three (3) years**.

2.11 DRAFT RECOMMENDATION 16.1

Brightwater concurs with the Draft Report that the **dual system of a National Disability Insurance Scheme and a National Injury Insurance Scheme (NIIS)** will be necessary at the start of the reformation process.

- We are hopeful that the greater focus on neurological disability in the NIIS will enable a targeted development of appropriate specialized assessment tools, funding arrangements and life plans. These will therefore be in keeping with the differences between acquiring disability as an adult and lifetime disability.
- There are existing strong and successful no-fault systems in larger states (New South Wales and Victoria) that can be easily built on by other states – there is no need to reinvent the proverbial wheel.
- There is a desperate need for a system that recognizes connections with Health and Mental Health at the early stages of accident recovery, and actively supports collaboration between the services. This is briefly addressed by Draft Recommendation 3.4.
- There is also urgent need to have a system that is inclusive of all Australians regardless of their financial worth so that early intervention and rehabilitation is available to all and is not means tested.

- The NIIS will also have the opportunity to work within areas of prevention.

3. Responses to Specific Information Requests

3.1 INFORMATION REQUEST – CHAPTER 3

The Commission has requested information around "*where **the boundaries between the mental health sector and the NDIS** might lie [*and about*] which system would be best placed to meet the daily support needs (not clinical needs) of individuals with a disability arising form a long lasting mental health conditions*" (page 3.29). Brightwater's experience is as follows:

- It is our experience that a number of people with acquired brain injury or Huntington's Disease experience co-existing mental health conditions.
- These conditions arise for a number of reasons, including a reduced capacity to compensate for marginal mental health presentations, changes to the chemical structures of the brain and substance abuse.
- Outcomes for these individuals have always been most successful when there is strong collaborative interface between both mental health service providers and the disability service provider.
- Ultimately, due to the diverse layers of complexity that are often part of the presentation related to the causal neurological impairment, the key responsibility for managing a successful outcome lies with the disability provider.
- Expertise in the area of neurological impairment enables the disability provider to support the individual to redress the issues that are exacerbating the impact of the mental health condition.
- It is essential that the disability service provider encourages the mental health provider to contribute their expertise related to the mental health presentation and incorporates the management of the mental health issues into the life planning for the individual.

3.2 INFORMATION REQUEST – CHAPTER 4

The Commission has also requested information around "*the arrangements that should apply in relation to **higher electricity costs** that are unavoidable and arise for some people with disabilities*" (page 4.11). Brightwater suggest that:

- Some people with neurological disability find that their ability to ensure that they maintain a stable body temperature is impaired.
- This may be due to the physiological impairment of their body's temperature regulatory systems or it may be due to impaired cognition that impacts on their decision-making capability around self management in adverse temperature conditions.
- For this group the installation and running costs of temperature control systems is essential, not only for their comfort but also for their future wellbeing. It is no less a necessity than is the provision of a wheel chair and its ongoing upkeep for someone who can't walk.
- As with all items provided within the Scheme, provision of temperature control systems should be subject to assessment including not only the individual need but also the environmental circumstances.

4. Additional Considerations

4.1 The Concept of Age and Aged Care

Brightwater applauds the thought and rigour that is evident in the Commission's exploration of the scheme's intersection with other services, particularly that of aged care. We further commend the Commission's proposal that sectors should actively work together to ensure that "*individuals do not 'fall between the cracks' of respective schemes*" (page 3.17) – a situation that is currently too common.

We suggest, however, that further clarification is required around the concepts of "age" as discussed in the Draft Report on page 3.20. We wish to provide the following points:

- The Draft Report mentions "*disability arising from age-related conditions like stroke and early-onset dementia*" (page 3.20). The presumption that stroke and early onset dementia are "age related" disabilities is inaccurate. They are neurological disorders that may have no connection with age at all.
- We would be concerned if people who are leading active and healthy lifestyles and even still working after the pension age and who then acquire a disability were slotted into the aged care system without opportunity for early intervention or choice in their accommodation arrangements

It is important that the challenge of supporting people with a complex disability such as Huntington's Disease in a residential aged care setting is addressed. It may be (as it is within the Brightwater Care Group – please refer to the box on page 6 of this submission) that the disability sector has a more specialized infrastructure that will offer improved outcomes for this group.

4.2 Making Transitional Care Work

On page 4.5, the Draft Report states "*Some people (typically those with a newly acquired disability) remain in hospital due to a lack of suitable alternatives*". This too was Brightwater's experience and from this experience was born our Discovery Way unit.

**THE TRANSITIONAL CARE MODEL –
BRIGHTWATER DISCOVERY WAY**

Brightwater Discovery Way is a 12 bed transition unit located in Perth's northern suburbs. Our clients come to us directly from the acute sector and are typically those who the hospitals regard as "bed blockers" – no longer ill enough to require acute care, but with nowhere else to go. Reasons for lack of placement range from simply no vacant beds in the appropriate system to requiring more rehabilitation before placement is possible. Clients typically have either an acquired neurological disability or an intellectual disability with coexisting physical impairment (often acquired).

Discovery Way addresses the issues that are preventing clients accessing long term accommodation such as health management, behavioural presentation or management of complex care. We broker appropriate support options with other agencies and in addition we support the new agency in accessing appropriate equipment, implementing programs of care and establishing appropriate staffing models.

Clients remain at Discovery Way until Brightwater is able to find a placement for them, or is able to negotiate a higher level of care with a disability support organisation. Clients will usually move to either a permanent disability accommodation option, a rehabilitation unit or aged care facility as appropriate.

Discovery Way is block funded by the Health Department of Western Australia, but eligible clients apply for disability funding while they are with us. This means that, as soon as an accommodation option becomes available, they are able to move.

Brightwater suggests that the NDIS is an ideal opportunity to investigate the development of other dedicated transition units for people with acquired disability.

4.3 Funding of Consumables

There is no doubt that the issue of whether Health or Disability pays for the consumables necessitated by a disability (such as PEG meals, tracheotomy care and wound care) is a contentious one. Brightwater agrees with the Northcott Disability Services submission that is quoted on page 4.11 of the Draft Report: "*the scheme should fund these needs if they would not have existed in the absence of a disability*" and asks that the Commission carefully considers the cost of consumables when it is investigating the true cost of care of delivering services to a disabled client.

CONTINENCE AIDS –
WHO PAYS HOW MUCH?

Brightwater is delighted to note the Commission's statement that "*specialist disability supports provided by the NDIS [will include]….continence aids"* (page 4.3).

Funding bodies in WA have long argued that the existence of the Continence Aids Payment Scheme (CAPS) means that there is no need for disability to fund aids. As any provider will confirm however, the difference between the amount of aids that the CAPS funds and the amount of aids that a client may require can vary greatly and therefore either the client's family or the service provider is left to carry the extra cost.

To have the true costs of continence aids met by the scheme is an essential inclusion.

4.4 Funding of Consumables – Other Hidden Costs

It is also encouraging to read the statement: "*The Commission considers that the NDIS should cover the costs associated with PEG feeding*" (page 4.11) and Brightwater encourages the scheme to also explicitly consider other costs that are currently hidden – for example the cost of tracheotomy care.

BOB – STUCK IN THE MIDDLE

Brightwater has been involved in liaising with the Health Department of WA around the placement of "Bob," a young man with ABI and a tracheotomy tube.

Bob has been in hospital since his accident over two years ago, and for the past 18 months has been fit to be discharged into the care of a supported accommodation provider. While he is in hospital, the very high cost of the consumables required for his tracheotomy care is paid by the hospital. When he is discharged, he will be required to meet this cost through his disability funding. His disability funding is too low to allow this, which means that any provider will be required to in effect pay for the cost of his tracheotomy care. He is not able to gain admission to the transitional system until there is agreement over who will cover the cost of his consumables.

The result is inevitable – Bob is stuck in a hospital bed when he should be in the community, the hospital effectively has a bed being blocked, and no service provider is able to provide a service to this young man.

Some hospitals in Perth have resorted to supplying the consumables to clients in the community free of charge. This is not a course of action that is indefinitely sustainable.

Bob is representative of an increasing number of referrals seen by Brightwater – someone who has high nursing needs that are unmet by disability funding, but who is misplaced in the hospital system.

We urge the Commission to consider the funding needs of disabled persons whose cost of consumables is currently unmet.