



SUBMISSION TO PRODUCTIVITY COMMISSION

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1. INTRODUCTION

Many millions of Australians have a disability of some kind. Disability comes in many forms, with different impacts and lasts for different lengths of time. Some people need a lot of help, and some a little. Some disabilities last a few years, some wax and wane over time, and others last for the rest of people's lives.

For most people with a disability, support and assistance comes mainly from family and friends. However, governments provide a range of services both directly and indirectly to help those with disabilities and the private and community sectors also provide significant resources in this regard.

While Australia's social security and universal health care systems provide an entitlement to services based on need, there is currently no equivalent entitlement to disability care and support services.

In 2010 there is general acceptance in government circles and the wider community that there is a significant problem of unmet need with respect to the provision of support and assistance for people with disabilities in Australia. A major drawback of the current disability services system is that the client is not at its centre.

The Australian Government has asked the Productivity Commission to undertake a public inquiry to examine the feasibility, costs and benefits of replacing the current system of disability services with a new and improved national disability care and support scheme.

The purpose of this paper is to help inform debate about the essential features of a new long-term disability care and support scheme, based on the experiences of Brightwater as a service provider to clients with particularly complex disabilities, in particular Acquired Brain Injury (ABI) and Huntington's Disease (HD).

2. EXECUTIVE SUMMARY

The Brightwater Care Group is one of the largest providers of residential care in Western Australia with 20 facilities located from Joondalup to Mandurah. As well as providing care to people who are ageing both in their own homes and in Residential Care, Brightwater supports up to 150 younger people with acquired neurological disabilities offering rehabilitation, transition and accommodation services.

In this submission Brightwater is proposing a disability care and support model with the following overarching objectives:

- *An aim to "maximise each individual's purposeful function". This differs from existing models which focus on "caring for" individuals, often creating dependence and reliance on the service provider and support networks.*

- *Eligibility that considers that all people in society, regardless of level of disability, should be entitled to support to ensure their basic needs (food, shelter, hygiene, comfort and safety) are met; and to help them develop life skills and a level of independence in order to meet their higher needs.*
- *Entitlement accompanied by responsibility for the individual to work towards greater independence and minimise long term support. This balance between entitlement and responsibility encourages those supported by the system to experience opportunities for self actualisation and achievement*

Key components of this model include:-

- **Early intervention to develop independence** by offering a range of services tailored to individual needs supporting people to plan for their future, identify achievable goals and outcomes and develop strategies to achieve them. The model acknowledges the need for flexibility to respond to changing needs of individuals over their life time and to enable people to move in and out of the scheme as their needs change over time.
- A **coordinated range of services**, including accommodation support, aids and equipment, respite, transport and a range of community participation programs. Rather than attempt to provide all of these as “disability services”, mainstream service providers would receive training to enhance their interactions with people with disabilities including those people with Acquired Brain Injury and Huntington's Disease.
- **Case Coordination** attached to the statutory body administering the scheme. These Coordinators would identify the most appropriate services for each individual and efficiently pull together local services including State and Commonwealth government agencies, non-government organisations and private sector providers.
- The implementation of a national suite of **disability specific assessment tools** that have been proven to provide an accurate indication of level of function for the relevant disability.
- A **non means or asset tested system** reducing the risk and impact of inequitable service provision, as is the case with the current insurance-based system in WA.
- **Support for people with disabilities to access activities within their means** (once their basic needs have been met) rather than funding the cost of attendance at preferred activity and thus risking the development of a system that results in positive discrimination.

Brightwater supports the Disability Investment Group's (DIG) proposal to introduce a National Disability Insurance Scheme (NDIS) to replace the current arrangements for funding disability services. A NDIS would work in a similar way to the no-fault injury insurance schemes that currently operate in some states. Additional cost of the scheme would be funded by a Medicare-type levy, thus reflecting the shared risk of disability amongst the population.

To be sustainable the NDIS must be well-governed and managed. Brightwater supports the DIG proposal that a new statutory authority be established to govern the NDIS, rather than allowing one agency to act as both fund-holder and overall decision-maker.

In acknowledgement of the complexities inherent in estimating the cost/benefit of a new scheme, especially while existing data on costs per disability subgroup is crude, Brightwater has recently engaged ACIL Tasman to undertake an economic evaluation of its Oats Street program. This program aims to facilitate the return of clients to community living within an environment suitable to their individual needs. The ACIL Tasman report will be available by mid October 2010. Brightwater respectfully suggests that the Productivity Commission arrange a time to discuss this report further and would be happy to make a copy of the report available.

3. WHO SHOULD BE THE KEY FOCUS OF A NEW SCHEME?

The terms of reference to this review indicate that the new disability care and support scheme is not intended to cover all degrees of disability, but ones where needs are greatest. The Issues Paper identifies the main source of disability for those currently needing constant or regular support as:

- physical conditions,
- mental illness,
- congenital anomalies and
- intellectual disability.

Rather than categorising disabilities in this way and focussing only on people with severe and profound disabilities, Brightwater suggests that ***all people with a permanent disability should be equal in terms of their eligibility to access support services to achieve primary purposeful functionality.*** All people with an acquired injury should be included in the scheme, regardless of how the injury happened.

Which Groups are Most in Need of Additional Support?

One group in the community that Brightwater considers is most in need of additional support and help through the new scheme is people with an acquired brain injury.

The Australian Bureau of Statistics (ABS) estimates that the Australian population amounts to just under 19 million people. Of those 19 million Australians, the 1998 ABS study on Disability, Ageing and Carers estimated that there were 3.6 million people with a disability (19 per cent of the total population).

The 1999 Australian Institute of Health and Welfare (AIHW) study on the definition, incidence and prevalence of acquired brain injury in Australia, estimated that there were 338,700 Australians (1.9 per cent of the total Australian population) who had a disability related to acquired brain injury. Of these, 160,200 were severely or profoundly affected by acquired brain injury and needed daily support.

This figure can be compared with the AIHW estimate of 328,000 people with intellectual disability (1.86 per cent Australians). Of these people 178,000 people required daily assistance.

Brain injury has dramatically different effects on different people. Even a mild injury can result in a serious disability that will interfere with a person's daily functioning and personal activities, often for the rest of their life. While the outcome of the injury depends largely on the nature and severity of the injury itself, appropriate treatment plays a vital role in the level of recovery.

Research indicates that the outcome of community integration for individuals with an acquired brain injury is variable, and the outcome of acquired brain injury is often complicated with long-term physical disabilities and cognitive, emotional and behavioural changes. No two individuals with an ABI are the same. Each individual will have various combinations of physical, behavioural, cognitive and social problems, and differing needs, requiring rehabilitation strategies that are unique to him or her. Cognitive and behavioural changes can be more disabling than the physical impairments.

The recovery period for people with ABI can last for many years after the injury, so rehabilitation services need to:

- Be interdisciplinary;
- Be comprehensive to address physical, cognitive and behavioural difficulties;
- Be individualised to meet each person's needs and capacities;
- Include the individual and her/her family in the setting of program goals and planning of treatment;
- Be modified as an individual changes over time; and
- Include community-based nonmedical services which provide educational, employment, social and recreational opportunities.

In 2008, WA's State Head Injury Unit identified intensive in-home support and monitoring for ABI clients in the community as an area of unmet need. Concern was also expressed regarding the availability of suitable accommodation support due to the lack of agencies willing to provide this care and the difficulties in accessing appropriate psychiatric management for young people with acquired brain injury.

The costs to the community associated with ABI can be significant if people are not appropriately supported. An acquired brain injury can exacerbate and magnify the risk factors associated with homelessness including family breakdown, loss of social support networks, lack of affordable housing, family violence, unemployment, illness, drug and alcohol use and violence.

There is also an association between homelessness and involvement with the criminal justice system. A number of studies in the criminality field have established a connection between brain damage and the increased risk of involvement with the criminal justice system. Reasons may include a lower level of cognitive skills that can reduce an individual's appreciation of what behaviours are legal or illegal; a loss of control of their emotions and their aggressive impulses; and deficits in cognitive processing may frustrate individuals with acquired brain injury, sometimes increasing emotionality and aggression.

How Can Those Eligible for the Scheme be Practically and Reliably Identified?

Assessment teams (comprised of Allied Health Professionals) linked to the statutory authority administering the scheme would receive referrals from hospitals, health professionals or GPs. The teams would then conduct a professional assessment using an appropriate tool relevant to the type of disability - such as the Functional Independence Measure and Functional Assessment Measure (FIM FAM) in the case of people with acquired brain injury.

Having determined an individual's level of function, the assessment team would then refer all clients with impaired function to an appropriate service provider for a period of rehabilitation.

The assessment would form the basis for planning tailored support to maximise each person's purposeful function. At the end of the initial period of rehabilitation, a professional assessment would again be completed and a determination made on the level of lifetime support required by the individual, which would impact on the level of funding provide by the scheme. Ongoing case management of each individual by the team would enable appropriate supports to be put in place to assist their integration into their community and ensure that steps are taken early should a change in a person's condition or circumstances mean additional supports are required, even for a short period of time, over their lifetime.

This model of support based on early intervention, rehabilitation and case management, facilitation and the ability for people to move in and out of the scheme as their needs change is recommended to ensure effective cost management.

4. OBJECTIVES OF A LONG-TERM DISABILITY CARE AND SUPPORT SCHEME

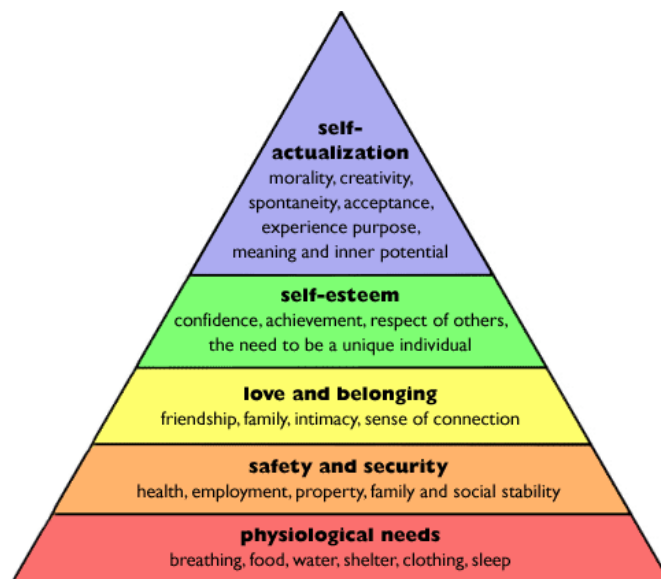
The overall objective of Brightwater's Services for Young People is to maximise community participation and role functioning of individuals with an acquired brain injury by overcoming the cognitive, emotional, social and physical difficulties resulting from the injury. Community integration involves competence in daily living tasks and decision making (with or without support), having leisure and productive activities to engage in, being accepted and having a social network.

This objective aligns well with the overarching goal of the Australian governments' current disability policies – *“to enhance the quality of life and increase the economic and social participation of people with disabilities and their families, including enhancing and protecting their rights”*.

What should a new system aspire to achieve?

The overall goal of the disability care and support model being proposed in this paper is to *“maximise each individual’s purposeful function”*. This is about working with an individual with a disability to identify goals using activities that are meaningful to them in relation to their occupational history, preferences, personal goals and needs, rather than simply aiming to improve function for the sake of improving function. So, for example, rather than just focusing on rehabilitation to enable a person to walk, if that person’s goal is to go shopping, additional skills may need to develop might include understanding road safety, catching public transport and money management.

Maslow’s Hierarchy of Needs can help to explain the overall objective of Brightwater’s proposed support model:



Maslow’s Hierarchy of Needs

Maslow's hierarchy of needs is a motivation theory often portrayed in the shape of a pyramid, with the largest and lowest levels of human needs at the bottom, and higher level needs at the top.

According to Maslow, a person will focus on satisfying their lower level needs before aiming to satisfy their higher level needs.

Air, water and food are basic requirements for survival, while clothing and shelter provide necessary protection from the elements. These are fundamental motivators for all people - if we are hungry or thirsty, then little else matters until we meet this need.

With physical needs relatively satisfied, the individual's safety and security needs take precedence and dominate behaviour. Safety and security needs include:

- Personal security
- Financial security
- Health and well-being

After physiological and safety needs are fulfilled, the third layer of human needs is social and involves feelings of belongingness. Humans seek a sense of belonging and acceptance, whether it comes from a large social group, such as clubs, office culture, religious groups, professional organizations, sports teams, gangs, or small social connections (family members, intimate partners, mentors, close colleagues, confidants).

Esteem needs represent the normal human desire to be accepted and valued by others. People need to engage themselves to gain recognition and have an activity or activities that give the person a sense of contribution, to feel accepted and self-valued, be it in a profession or hobby.

The final and highest need level is self-actualisation. This is about “becoming what we are capable of becoming”, which would be an individual's greatest achievement. Maslow suggested that only two percent of the people in the world achieve self actualisation.

Based upon this framework, Brightwater considers that all people in society, regardless of level of disability, should be entitled to access support to:

- a. ensure their basic needs (food, shelter, hygiene, comfort and safety) are met; and
- b. help them develop life skills and their level of independence in order to meet their higher needs.

Along with this entitlement, however, comes responsibility for the individual to work towards greater independence to minimise long term support from the community. Without a balance between entitlement and responsibility, we encourage those supported by the system to become dependent and reliant – to be “cared for” in order to have their lower level needs met – yet we restrict their opportunities for self actualisation and achievement – that is, to meet their higher needs and become a contributing member of their community.

While this approach may be outside the parameters of the current disability framework, it supports the eight guiding principles that underlie the United Nations Convention on the Rights of Persons with Disabilities, which Australia has ratified:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices and independence of persons;
- non-discrimination;
- full and effective participation and inclusion in society;
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- equality of opportunity;
- accessibility;

- equality between men and women; and
- respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

5. KEY DESIGN ELEMENTS OF A NEW SUPPORT SCHEME

The underlying philosophy of the model proposed by Brightwater is the belief that individuals with disabilities can be assisted to maximise participation in valued roles in the home and community. Adjustment, community access and integration are considered best facilitated through:

- Goal-centred planning of rehabilitation, recognising that there are two experts in the process – the individual who is an expert on who they are, and staff who are expert in rehabilitation;
- A holistic, person-centred interdisciplinary rehabilitation team approach and case management; and
- Individualised, graduated, competency-focused learning through doing.

This model is not impairment focused. Instead, the focus is on each individual's participation restriction and the personal and environmental factors that impact on their participation level. Support strategies can be implemented at all levels – i.e. body function and structure, activity and task execution and participation, dependent on the individual's needs and goals. The model takes into consideration that a person's inability to engage in a given life task or role is not necessarily due to only physical impairments.

Facilitation

A flexible individualised rehabilitation model is proposed for people with disabilities through a planning process which fully involves the person and their family. Individualised, person-centred, experiential learning that focuses on the development of those competencies the individual requires to achieve the goals he/she has identified is the basis of the model. The model is about supporting people to achieve their goals and objectives, rather than "caring for" them. It is also about creating a safe environment in which this learning can occur.

A focus on developing skills or compensatory strategies to enable independent living, decision making and choices and engagement in meaningful activities is the key to maximising an individual's purposeful function and effective cost management of the scheme.

Early Intervention

Brightwater considers that early intervention to develop independence is the basis of creating a sustainable support model. By offering a range of services tailored to individual needs, people can be supported to plan for their future, to identify achievable goals and outcomes and develop strategies to achieve them, thus up-skilling themselves to maximise their purposeful function, rather than be “cared for” indefinitely.

Dynamism

The model also acknowledges the need for flexibility to respond to changing needs of individuals over their life time and to enable people to move in and out of the scheme as their needs change over time. People can move out of the scheme once they have reached the ceiling of what will be funded and they are functioning with purpose in the community, but life changes over time may require them to move back in for additional support, education or equipment, even for a limited period of time.

Supported Choice and Responsibility

The model reinforces choice and assists individuals to take control of their life through engagement in problem solving and decision-making strategies and the ability to explore satisfying community based occupations with or without a vocational focus.

Including people with disabilities and their families in decision-making is fundamental to the effectiveness of this model and involves an interaction between information provision, understanding of impact/consequences, ability to understand and consider all information that is provided, consistent choices and the capacity to change decisions if circumstances alter.

Coordinated Support Services

The major Australian Government role in non-aged disability is the provision of employment services and payments of income support through programs like the Mobility Allowance, Carer Allowance and Disability Support Pension. The latter is not allied with rehabilitation or other disability services, which are state responsibilities. People with disabilities and their families also access many mainstream services provided across the population.

It is considered important that the new scheme provide access to a coordinated range of services, including accommodation support, aids and equipment, respite, transport and a range of community participation programs. However, rather than attempt to provide all of these as “disability services”, it is likely to be more cost effective to ensure mainstream service providers receive training to enhance their interactions with people with disabilities including ABI. Case Coordinators attached to the statutory body administering the scheme would be ideally positioned to identify the most appropriate services for each individual.

The range of support services accessible through the scheme might include the following:

Education & Upskilling Social Services

Services

- Rehabilitation – physical and cognitive
- Training
- Community training
- Education
- Employment
- Drug and Alcohol
- Mental Health
- Sexuality services, etc
- Health & Aged Care

Environmental Controls

- Cue cards
- Open plan design
- Paging systems
- Community – buses, signs, etc.

Aids & Equipment

- Communication
- Showering
- Walking
- Mobility, etc

Hands on Care

- Care
- Counselling
- Physical intervention

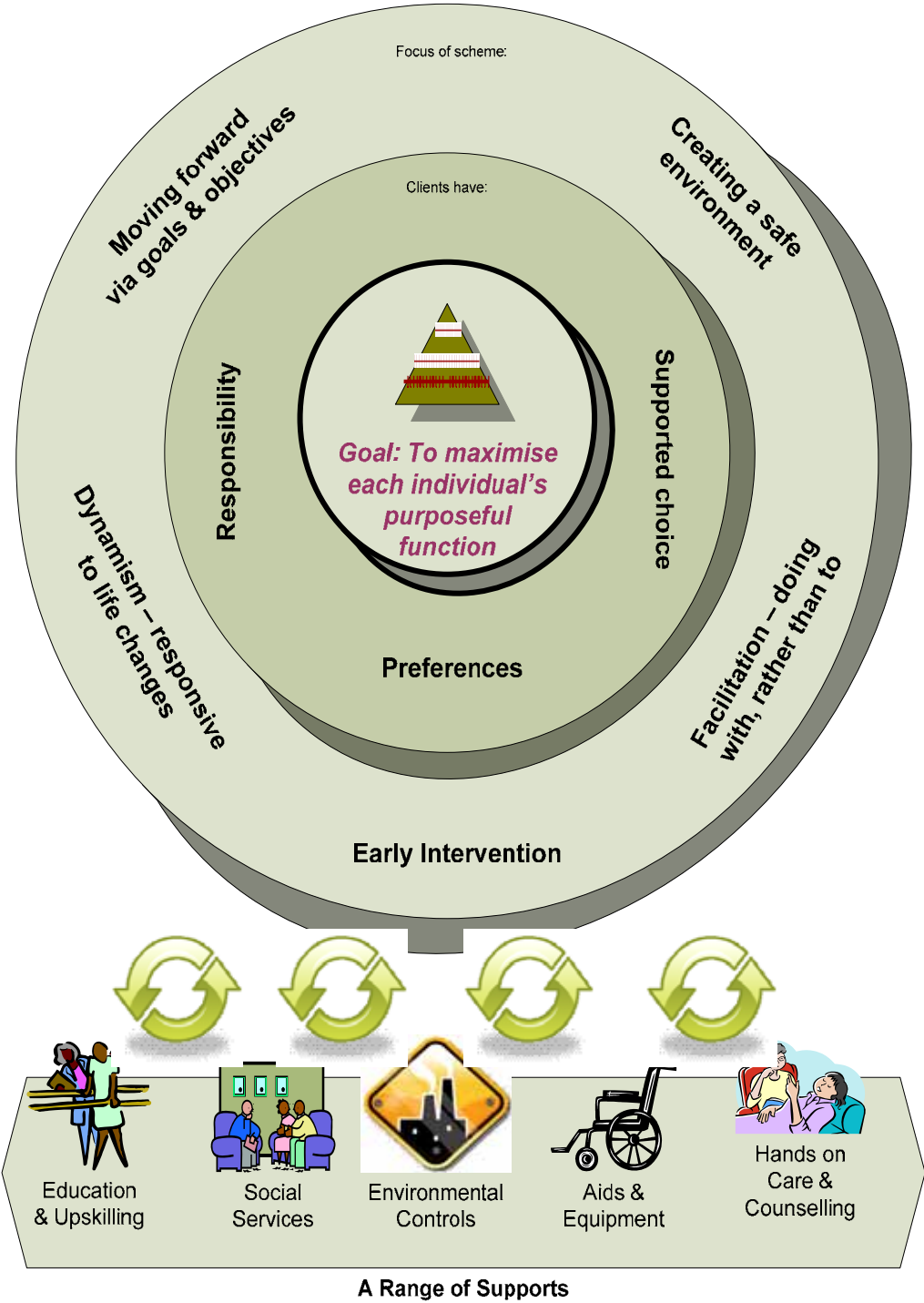
Brightwater considers the inclusion of Cognitive Rehabilitation in the scheme is of particular importance to compensate for the difficulties some people with disabilities like ABI have in successfully completing everyday activities of living. Programs typically focus on improving everyday skills in the following areas:

- Planning, organising and completing tasks
- Creating a daily and weekly routine
- Solving day to day problems
- Managing money
- Accessing the community
- Planning and preparing meals
- Managing personal hygiene
- Laundry and cleaning
- Participating in leisure pursuits
- Gaining employment or returning to work
- Managing behaviour in different environments
- Improving self awareness and emotional regulation

A diagrammatic representation of the Disability Care and Support Model being proposed by Brightwater is presented over page.

Proposed Disability Care & Support Model

Monday, July 12, 2010



6. WHO SHOULD BE ELIGIBLE?

Brightwater supports a national disability scheme with the potential to provide support and services for all people with at least a reasonable degree of need, but with support graduated to the level of need and a focus on early intervention.

Brightwater does not consider that severe or profound disability should be the basis for eligibility, having witnessed that early intervention and skill attainment can be as effective and as necessary for people considered to have a mild to moderate disability as environmental change. 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.

What about natural ageing?

Brightwater's preference is for the new national disability scheme to fund and manage the provision of services for all sources of disability at all ages, with the exception of some conditions that are strongly related to ageing.

Under this option, the scheme would appropriately cover:

- people over 65 years of age still in the workforce or leading active lives who suddenly acquire a disability; and
- people with a degenerative disability.

Comprehensive versus narrow coverage

Brightwater supports a national disability scheme with wide coverage, having witnessed that a small amount of support at one time in a person's life can save large amounts of support later.

Concerns that near universal access and graduated levels of assistance may lead to "needs inflation" and cost blowouts can be managed by appropriate assessment tools used by professionals.

Health funding through Medicare should cover people experiencing short-term disability (7 to 12 months) compared to people whose disability is expected to last for many years.

Should eligibility take account of people's income or assets?

Brightwater is concerned that should means or asset tests affect eligibility for the scheme, the impact is likely to be inequitable service provision, as is the case with the current insurance-based system in WA.

7. WHO MAKES THE DECISIONS?

In the past, people with disabilities and their families were seen as passive recipients of government-funded services, with officials and service providers determining what, when and how much support was given. Recently, individualised funding or consumer-directed care arrangements have been developed to give people with disabilities or their carers greater control over their lives. People receive an annual funding entitlement and might buy mainstream services, hire their own carers on their own terms and choose between attendant care and home modifications.

While individualised funding can give people with disabilities better control over their lives, a question that needs to be asked is whether the scheme should support people with disabilities and their families who reject rehabilitation support to enable improved independence because of the work and time involved and elect instead for a "quick fix" solution of buying care hours to be "looked after". (ie. the balance between entitlement and responsibility).

8. THE NATURE OF SERVICES

People with disabilities need a range of services. Services not provided as part of the current disability support scheme that Brightwater considers people with disabilities should have access to include mainstream services such as mental health services, alcohol and drug services and sexuality services, targeted at people with disabilities.

Brightwater firmly believes that early intervention, rehabilitation support (both physical and cognitive) and case management are the keys to increasing the likelihood of participation by people with disabilities in work and the community in the longer term.

There is a danger, however, in attempting to meet every need of a person with a disability. People without disabilities have varying levels of income which impacts on their ability to access services and activities within their community. Funding music lessons, for example, for a person with a disability who would not normally be able to afford this creates reverse discrimination. Supporting people with disabilities to access activities within their means (once their basic needs have been met) is considered a more equitable approach.

How should people's needs be assessed?

Brightwater agrees that assessment tools are critical in determining eligibility and the level of support people need, but would be concerned at the introduction of a single assessment tool for all people with a disability unless it had been tested and found to provide an accurate indication of level of function across a range of disabilities.

A professional assessment using an appropriate tool relevant to the type of disability - such as the Functional Independence Measure and Functional Assessment Measure (FIM FAM) in the case of people with an acquired brain injury – is important to establish eligibility. A strength of the FIM FAM is that it provides an overall indication of a person's level of function, taking into account such matters as:

- self care items (feeding, grooming, bathing, toileting, etc)
- sphincter control
- mobility
- locomotion
- communication
- psychosocial adjustment and
- cognitive function.

Brightwater has found that the breadth of issues assessed by this tool provides a useful measure of functional independence as the basis for planning tailored support to maximise the purposeful function of individuals with brain injuries.

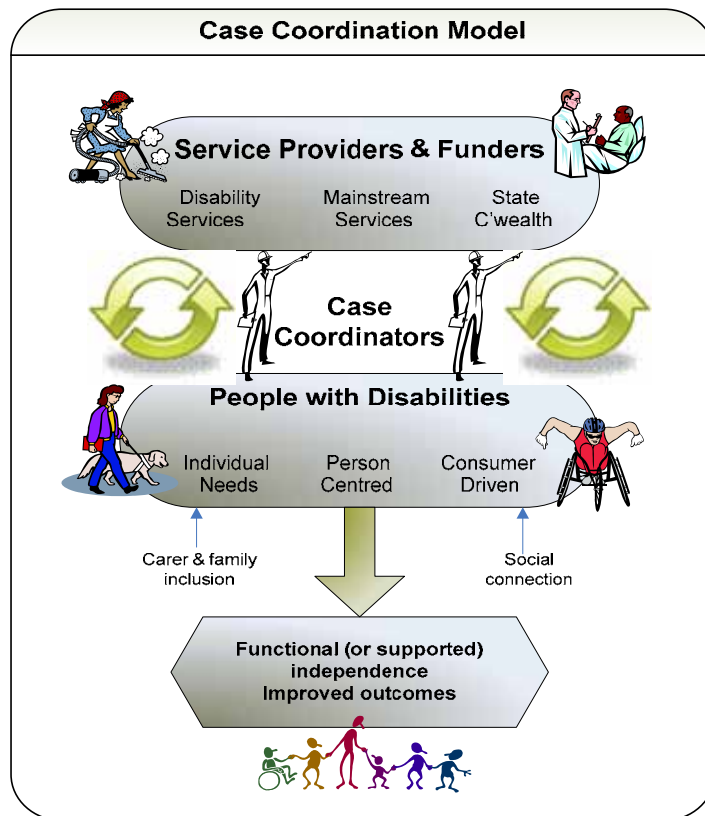
Service coordination and linkages with mainstream services

People with disabilities and their families need to access a range of services, some of which are mainstream services and others that are disability-related. Brightwater advocates the use of coordinated support for people with disabilities to access the range of services they may require to live meaningful lives within the community.

Case coordinators are probably best attached to the statutory authority administering the scheme. Case coordinators can assess each person's needs and pull together local services including State and Commonwealth government agencies, non-government organisations and private sector providers.

Case coordinators can:

- provide a single point of contact and a single support plan for each client;
- promote access to a range of services; and
- review and report on overall progress and specific outcomes.



Case management will help to facilitate independence, maximise potential and work with individuals and families to plan transitions over their lifetimes.

Brightwater considers that the use of case coordinators will help improve support planning and continuity across service boundaries, improve communication between service providers, reduce duplication in service provision and improve the use of available resources.

How should insurance arrangements for catastrophic injury link in with a disability scheme?

Brightwater supports the proposal by the Disability Investment Group (DIG) to introduce a National Disability Insurance Scheme (NDIS) to replace the current arrangements for funding disability services. A NDIS would work in a similar way to the no-fault injury insurance schemes that currently operate in some states. The scheme would operate as a social insurance scheme reflecting the shared risk of disability across the population.

Under a social insurance approach, the risk of disability and the costs of meeting lifetime needs are the starting point. The necessary funding is then actuarially estimated after considering the expected claims, expenses and the cost of capital, while also considering the desired outcomes for scheme participants across their lives. A more accurate picture of an individual's needs may be best determined after an initial period of rehabilitation.

Funding for the scheme should come from a Medicare-like levy.

The proposed scheme would help to address unmet and under-met need for care and support and the unsustainable reliance on carers. At the same time, the scheme would ensure a viable system and engage in partnerships between funded support, informal support and community-based activity and infrastructure.

Coordinated services based on need would provide care and support including respite, aids, equipment, transport, home modifications and a range of community and day programs. Other support funded outside the scheme such as income support, housing and employment services would be integrated to provide support and opportunities for people with disability as part of a holistic approach. There would be an emphasis on early intervention and access to coordinated rehabilitation to maximise long-term independence and potential.

The DIG recommended that people who are covered by state/territory-based accident compensation schemes should continue to be covered by them, but the interaction of the schemes should be further investigated.

9. HOW MUCH IS NEEDED?

The DIG noted that such a scheme is not beyond Australia's capacity to deliver. While increased expenditure would be necessary initially to address currently unmet need for care and support, because of the more active management and support model, sizeable offsets will be available from Disability Support Pension, Carer Payment, health and other social programs.

Ultimately a National Disability Insurance Scheme is expected to be a net saving on government expenditure through a more effective service system and better employment, health and social outcomes for people with disabilities.

What does an entitlement entail?

As mentioned earlier, Brightwater suggests that the scheme should focus on support to enable all people with disabilities to have either learnt or supported capacity to have baseline functionality. Each person would be entitled to an appropriate whole-of-life suite of services that would facilitate independence and maximise potential. As in other families, this is still likely to be a mixture of formal and informal care, as individuals and families make decisions about appropriate arrangements at various stages of life.

Along with this entitlement, however, comes responsibility for the individual to work towards greater independence to minimise long term support from the community.

With the capacity for people to move in and out of the system according to need, the cut off point for the active funding might be when a person is able to work unsupported for a specified number of hours per week at or above the relevant minimum wage.

10. FINANCING OPTIONS

Brightwater supports a funding method that manages future liabilities associated with the long-term care needs of people with disabilities.

Re-engineering the way public and private resources are invested in disability would allow people with disability, their families and carers to plan with more certainty across the life course, and to contribute more to Australian community life. By introducing a new approach government investments would no longer focus on just the care and support that people with disability need, but shift to assisting people with disability to manage their own lives, to maximise their independence and contribute more to the community.

Income support and the new insurance arrangements could operate side by side, supplemented by improved arrangements for families to make planned complementary provisions for the future for family members with disability. Improved employment and social housing services would maximise the potential of these long-term investments.

Brightwater supports the DIG proposal that the additional cost of the scheme be funded by a Medicare-type levy reflecting the shared risk of disability amongst the population.

11. GOVERNANCE AND INFRASTRUCTURE

To be sustainable the scheme must be well-governed and managed. Brightwater supports the DIG proposal that a new statutory authority be established to govern the NDIS, rather than allowing one agency to act as the fund holder and overall decision maker.

The scheme will also require disciplined monitoring and evaluation across a number of dimensions of each client's life plan such as health outcomes, work outcomes and service use.

Phased implementation of the scheme would enable the necessary growth in service infrastructure and workforce.

12. APPRAISING COSTS & BENEFITS

The long-run costs of a new scheme will depend on the number of people eligible, the prices of services and their quantities, both now and in the future. A support model based upon early intervention and coordinated rehabilitation to promote an individual's independence seems the approach most likely to reduce lifetime costs and providing better support for informal carers may create long-run savings for formal care.

Brightwater appreciates the complexities in estimating costs and benefits of a new scheme and acknowledges that existing data on costs by disability subgroup are crude. Despite rapidly increasing knowledge of the biological, physical, emotional and social impact of brain injury, our understanding of the economic impact of neurotrauma has been limited.

In 2005, the Victorian Neurotrauma Initiative (VNI) health and medical research fund commissioned Access Economics to report on the economic costs of traumatic brain and spinal cord injury to enhance knowledge in this area.

The report found that whilst TBI/SCI are relatively uncommon injuries, patients are typically injured at a young age and are disabled for the remainder of their lives, leading to very high costs. The lifetime cost of new cases of brain and spinal cord injury occurring in 2008 alone was \$10.5 billion in Australia. The largest cost was attributed to burden of disease, but direct costs such as provision of attendant care and healthcare services are also significant.

At the level of the individual, the economic impact of these injuries was reported to be comparable to or greater than that of diseases commonly considered to be 'high-cost', including other neurological conditions.

Brightwater has recently engaged ACIL Tasman, one of Australia's leading economic consultancies, to undertake an economic evaluation of our Oats Street program. Brightwater Oats Street is a 27-place Rehabilitation Facility for people aged 16 and over with an acquired disability and issues of cognitive impairment. The Oats Street program aims to facilitate the return to community living, within an environment suitable to each client's needs. It is expected that clients will participate in the Oats Street program for a period of one to two years with a short end phase of community integration supported by the Oats Street staff.

The report by ACIL Tasman should be available by mid October 2010. Brightwater respectfully suggests that the Productivity Commission arrange a time to discuss this report further and would be happy to make a copy of the report available.