30 June 2010

Productivity Commission
Canberra ACT

Dear Sirs/Mesdames

Long Term Disability Care and Support submission

I make a submission regarding the current inquiry by the Productivity Commission regarding a disability care and support scheme (“CSS”) for people with disabilities. I set out below my submission, with accompanying personal information to illustrate the issues.

Background

My 10-year-old son has autism, is severely intellectually disabled and has attention deficit hyperactivity disorder and I am his primary carer. He is a sweet, healthy child who loves music. He cannot speak meaningfully, he has behavioural problems, is not toilet trained, has very limited play skills, no independent care skills and he is highly mobile and overactive with almost no understanding of danger. It is likely he will act like an extremely hyperactive two-year-old for the rest of his life. Medications have had no positive effect on him. He requires a certain amount of physical confinement and constant care to ensure he does not harm himself or others or damage property.

We live in the eastern suburbs of Sydney. I have three degrees from the University of Sydney including undergraduate law and economics and postgraduate law. For many years my ability to engage in paid work has been severely limited due to my eldest son’s disability. My income is negligible but my husband works and is very active in caring for our two children. Both my sons attend primary school five days per week. My personal circumstances and location have allowed me actively to manage my sons’ care.

I am often on the point of total collapse due to exhaustion. Each year my mental, physical and pecuniary resources are substantially diminished by the impossible task of caring for my disabled son. At some time in the coming decade all my resources will be depleted by this task, then I will have to renounce the care of my eldest son to the State (which, based on what I have seen of public care, I consider tantamount to torturing him). I beg you to work for extreme improvements to public supports for people with disability (“PWD’s”).

Overview

It is widely accepted that the current system of public support for people with disabilities in Australia is woefully inadequate and discriminatory. I urge you to focus your efforts on ensuring that at least a reliable system of public support is introduced for the most extremely disabled members of our community. I understand your inquiry is limited to people with severe or profound disabilities, which is the sensible place to focus first efforts.

Cost considerations must impinge on any system introduced. However, in Australia we have seen with the special disability trust arrangements for PWD’s and our income tax system, an excessive focus on countering even the slightest hint of fraud to the point of creating unworkable administrative burdens and undermining the usefulness of the system. I caution you to avoid unnecessary complexity in a CSS that may undermine its effectiveness. Take great care to ensure the CSS you propose is as humane, simple and practical as possible.

Accordingly, I submit you should recommend a CSS that is limited to those people with severe disabilities who are expected permanently to require constant or frequent care. This relatively small population have high and somewhat homogeneous needs that can allow a lower burden of anti-fraud measures than is necessary for a system applying to a larger group.

I propose you set up a CSS administered by a CSS Body within the federal government under which eligible people have a legal right to services required to support the basic necessities of life. Eligible people should be given an annual CSS Budget and CSS Capital Budget by the Federal Government to purchase goods and services under an individualised funding arrangement. All decisions of the CSS Body should be subject to appeal by the PWD to an independent, binding mediator appointed by agreement between the parties. I set out my views of these issues in more detail below.

What to Aspire to Achieve?

Address Unmet Need particularly for Supported Accommodation

The main reason I see for a new CSS for people with very high support needs is the current severe absence of services, particularly supported accommodation. The description of this on page 10 of the Issues Paper as “There are insufficient resources and gaps in certain kinds of services in some jurisdictions and locations” is so very understated and conditional as to be a misleading and unfair characterisation.

I would challenge you to identify one jurisdiction in Australia containing a significant number of people with constant or frequent care needs where there is not a marked shortage of supported accommodation for them. Certainly NSW (where I, and millions of others, live) has an extreme shortage of supported accommodation for people requiring constant or frequent care (see for example front page of Sydney Morning Herald 28 May 2010 “Disabled children face years in crisis care”).

A fairer and more correct description of the lack of services for PWD’s must use stronger language. I would describe the system for providing supported accommodation services to people requiring constant care as so severely dysfunctional and inadequate as to constitute a collapsed system in crisis.

Obtaining reliable information on the unmet need for supported accommodation is difficult because it is common knowledge among families of PWD’s that there is no supported accommodation to be had through orderly channels, so very few waste their time applying for a service they have no prospect of receiving. Accordingly, the tragically common practice of deserting one’s family member with severe disabilities at a respite centre or hospital has arisen. Your research should include data on this occurrence and on the length of time it takes to find a stable supported accommodation place for those people abandoned by people who want and love them, as well as for other families who battle on in permanent crisis.

One way to try to quantify unmet need is to send a survey to all relevant recipients of the Carer Payment or Carer Allowance and ask them about the unmet needs of their PWD, existing now and expected in the future.

The Issues Paper very mildly observed that the insufficient services in the current system have the result that “informal carers and people with disability bear too much of the costs associated with disability” and note the high levels of depression among carers. This again is so understated as to give a false impression. Many carers and PWD are living in desperate, untenable circumstances without any human dignity or quality of life and the Issues Paper should acknowledge that as an important reason for a CSS. I expect you would find the levels of depression in carers of PWD requiring constant care would exceed 90% if you cared to survey them.

A CSS should be set up as a matter of urgency for PWD requiring constant or frequent care so:

- families are not required to care for family members when they cannot (and certainly are not expected to do so for more than 20 years); and

- families are flexibly supported in caring for a person requiring constant care with at least 5 hours of respite every single day (assuming they get normal sleep, if not then more respite would be required).

Addressing the severe shortage of supported accommodation services is of a much higher order of importance, and would go a long way in addressing, the other objectives you identify, for example, certainty for the future, opportunities for employment and community participation and inappropriate models of service. This objective should be the single most important objective against which all other objectives should be traded off. Failure to address the absence of supported accommodation services seriously undermines gains on other, less important objectives.

A new CSS aspiring to address the unmet need for supported accommodation must be designed to include sufficient funds for the ongoing staffing requirements this entails. It will be very expensive but must be done.

Recognise permanence and reduce administration

A serious shortcoming of current disability support services is their focus on short-term assistance to overcome a crisis. A CSS should aim to implement a system that acknowledges the permanence of many disabilities and addresses permanent disability in a more efficient way. This objective should be added to the other aims you identified and can be addressed by providing PWD’s with a right to service.

My 10-year-old son has a severe and permanent disabilities that should be addressed by a disability support system (especially in respect of respite) that acknowledges his chronic requirements and gives him a right to necessary services. However, my son has no security of tenure in obtaining publicly funded respite services. He is offered respite for short fixed periods such as a two-week school holiday period, or a 10-week school term. The longest period of respite he is offered is on an annual basis and at the end of every year he must re-apply again on the same footing as everybody else. Every year he could easily be refused this respite service due to random factors such as a large influx of even more severely disabled people into our local area. There is no understanding of his permanent needs and no medium term planning of our household work and leisure time is possible.

These short-term services also cause an unnecessary burden on carers to constantly apply for piecemeal service. Applications often involve long forms and require individual medical certification of disability. This is a financial and time burden that carers can ill afford and should be removed by a CSS.

UN Convention on the Rights of Persons with Disabilities

Australia is currently seriously breaching its obligations under the UN Convention by its failure to provide a reasonable amount of public support for people with disabilities. Social housing authorities discriminate with impunity against PWD's requiring constant or frequent care by failing to provide suitable accommodation. The CSS should be designed to redress the current discrimination against PWD in the provision of social housing.

The UN Convention supports a requirement that the CSS should be designed to allow users and their Advocates to make decisions about the use of funds in order to maximise the autonomy of PWD's.

Who to benefit?

Permanent need for Constant and Frequent Support only

The proposed CSS should focus on those with severe or profound intellectual and/or physical disabilities. It should target those who require constant or frequent support because this type of support cannot be reasonably and reliably provided by a circle of family and friends, no matter how well-meaning. The current model of family care for this population of PWD's with state support has been an abject failure due to lack of commitment and an extreme shortage of funds from government. This group is most in need of help and have very distinct specialised needs, such as supported accommodation with high staffing of personal carers on a permanent basis.

The CSS should provide a lifelong, permanent right to support, therefore it should include only those who are reasonably expected on the balance of probabilities to have a permanent need for support.

Medical Testing

Those people requiring this support should be identified by submitting themselves to a formal medical testing process that is subject to appeal determined by independent medical specialists. This test should identify whether the disability can be expected to be permanent, in which case there should be no need for regular tests to confirm this but merely a system of audit of a small sample of the group and an undertaking to advise the CSS Body if circumstances change.

If medical test identifies a reasonable possibility of the disability changing in the future to such a degree that a person may no longer be eligible, it should specify the time period for re-testing.

Medical testing should encompass both formal medical diagnosis of recognised conditions as well as an assessment of the need for support in daily life. For example, a diagnosis of autism spectrum disorder should not be sufficient by itself to satisfy the criteria of the CSS because many people with this condition have only low support needs. It is only the group who have a very high need for constant or frequent support with self-care, safety, communication, behaviour and/or other requirements who should be eligible.

Medical testing for eligibility should also form a view as to whether the person with disability is able to make informed decisions fully independently or not.

Data from this medical testing should belong to the PWD. The PWD can choose to provide it to the CSS Body and service providers. The CSS Body should not provide it to anyone without express permission from the PWD.

Age

No minimum or maximum age should be set for eligibility to the CSS but people should only be accepted in the CSS if they are found to be eligible by the appropriate medical test before they turn 65 years of age. This requires a transitional rule for the start of the CSS to accept those tested as eligible at any age provided they were at least say 60 years old when the system is introduced and it is reasonably believed by medical experts that they would have satisfied the eligibility conditions in the absence of any age-related conditions they have.

Simple Medical-based Eligibility Criteria only

Other potential eligibility factors mentioned in the Issues Paper such as remote location, family support, expected greater benefits from greater support and so on should not be relevant in determining eligibility. Additional factors such as these increase complexity and will create unfair outcomes. Eligibility should focus on need for constant or frequent support.

Tandem Systems

The existing support systems for aged care and people with disabilities should continue in tandem to this narrowly focused CSS for the most needy. Once the CSS is operating it would always be open to expand eligibility in the future.

The existing systems for PWD should continue and people accepted into the CSS should be excluded from using those supports.

Existing conditions

The CSS should not be limited to new cases of disability but should include people with existing disabilities. The alternative would be perverse having regard to the well-known unmet need for support.

Means and Assets Test

No means test or assets test should apply in relation to eligibility for the CSS. It would have very little effect as the vast bulk of those eligible would be children (with no assets or income) or those who are so impaired they cannot earn substantial income. A narrow focus by the CSS on PWD whose support needs are constant or frequent removes the need for financial testing. Financial testing adds unnecessary complexity to the system.

Test for Need for Constant or Frequent Care

Until seeing the definitions of the level of care (eg constant, frequent etc) required by a PWD on page 8 of the Issues Paper, I have never come across this concept in my extensive dealings with government support services provided by disability services, health or education bodies in respect of my severely disabled son. I would be aware if such a test had been applied because my permission and involvement would have been necessary.

Now that I am aware of the concept, I am shocked it has never been applied to my family. The only testing we have been subjected to by government agencies has been medical diagnosis, IQ tests and the tests for the Carer Payment.

Testing to determine the level of care needed (eg constant, frequent etc) obviously is rarely (if ever?) done in our current disability services system in NSW. Understanding the level of care needed is fundamental in determining the quantity and nature of support required by a PWD, particularly in relation to respite, education and supported accommodation. Respite service providers compose their own application forms that try to measure need and set priority but it is never a comprehensive test for constant care needs.

The failure of the current system to test for level of care needed in relation to my son is a stark example of the total failure of current disability support systems in NSW to make a reasonable attempt to provide the help required by PWD’s needing constant care.

Appoint an Advocate

It is expected that a majority of people with only physical disability would not qualify for the CSS. We should expect the bulk of those eligible to have an intellectual disability or mental health condition (with or without other conditions).

In order to manage the administrative aspects of the CSS, people who are unable to communicate informed decisions on their own behalf should have a person or persons appointed to a formal Advocate role at the time of eligibility testing (in case an appeal is required in respect of the eligibility test). In the first instance the Advocate should be appointed by parents of the PWD. In many cases the Advocate would be a parent of the PWD and this should be encouraged.

If parents or other close family are unable or unwilling to appoint an Advocate or in the case of a dispute, a body such as the Guardianship Tribunal should determine the appropriate Advocate, preferably a family member or friend of the PWD but if no-one else is available a paid Advocate should be provided who is independent of the CSS Body.

The Advocate would be the decision-maker for all aspects of the CSS and would have to make appropriate legal undertakings to act in their reasonable opinion of the best interests of the PWD; to try to comply with the wishes of the PWD as far as possible; to apply all CSS funds for the benefit of the PWD; and to co-operate with the CSS Body in a reasonable manner eg by informing it of significant changes affecting the PWD’s eligibility.

In cases where family members choose not to apply for the CSS on behalf of a mentally incompetent PWD, an Advocate should be appointed to participate in an independent process to consider if this is in the best interests of the PWD.

Who Makes Decisions about Spending

Individualised Funding

The PWD or Advocate must have the power to make all decisions about use of funds provided under the CSS, subject to broad parameters (eg prohibition of certain expenses such as gambling) and subject to a requirement to provide simple, unaudited, annual accounting to the CSS Body. I strongly support an individualised funding model as it maximises value to the user and minimises waste. This flexibility will also maximise opportunity for participation in work and the community by PWD and family carers.

A fundamental flaw of most current disability service models in Australia is the absence of power by individual users to determine use of funds. This feature causes the following problems:

- massive waste due to duplication, bureaucracy and service providing no value to the user; and
- significant reduction of the quality of life of the PWD.

In my life I see many examples of disability funds wasted due to decisions being made by a service provider rather than me. For example I am offered respite services that I refuse or partially use (despite our desperate circumstances) because they offer me no benefit. An inappropriate respite service for a person with severe disability can easily affect them to such a degree that they are more difficult to care for after that service ceases, therefore rational users must refuse such as service (even apart from the issue of carers loving their family member and therefore refusing inappropriate service). Issues that may seem inconsequential to a large government body or service provider, can have severe effects on the value of a disability service to the user.

A common example of useless disability services in the current system are some centre-based respite services for a group of PWD’s. A respite service which I am offered (for example a five-hour service at a centre for my son in a group) may have disadvantages for me - it may fall on a date on which I cannot use the service; its duration may be too long (eg a five hour outing is difficult for my son who is better able to cope with a 2-3 hour outing); I have to spend 2 hours in total driving to and from the centre to drop off and pick up my son; the activities they undertake may be too hard for my son and it is in a group with people with unusual behaviour so my son may be physically harmed by others in the group etc. These disadvantages sometimes become so great that I refuse even this small service because the costs outweigh the benefits. Due to lack of alternatives, I sometimes accept such a service but pick up my son hours earlier than the scheduled end time in order to mitigate the problems of the service. This causes terrible waste in the system because funds are expended to provide a much longer service than we actually receive.

Similar considerations apply with overnight respite. My family is offered overnight respite, however I believe this service would so upset my son that I am better off without fully using it. I do however accept this service but only leave my son at the service for about 3 hours during the day, then I collect him (the day before the appointed end time). Yet the costs of staffing and holding the house (which is underutilised) are borne by the service provider despite my very limited use of the service.

I would obtain much more benefit for the same cost to this respite service if it was flexible, for example if they allocated me a budget to spend via their service each financial year. A better service would allow me to set the hours and times for a regular fortnightly/monthly wage to a paid carer to pick up my son for a one-on-one outing for 2-3 hours. This model of service does not need to add an administrative burden to the provider. Those who obtain full value from a centre-based service could choose it if they want under a flexible system.

The same issues of flexibility apply to many services for people with disabilities. Many services are rendered useless by lack of decision-making power in the PWD.

In my experience case managers are another example of waste due to service provider decision-making. I have no need of a case manager and they actually provide a disservice to me because I have to waste my time managing the relationship with them. However many disability services are only available to me if I have a case manager eg NSW ADHC Family Assistance Fund. Yet some people need a case manager, so those who do should be able to allocate a portion of their CSS Budget to this service if it provides value.

I imagine all individualised funding models must include a fallback mechanism of centralised control of funding in cases where the PWD or Advocate have demonstrated an implacable inability or unwillingness to use the funds as required by the system eg for the benefit of the PWD. This should only apply on an exception basis to those individuals, for example by appointing a Financial Advocate paid by the CSS to control funds (who is separate from the PWD or Advocate, who can continue to make non-financial decisions). The people subject to this arrangement could be identified by the CSS Body checking the accounts of a small proportion of users each year.

Each eligible PWD should be advised of an annual CSS Budget in advance, which should be adjusted and indexed annually. Regular payments should be made to the PWD, for example fortnightly, in order to avoid risks associated with management of lump sums. The CSS Budget would be used for recurring expenses such as carer wages and education.

In addition, each PWD should be advised of a CSS Capital Budget that can be used for the purchase or hire etc of capital items, such as a wheelchair, modified car or accommodation. This budget would need to be determined by the CSS Body based on individual needs.

Individual application should be possible to bring forward CSS Budget amounts from future years for specifically approved larger purchases provided necessity, ability to repay and value for money could be demonstrated in a process of CSS Body approval, although it would be preferable if users accumulated savings of their CSS Budget for this purpose. Prepayments could be recouped from future CSS Budgets at a reasonable rate.

Usual Costs

The usual and main types of costs arising for a PWD requiring constant or frequent care in addition to the ordinary costs of life are as follows:

1. supported accommodation;
2. family carers and careworkers;
3. home modifications;
4. transport;
5. therapy and education;
6. specialised aids, equipment, clothing, diet etc; and
7. leisure activities.

The CSS should be sufficient to address these costs listed above and should be able to be spent by the PWD (or their Advocate) flexibly to address these needs. If concerns exist, expenditure not related to these defined types of costs could be disallowed by the rules of use of the CSS.

Supported accommodation and capital costs

Supported accommodation is a special category of costs that requires different treatment from other costs to be covered by a CSS because it requires large capital outlays upfront. Supported accommodation under individualised funding arrangements will encompass a range of choices including part-time or fulltime living with family or mainstream friends; regular overnight care in a small to medium sized group of PWD in an institution (eg boarding school like the Kingsdene special school); or living in a home alone or with a small number of other PWD's.

If sufficient demand exists for a group accommodation institution such as Kingsdene special school, the CSS Body would be required to provide capital contributions. Perhaps a user could draw on a CSS Capital Budget to provide a cheap form of funding for the service provider similar to a refundable security deposit for aged care. Due to the long term nature of accommodation, the Government may need to be the service provider in some cases.

The PWD must retain the power to change the provider of supported accommodation, although a reasonable period of notice (say 3 months) may be required in ordinary circumstances.

Similar use of CSS Capital Budget or prepayments of CSS Budget may be required for home modifications and equipment purchases. For home modifications above a certain value, some mechanism may be needed to recoup some of those costs when the relevant home is sold (before the value of the modification is fully depreciated). Perhaps a concept similar to the capital gains tax rule that looks to any increased value reflected in the consideration received upon disposal may be useful.

The CSS Body may need to maintain a pool of commonly used expensive equipment in order to use disability-related equipment efficiently over the whole of its useful life eg wheelchairs for children may be outgrown while still reusable. Equipment above a certain value may be required to be returned to the CSS Body after use ceases, provided it is still usable, and the user's CSS Capital Budget should be credited with the item's residual market value on return. In order to minimise disagreements about value, the PWD should be able to provide a cash substitute to the CSS Body instead of returning a used piece of equipment. If the PWD could obtain a higher cash amount than the residual value offered by the CSS Body a market in disability equipment would soon develop on Ebay.

Therapy costs

It may be argued that therapy costs should not be included among the costs to be covered by the CSS as it is a medical cost and I think that argument has merit. The Federal Health budget should cover this cost, as it currently partly does via Medicare. However my son obtained free therapy from a public hospital when he was younger and he was merely diagnosed with developmental delay. As he became older and his diagnosis worsened to autism we were told hospitals cannot provide therapy to PWD such as him. This distinction should not exist in public hospitals and PWD should be able to obtain speech- and occupational therapy via hospitals without discrimination. This would be more efficient as they are already set up with appropriate equipment. If that change occurred then the CSS would only need to cover therapy costs above those covered by public hospitals.

Leisure costs

It is also arguable as to whether the CSS should cover leisure costs. It should because PWD requiring constant or frequent care are rarely employed. They have a lot of leisure time to fill and they need to be supported to engage with the community.

An alternative would be to provide people who qualify for the CSS with a distinct identity card similar to the Companion Card. Holders of such a Card and their carer should receive free entry to all federal, state and local controlled public recreational venues that do not involve tickets for individual seating including museums, zoos and indoor sports venues such as pools via a pooled compensation payment arranged by the CSS Body. This would be a practical measure to facilitate improved quality of life.

Education costs

It should be considered to include additional education costs incurred by PWD’s in the CSS. Current educational support for PWD is totally inadequate. My son requires constant care yet he does not receive it in school, therefore his behaviour is deemed challenging. Many people who are labeled as displaying challenging behaviour by our current disability system are merely people who are not receiving the level of care and support they require.

My son is in a class of 5 children with classic/low-functioning autism in the care of a teacher and a teacher’s aide. The usual staffing level is one carer to three children with autism in the classroom, which is clearly inadequate. The obvious result for my son is no learning and a constant struggle just to keep the behaviour of the kids within acceptable limits.

Pay Family Carers

Primary carers and family members should be paid using a CSS Budget for providing care. This would provide family carers with a real choice of providing care or undertaking paid employment elsewhere. It would be more efficient if family members could take other employment if the conditions/pay etc suited them more than the carer role. I am a good example of the inefficiency that can result from lack of care options. I worked fulltime for 9 years in the city as a tax adviser for a large accounting firms (eg Arthur Andersen) and as in-house corporate tax adviser in an investment bank and when I ceased working as an external adviser my time was charged to clients at $300 per hour. My education and experience give me extensive career options provided I could manage my household responsibilities, yet my professional income last year was around $4,000 due to lack of flexible care.

Family are the most reliable care providers (see research on abuse of people with intellectual disability in out-of-home care). The rate of payment for family members could perhaps be set by recent arms length transactions by the PWD or, if that data is unavailable, by the CSS Body having regard to the average rate paid under arms length comparable circumstances, with different rates applying for evenings and weekends.

Staff to PWD ratio

Serious consideration needs to be given to the level of staffing required to provide constant care to PWD's in group situations. How many PWD's can one person give constant care to simultaneously before the PWD's are, in truth, not receiving constant care? Child care centres seem to have a ratio of one carer to approximately 4 babies, yet larger children and adults with severe or profound disabilities can be much more mobile and require much more hands-on attention than a baby. The staffing ratio for care of PWD should be affected by various factors such as the following:

1. the individual disabilities and needs of the people involved;
2. the adequacy of the location for the purpose – is it big enough? does it contain activities that can be used independently? is it physically contained? does it contain other people or equipment that need to be protected?;
3. purpose of the care, that is, what is proposed to be achieved during the relevant period, for example, more staffing would be required in circumstances where the goal is to educate the participants rather than merely entertain.

These considerations lead me to conclude that a child requiring constant care must have a one-on-one carer throughout their education. I know from my own experience that I can care for both my children simultaneously but my mainstream child gets minimal attention and the nature of the activities we can undertake is significantly curtailed. It is my opinion that a PWD requiring constant care should always have a one-on-one carer for their whole waking life or their quality of life will be significantly restricted.

Funding bands in CSS

The CSS should identify different levels of care needs among the eligible population in order to determine the level of funding required for care workers and supported accommodation. Funding bands could be set according to a small number of relevant factors that should include:

1. does the PWD require frequent or constant care?
2. does the PWD have a normal sleep pattern or is active care required through the night?
3. Is the primary carer up to 44 years old; 45-55 years old; 56-66yo; 66yo or above?
4. Has the primary carer been caring for a PWD with high support needs for 0-5 years; 6-10 years; 11- 15 years; 16-20 years; or more than 20 years?

In my experience, a PWD with a normal sleep pattern requiring constant care would require non-family carers for at least 5 hours per day every day of their life when the primary carer is less than 44 years old and has been providing care for 6-10 years, in order to provide decent support to the family that is sustainable over many years. I expect that every PWD requiring constant care would require non-family carers for 24 hours per day when the primary carer is 66 years old or above or the primary carer has been providing their care for 20 years or more.

Your inquiry should look to set guidelines of sustainable levels of care that a family can provide for people with various categories of requirements in the eligible population. This would inform funding for the CSS Budget in relation to supported accommodation and assist planning for how many non-family workers are required by the CSS.

Conflict of Interest

The Issues Paper identifies concern about the potential conflict that may arise between the PWD and their Advocate over use of funds, for example for respite. Surely a commonsense approach needs to be taken to this. A PWD would only have an Advocate if their high support needs included an inability to communicate informed decisions. The Advocate would ordinarily be in a loving relationship with the PWD. Paid and unpaid Advocates should be bound by a legal requirement to act in their reasonable belief of the best interests of the PWD or could be replaced (or in extreme cases subject to a criminal sanction for theft or fraud). We should be comfortable allowing the Advocate to decide in these circumstances.

The Issues Paper identifies this issue in relation to “respite services for the carer”. This is a flawed characterisation of respite and perhaps the label of ‘respite’ is so misleading that it should be discontinued and substituted with references to care provided by a ‘family carer’ or a ‘careworker’. The CSS should be providing all the companion care that a PWD needs. That care may be provided by a family carer or careworker, both of whom should be paid. It should be implicit in this system that no one person or couple can provide constant care for another over an extended period. The alternative is unsustainable.

When the family carer is not providing care, another person is providing care for the PWD (that worker is not providing a respite service to the family member). The paid worker is required to assist the PWD to undertake whatever activity is scheduled during that period of time, so the PWD should be the focus of their attention. The family carer is merely a special class of carer (they normally provide better quality care and they may also be the Advocate and hirer of the paid carer). The purpose of a CSS is only to provide care and services to a PWD and all expenditure of the CSS Budget should be considered in that light. Indirect benefits to the family of the PWD are incidental and irrelevant to the ongoing operation of a CSS, these indirect benefits are only relevant in identifying the need for implementation of a CSS.

Dependency risk

In my opinion the risk of dependency identified on page 23 of the Issues Paper is of no real concern. If the CSS is targeted to a narrow pool of very dependent people the goal of achieving independence for the PWD is relative, and very limited for those with an Advocate who have intellectual impairments. Do not be distracted by this illusory threat to Revenue, keep focused on the vital job these families are doing and the need to keep the CSS as simple as possible to administer. In reality the families of people with severe disabilities would be elated to maximise the independence of their loved one.

Impact on Service Providers

The impacts of individualised funding on service providers is of negligible concern. Service providers have arisen to date for a variety of historical reasons and have been protected from real choice by the consumer for too long. Competition among service providers is to be encouraged as it will reward quality and drive innovation. I hope a CSS would force change among many service providers because many currently provide a low quality service providing poor value for money.

Co-payments and Top-up payments

Co-payments will add significant complexity to the CSS for little financial benefit. Having regard to the narrow focus of eligibility I recommend, the vast majority of this group will have effectively no independent income or assets. Those who do may be adults who suffer catastrophic injury after accumulating wealth and, in that case, is it good policy to require co-payments that effectively remove the inheritance of their children when their parent is now requiring constant or frequent care?

If a co-payment was required, consideration should be given to its effects for the purposes of Medicare, private health insurance cover, child care tax rebate, Child Care Benefit or the medical expenses tax offset. Respite for children with disabilities is clearly analagous to child care however I currently spend approximately $900pa on respite co-payments that are unfairly excluded from tax support. My annual cost of $3,600 to send my elder son to a school run by a charity that is the peak autism body in Australia is directly related to his disability yet gains no government recompense. The form of co-payments unfairly discriminates against PWD under the tax regime. The medical expenses tax offset itself includes an unfair discrimination on the basis of disability as it reimburses part of the cost of care only for people who are blind or permanently confined to bed or a wheelchair, while ignoring people with more severe disabilities.

I expect that in a large minority of cases the family of a PWD may wish to make voluntary additional payments for some disability services, for example to upgrade the quality of service or purchase a home for the PWD. Resist bureaucratic temptation effectively to coerce these payments from families by under-providing basic services. These payments would be voluntary and cannot be required as families will opt out.

The CSS should be set up to make voluntary contribution simple eg allow ownership of the PWD’s home to remain with a family trust and use CSS funds to cover ongoing staffing and rent the premises. Small groups of families would possibly group together for this purpose and should be supported to do so as this would shift significant burden in sourcing and setting up the accommodation to the family. It would also lead to better quality, tailored outcomes with buy-in and likely ongoing close involvement by family and community members. The individualised funding model supports voluntary additional payment.

Workers providing care

Giving users greater control over a CSS Budget can help to attract paid workers to provide care because it can assist in forming a personal relationship between the worker, the PWD and their family. This has been my experience in the past with a flexible respite service which allowed more communication directly between me and the worker. This personal relationship appeared to me to increase the feelings of job satisfaction of the worker and supported a long-term stable work arrangement. It also certainly increased my satisfaction with the service received because I could feel more comfortable of the quality of care received by my son. This relationship and direct communication also made it easier to resolve issues with my son’s behaviour.

People requiring constant care need a group of people to provide that care. I welcome the creation of a partnership with paid workers to strive collaboratively to provide what my son needs.

The main skills I look for in choosing a carer for my disabled son are reliability, maturity and empathy. For people who are unable to communicate (like my son) the personal qualities of trustworthiness and reliability are paramount because he will never be able to speak of mistreatment.

I need workers who are energetic, physically robust and vigilant. I prefer women because they are less likely to sexually abuse. I prefer people who have some health training or experience but education really is unimportant for my purposes. I like workers who are willing to engage in a dialogue with me about my son’s needs and provide feedback after each care session. I prefer workers who can drive because my son is happiest and easiest to care for out in a park. I prefer workers who speak English quite well as my son has comprehension problems. I prefer working with as small a number of carers as possible as they need to be provided with informal training from me as to our needs.

I would have thought offering respite care would be a convenient job for mothers with children at school during school hours. I find tertiary students are a good source of workers for weekends.

A police check for working with children should be applied for all workers working with people with communication disabilities.

I understand other countries such as Canada offer a specific visa classification to encourage foreign workers to immigrate to work in the care industry. I believe this is a good idea that should be used to attract care workers to Australia from Asia and the Pacific.

Supported Accommodation and ‘Bad old Institutions’

Consideration should be given to how a CSS for people requiring constant care could provide care. I find it surprising that any government could expect a family to provide predominant care to a family-member who may have extremely high support needs including medical requirements and 24-hour intervention. A small proportion of our population have such high needs that they could only be provided by a government-funded service involving a team of paid workers in addition to, or in substitution for, family members. Your CSS should ensure this service gets implemented.

It is my experience that historical examples of ‘bad old institutions’ are inappropriately used in the current system. The choices considered for supported accommodation are often limited to ‘bad old institution’ versus family care. The ‘bad old institution’ should not exist as a current scare tactic because social policy and administrative transparency have moved on since the 1960’s. The cut-price institutions that existed 30 and 40 years ago in Australia were paired with an expectation of zero family participation in the lives of PWD’s, which is a fundamental change compared to today.

Yet Australian governments at state and federal level seem to have a dogmatic aversion to group care for children with disabilities. For example, the failure of governments to recognise the role of Kingsdene Special School in Sydney with appropriate funding, causing its closure, is disappointing as this was a successful 5-nights per week boarding school.

Supported accommodation should be chosen by users and Advocates from a flexible variety of alternatives, including individual care and group care with appropriate modern safeguards allowing close involvement by users' Advocates and family.

Information Management

All information in relation to a PWD under the CSS should be available to the PWD and their Advocate. In addition, the immediate family of a PWD should have the power to appoint any person (for example an accountant) to review all or part of their CSS documents. This will allow family review and oversight of issues in relation to the PWD.

Lack of transparency in relation to information, particularly financial information, is a real shortcoming of the current disability system. In the area of education for example, when a PWD attends a NSW school the information on additional funding provided to the school in respect of an individual's additional needs is confidential to the school. The school determines how to use those additional funds and may choose to apply those funds in ways that do not relate to, or benefit, the PWD. As the PWD is outside the loop of information, they are unable to advocate effectively for application of the funds. This lack of transparency also causes unnecessary friction between PWD's and their service provider.

Another example of PWD's being refused information concerning them of which I am aware relates to IQ scores. My son received an IQ test at a public hospital by a psychologist and the psychologist gave us a written report. However the psychologist always refuses to provide users with the raw data of IQ scores, because the professional body for psychologists only allows these scores to be given to another psychologist. This limited my ability to advocate on my son's behalf and to manage his medical care. I was only able to obtain those scores from the psychologist because I am a lawyer and was able to quote Freedom of Information legislation to her. Information is power and PWD's need it all.

Other Submissions

I have had the benefit of reading other public submissions to your inquiry on your website and wholeheartedly wish to endorse submission 25 written by Ms Sally Richards. Ms Richards made excellent arguments regarding supported accommodation; shared care; right to service; focusing on the most needy and marginalised; individual and portable funding; and one-off testing.

I would also like to draw attention to submission 16 from a service provider in the UK where a successful CSS exists which Australia should copy. The view given by that submission of a system of rights and individual funding empowering PWD's and driving improved quality services is a dream that should be made reality in Australia.

Time to Start

The time to start a CSS is now. The unmet need is already acute. While a CSS is being set up, planning and increased respite can begin immediately. Planning activities to identify the eligible population can take the following form:

1. set up a preliminary screening system to begin to identify those people who may possibly be eligible. This may require the establishment of a Medicare item for GP's to test whether a person has a severe or profound disability and to begin to gather information relevant to meeting other eligibility criteria, for example, level of care required. GP's should be expected to send basic results from this test to the CSS Body (patient permission should be forthcoming once use of this information is explained);

2. identify the people who may be eligible from those already known to government departments through Centrelink payments, disability services, education and health to be likely to have the requisite level of disability and care needs and write to them to suggest they participate in the preliminary screening in step 1;

3. Survey in detail the circumstances and current and future needs of the population identified in step 1; and

4. Once a medical test for CSS eligibility is finalised (which should be considered urgently) then that can be undertaken at public expense for those identified as possible to be eligible by step 1.

Planning to provide increased supported accommodation must start in the interim before the details of a CSS are finalised due to the extended lead times for providing such services. The obvious place to start is by reviewing worthy programs that have been proposed by charities and families to government bodies in recent years yet rejected due to lack of funding, for example RASAID in Ryde, Sydney.

An immediate step that can be taken while shaping a CSS is to provide additional new respite funding to those people identified by the preliminary screening in step 1 above. I would propose individualised funding of $3,000 pa per person. These programs already exist (for example Sunnyfield's Respite in Action program) so it would be quick and simple to expand these in many areas.

Conclusion

Before you make a glib conclusion about paying family carers; or co-payments; or family dependence on a CSS, you should try to imagine what it can be like to care for a family member requiring constant care. You should understand that while the definition of constant care refers to people being unable to be left for an hour, it includes many people who cannot be left unattended for 5 minutes. It includes people who are physically strong and mobile, as well as people who are heavy and unable to move.

Providing constant care involves doing a huge amount of boring, disgusting, repetitive, dangerous and upsetting things. Whether a carer is tired or is bleeding from an accident or hears important news or it's Christmas Day or it's 5am – there is no negotiating with a person requiring constant care to give you a few moments to compose yourself or do something else. It involves physically protecting my younger son from his older brother. In about 4 years when I can’t physically restrain my older son, it may be impossible to continue. Providing constant care makes the carer struggle to care for themself (to go to the toilet; get dressed; eat; converse; shower; do laundry; shop; cook; or tidy up) while caring because this requires attention or leaving the room. It makes your home like a prison. Many family carers work through the night and day; they have medical problems; and/or they can’t afford the home modifications necessary to physically contain their child.

It is heartbreaking to see your child never receive an invitation to a friend’s house. Having a family member requiring constant care is a very real disaster that can never be matched by receiving payment for the time spent providing care. Yet the absence of money can totally undermine a family’s ability to provide care. Providing constant care is impossible for many people due to current inadequate government support.

Some advocacy groups object to plain speaking about the difficulties of family caring for PWD’s because they feel that we don’t care about our family members, are removing their dignity or are trying to shift the focus of support from PWD’s to carers. They are incorrect. I am the same as any parent. I love both my sons, I want them to live with me for about 20 years and I want them to be happy and safe for their whole lives. However these issues are too important to sugarcoat. I am surrendering my privacy and dignity with this submission in order to try to obtain necessary support for my elder son (and indirectly me) and others like us.

My household would have to be objectively considered much more able than average to provide family care for a person requiring constant care, yet we are failing. When my eldest son was born I was 31-years-old, well supported in a happy marriage, well educated, rich, living in the city, had English as first language and was a native of Sydney with a network of friends and family. We receive an above-average quantity of respite – my sons attend school for 6 hours a day, five days a week for 40 weeks of the year. We also receive various other respite services that total about 5 hours per week on average all year. Yet I am slowly and quietly collapsing due to the impossible burden of my elder son’s constant care needs. If my household cannot provide family care, then it is reasonable to assume almost nobody can and the supports we receive are seriously inadequate.

It is obvious that the government is going to be required to care for a large number of people requiring constant care as family carers die or become unwilling or unable to care for their family member. Current government policy of guilt-tripping siblings into providing care by using veiled threats of neglecting PWD’s is highly unlikely to see much success after the siblings have seen what it has done to their parents. The improved survival rate from medical advancement must create a significant and growing pool of PWD’s under government care who require constant care. Setting up a CSS as I propose is merely a decent and orderly method of undertaking what the government will nevertheless be forced to do.