

THE PRODUCTIVITY COMMISSION DISABILITY CARE AND SUPPORT INQUIRY

Response to the Issues Paper

Dear Commissioners,

Introduction

I have received your email with the link to the attached *Issues Paper* and the submissions already received. But, quite frankly, if additional services and new funding were going to 'fix' the problem of unmet need, this would have happened a long time ago. At 36, life with cerebral palsy has taught me a number of things. Most importantly, no new government engineered "system" or "program" is going to make my life better. You will note that throughout my commentary to the Commission, there will be references to papers and submissions I have written elsewhere. This is because, while the body undertaking the inquiry changes, the issues surrounding disability policy never change that much.

A reform of substance would be the broad retreat of government bureaucrats from the lives of individuals; you might think this a highly unreasonable request, but as a disabled person one can often feel overwhelmed and overrun by social workers and others in the 'welfare industry'. My family has found this in relation to parts of the Ageing and Disability and Homecare Department of NSW (AHAC). Several years ago, we responded to a newspaper advertisement to become part of a pilot scheme called the Attendant Care Program. (ACP) This was targeted at people with disabilities and their carers/parents, particularly as both groups age. After our initial inquiry in 2007, we did not hear much until late 2008.

My experience

As John Farnham¹ once sang: 'Well, it seemed liked a good idea, at the time!' The first challenge with the ACP was to maintain my current ADHC funded Homecare Services. I have been a Homecare client since 1987, and have a very stable group of regular Homecare attendants. Particularly given that I have current, regular, employment, experienced, reliable early morning care is essential. This is to allow me to meet a specific, wheelchair accessible bus, to take me into the city. Managers of the ACP (who were also officers of ADHC) insisted that I had to progressively forgo all current arrangements to be part of the ACP scheme.

I was advised by staff at the ACP unit that whilst both programs are administered by the Department, the funding is different. Although Home Care are not an approved provider for the Attendant Care Program, clients with a lengthy existing relationship with Home Care are able to select them as a provider if the branch is willing and has capacity. ACP advised me that the reason ACP encourages clients to select a provider from the list

¹ See generally http://en.wikipedia.org/wiki/John_Farnham as at 19 May 2010

is because Home Care are not able to be as flexible with services as other providers due to their policies and the fact that they are the provider for both the High Need Pool and HACC clients, which means their resources are stretched to capacity. Further, they advised the approved providers listed under the Attendant Care Program are able to be more flexible and that the program overall is more flexible and the ability to bank hours would assist me when I travelled and that I would be able to use one-off funding and these banked hours to assist me when travelling and that ACP encourage clients to discuss possible future plans when meeting with providers to ensure that they will be able to meet their needs.²

To be fair, I understand the need to meet criteria and conditions for service delivery. Furthermore, the matter was concluded satisfactory; my Homecare service has been maintained. My point in quoting the above paragraph is to show what 'flexibility' means in practise. Flexibility is often the client's flexibility to contort their life (and that of their family's) to meet an agency's or program's selection criteria. Even where there are identified features a recipient seeks,³ there are other parts of a package which come along that are about as welcome as the fox in your chook pen.

In my case, it was a round of meetings and assessments, which at times saw Mum and I reorganising our work and other commitments, to meet ACP demands. There was also the speed which our attendant care provider wanted to rearrange large parts of our lives. We had only suggested, for example, that we *might* be in the market for a second hand van. This was to permit me to travel with Mum, without the need for me to get out of my wheelchair and transfer to a car seat.

Suddenly, we received emails about various vans for sale and advice that a funding application needed to be made, within certain timeframes. Again, we found that we were being asked to dance to the 'service provider's tune' and make decisions that suited their schedules. I now make even greater use of Wheelchair Accessible Taxis (WATs) than I did prior to my experience with the ACP and, my mother and I will persist with the chair to car transfer for as long as we both feel able to do so.

This should lead the Commission to consider several points. Firstly, you should examine very closely the financial costs of a system, such as the one you propose.⁴ It would not appear that you are intending to sweep multiple programs away, but rather overlaying a new scheme on existing infrastructure. While acknowledging that the *Issues Paper* says the Government aims to rethink current funding and support arrangements,⁵ the diagram

² Advice received by ACP Wednesday, 1 April 2009

³ My mother and I were seeking to plan for our future, in a time when she is less physically able to manage my needs and/or my needs were placing undue strain on her health. We always felt that this was "in the future" and that we were the ones with the ability to call for more support when we needed it.

⁴ See Productivity Commission, *Disability Care and Support: The key questions*, May 2010, p.4 (Diagram: The main aspects of any system) <http://www.pc.gov.au/data/assets/pdf_file/0008/98027/key-questions.pdf> at 18 May 2010

⁵ See Productivity Commission, *Disability Care and Support: Issues Paper*, May 2010, p.3 (Figure 2: Key design elements of a disability care and support scheme) <http://www.pc.gov.au/data/assets/pdf_file/0007/98026/issues.pdf> at 18 May 2010

believes an all too familiar gauntlet of 'gatekeepers' and eligibility criteria. It would be worthwhile for the Commission to undertake some economic modelling as to administrative costs and time taken with applications, processing and assessment. My case should stand as an example of the inefficiencies in a system, whereby the recipient of funding declines to proceed with available, additional funding. This is because dealing with my own current personal circumstances and arrangements (i.e.: continuing to be transported either in a standard vehicle or using more WAT's) is currently easier and less emotionally taxing, than engaging with the bureaucrats of the ACP.

In making its inquiries, the Commission should not hesitate to both critique and be critical of both the government-run and non-government welfare/social services sector. In my experience with the ACP, it seemed assumed that recipients and their families would automatically be grateful for any service package produced (even if it didn't meet an individual's stated needs).

For example, I recall taking a telephone call early last year, at work, from my ACP service provider. She had just had a conversation with my mother, which ended badly. In short, the enquiry revolved around whether we intended staying with the ACP; the question ending with a reminder of the funding on offer. I quickly explained to her that the terms of my staying were clear: both my mother and I had one clear message from the beginning – whatever else happened we wished to retain our Homecare service. This was the one thing that, up until Ms (Name suppressed)'s intervention, was specifically refused. Therefore, I advised that I was very dissatisfied with the ACP initiative and, was prepared to leave the program. Thereupon started the provider's blackmail argument, which was that I had 'failed to consider my mother's future needs' by unilaterally exiting the program.

These comments fitted a pattern of behaviour engaged in by the provider, when it became clear to her that we were not going to say "Yes" to everything she suggested, nor be managed to her funding timeframes. At times when it suited the ACP provider, I was the client; at other times it was my mother. It never seemed to occur to her that the first thing a mother and son would do, was to check with each other as to what had been said to us. A less than subtle 'divide and conquer' strategy failed. After I told the provider that I thought she was little more than a bully (to which she claimed deep offence) putting down the phone only made it ring again. It was Mum, in a very distressed state, after also having been interrupted at work by a call from the ACP provider. From then on, we decided I would be the only contact point for ACP, and that would be by email.

It has been about a year since direct contact; ACP funds my Homecare service and otherwise stays out of our way. Ironically, and perhaps sadly, this is the way Mum and I prefer it. It is sad, because I did have hopes for the ACP providing a *Minder*⁶ style relationship – a 'Terry' to my disabled/incapacitated 'Arthur Daley', though I would claim far better scruples than Arthur ever had.

⁶ See [http://en.wikipedia.org/wiki/Minder_\(TV_series\)](http://en.wikipedia.org/wiki/Minder_(TV_series)) as at 18 May 2010

What was produced was the same as any government-run program. It resulted in lots of paperwork, including medical and Occupational Health and Safety (OH&S) assessments, along with an alleged requirement to change service providers. As shown by the advice I received from ACP in April 2009, while this was presented as being for my benefit, it also served internal departmental objectives about 'which bucket of money' my service was funded by. It was also clearly an attempt to allow an overstretched Homecare service to shed clients to other providers. Ironically, the ACP funding was still provided by ADHC, a State Government department.

This is one of the greatest ironies of modern government. It will go to great lengths to adopt the language of the markets, turn citizens into 'clients' and tell you how much 'choice' you are receiving. Funny then, how this market is shackled by the same sort of government red tape that Sir Humphrey Appleby⁷ would be proud of. Furthermore, it would appear that the suite of 'choices' a 'client' is invited to make conveniently suits the administrative arrangements of the service provider.

- *Recommendation 1: Freedom of choice must mean a service recipient's freedom of choice, not the convenience of the service provider.*

Occupational Health and Stupidity

Part of my problem was that we also initially asked for a carer to take me to a fortnightly evening meeting and, then for that person to put me to bed on the return home. This lasted for about two services, until we heard from the service provider that it could not continue. The issue: there was some pushing and shoving of me in and out of cars, as well as the need to lift my legs into bed. All of these things my mother has been doing since I was born, and into my adult life. Bring in a third party and, government regulation can complicate the most mundane aspects of daily life.

While OH&S may have started with the best of intentions, it has become an administrative scourge in the workplace, operating much like a plague of locusts on a wheat farm. The resolution of the question about how to lift my legs into bed required yet another occupation therapist's assessment. This resulted in a recommendation that a large hoist be installed in my house, simply to lift me in and out of bed. While this would be provided by a State-run program, Physical Aides for Disabled People (PADP), this required another application and placement on yet another waiting list.

Ultimately, Mum and I decided that asking the ACP to handle a fortnightly appointment was more than the scheme could cope with. Besides, we did not want another large piece of equipment to gather dust in our house, nor pander to the needs of a (male) carer who seemed reluctant to lift anything heavier than a bed sheet. We also suspended the PADP application until further notice.

⁷ Sir Humphrey Appleby (http://en.wikipedia.org/wiki/Humphrey_Appleby) was played by the late Sir Nigel Hawthorne (http://en.wikipedia.org/wiki/Nigel_Hawthorne) at 19 May 2010

The reason for telling these stories is threefold. Firstly, I want to emphasise that having the Federal and/or State Governments set up another 'system' will simply repeat all the mistakes and bureaucratic processes outlined above. And it should be remembered that for all the discussion above, all the assessments and all the administrative man hours, the ACP is yet to deliver one new or enhanced service I can use. Nowhere in this debate have we put a value on people's time; either those who will be applying under a disability care and support scheme, or those who will have to administer it. In my case, the ACP represented many largely wasted (and highly stressful) hours.

Furthermore, unless the Productivity Commission is prepared to put a cap on both the number of administrative staff to run a disability care and support agency, as well as limits on the percentage of funds to be expended on governance, executive remuneration and consultancies, then millions of dollars could disappear in fees and commissions. We have seen many examples of waste and mismanagement in other Government programs, such as the current Federal school building scheme.⁸ Examples such as these should be informing our thinking about whether it is even appropriate to establish a new central body?

Questions should also be raised over the competency and motives of some involved in any national disability care and support scheme. Reflecting on my ACP experience, I became convinced that the provider was having growing difficulties understanding her "unhappy customer". Becoming increasingly shrill with me was never going to work though; I knew I could do far more damage to her Community Care organisation by leaving it, than she could ever do to me. After all, my presence brought funding, which was what, in my view lay at the heart of her concern about my potential departure. Expressing apparent concern for my mother's future health and wellbeing (and insinuating that I was being recklessly indifferent) never blinded me to what was really at stake.

- *Recommendation 2: The Productivity Commission should put a cap on both the number of administrative staff to run a disability care and support agency, as well as limits on the percentage of funds to be expended on governance, executive remuneration and consultancies.*

Where to from here?

⁸ See for example *Opposition slams Rudd revolution 'waste'*, Justine Ferrari, *The Australian*, March 16, 2010 12:00AM <<http://www.theaustralian.com.au/news/nation/opposition-slams-rudd-revolution-waste/story-e6frg6nf-1225841121512>> as at 20 May 2010; also see *Bureaucracy eats third of school funds*, Justine Ferrari, Education writer, *The Australian*, May 22, 2010 12:00AM, <<http://www.theaustralian.com.au/news/nation/bureaucracy-eats-third-of-school-funds/story-e6frg6nf-1225869810507>> at 22 May 2010

At this point, you might be wondering what I am seeking from this inquiry? Initially, it is important for the Productivity Commission to remember its focus on productivity, as opposed and distinguished from welfare. Reading through your *Issues Paper* dismayed me somewhat, in the ‘front and centre’ role you give to government.⁹ Individualised funding will be little more than rhetoric, unless we are prepared to allow people with disabilities and their families to spend at least some time living outside the regulatory *Leviathan*¹⁰ under which care and support services are currently delivered. This is a point I attempted to make to the *National Human Rights Consultation* headed by Father Frank Brennan last year, when, highlighting my university studies as an example, I said:

(A)s someone with a physical disability, I have at many times in my life found myself being case managed to within an inch of insanity. For example, while it might have been very generous of the taxpayer to partially fund my transport expenses while undertaking undergraduate study, via the Commonwealth Rehabilitation Service (CRS), the level of influence this gave CRS caseworkers over the nature and direction of my studies was incredible. At one point CRS raised queries over my subject selection 24 hours before I was to enrol, while on another occasion a case officer insisted that I produce a full subject plan covering the entire life of my undergraduate study. The document was produced, but I contacted the Dean of Students who advised it was unrealistic to plan so far ahead; the University could not guarantee staff and subject availability, beyond what was offered that year. I requested that she put that in writing to the CRS.

While, on one level, these problems are minor and were ultimately resolved, they demonstrate how willing government is to intervene in the day to day life of individual citizens.¹¹

I fear similar outcomes in relation to a national disability care and support scheme. This is particularly if as suggested, a single agency could ‘act as the fund holder and overall decision maker’.¹² Such a structure should be recognised as both having the appearance and the reality of an inherent conflict of interest. It is not hard to foresee a scenario where a poor budgetary outcome may press the agency into applying their eligibility criteria more exactly one year than in this next, thus leading to claims of bias and the perception of decisions not being made on their merits.

⁹ For example, your *Issues Paper* states on page 24 that ‘even where individualised funding (and personalised care) might be the dominant basis for decision-making in a new scheme, inevitably service providers and governments will continue to play a major role (determining who is eligible, funding rules, promoting innovation, quality assurance and so on).’

¹⁰ *Leviathan* by Thomas Hobbes <<http://publicliterature.org/pdf/lvthn10.pdf>> as at 22 May 2010; A more easily read version can be found courtesy of Adelaide University’s e-books collection <<http://ebooks.adelaide.edu.au/h/hobbes/thomas/h68l/complete.html>> at 22 May 2010

¹¹ *Key Consultation Questions* by Adam Johnston (submission) 10 April 2009, pp. 1 -2 <[http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth2-010/\\$FILE/010_Adam%20Johnston%20pt2_31-12-09.doc](http://www.health.gov.au/internet/main/publishing.nsf/Content/eHealth2-010/$FILE/010_Adam%20Johnston%20pt2_31-12-09.doc)> as at 22 May 2010

¹² *Issues Paper*, p. 40

This should not occur; rather, there should be no single agency and no immediate move to replace current services. In my submission to the Commission's *Review of Mutual Recognition Schemes*, I argued that States and Territories implementing new programs, incentives or concessions in the welfare sector (or any other area of policy) should be required to ensure the scheme's interoperability between jurisdictions 'before a measure is introduced, in an attempt to avoid costly amendment or duplication of regulations post facto'.¹³ In the same submission, I related the story of approximately four years of lobbying it took to achieve interstate reciprocity for State-based taxi transport subsidy schemes, amongst other complexities of dealing with government.

It is because of these experiences, alongside the ACP's recent attempt to smother me with case management¹⁴ that makes me reticent about a government initiated long term disability care and support authority. We only need to look as far as the earlier cited school building initiative, to have concern about public sector governance and management. Equally, for an example of a government stuff-up in relation to disability services, look to my submission to your inquiry into *Government Cost Recovery*.

In that submission I related how the formerly State-based Continence Aids Assistance Scheme (CAAS) was reorganised on a national level with a single contractor. When a consignment of supplies I ordered went missing, a complaint which turned into a Freedom of Information Application revealed multiple problems with the new arrangement and, a distinct lack of planning on the part of the Federal Government. In particular:

- For an arrangement that was supposed to represent value for money, it was surprising that pricing policies were not initially specified
- If the new contractor had little lead-time to make necessary arrangements, this situation tended to undermine the very claim of efficiency and value for money
- Further, if the contractor hadn't the resources in the first instance, I challenged whether the new arrangements really represented an improvement. State based mark-ups may have been removed, but a handling charge now existed for the return of incorrect goods
- Finally, one has to question the astuteness of a Department that concedes a failure to obtain 'appropriate legal and commercial contract advice'¹⁵

While conceding that my *Cost Recovery* submission is dated and the problems long resolved, you can still potentially draw a line between the CAAS reorganisation and contemporary government implementation blunders. This line is that implementation of new programs rarely seems to improve over time. A potential reason for this goes to the

¹³ *Submission: Review of Mutual Recognition Schemes* by Adam Johnston, 24 November 2008, p. 4 <http://www.pc.gov.au/data/assets/pdf_file/0011/84494/subdr58.pdf> as at 22 May 2010

¹⁴ My mother is a scientist who manages one laboratory and has established or accredited several others. I am a solicitor. Naturally, we cannot possibly be qualified to run our own lives.

¹⁵ *Submission to the Productivity Commission's Cost Recovery Inquiry*, 6 May 2001 by Adam Johnston, p. 2 <http://www.pc.gov.au/data/assets/pdf_file/0019/39340/subdr112.pdf> as at 23 May 2010.

very nature of government itself, as identified by former civil servant Peter J. Crawford. In his book *Captive of the System*, Crawford states:

(Government) agencies continue to concoct sets of guidelines, rules and protocols that they hope will aid them... They and we are destined to be disappointed, however, if these efforts simply lead to new rule-based management regimes to replace the old. This is part of a much broader phenomenon. At Commonwealth and State level, agencies and authorities continue to discharge similar roles, despite changes in governments and their goals. The names and the size of the agencies may have changed, or there may have been some interchange or repackaging of responsibilities, but the legal requirements, administrative procedures and programs often endure.¹⁶

The question which necessarily hangs over the *Issues Paper* is: why should a national disability care and support scheme be any different from the multitude of state or federal government programs in the disability sector, which have preceded it?

New thinking

Avoiding a repetition of mistakes of the past is essential, if this inquiry is to produce more than a series of 'motherhood statements' about 'how the community must better support people with disabilities and their families.' However, I see little in the *Issues Paper* that suggests anything other than a new institutional structure funded by the taxpayer.

My concern is only increased when you suggest that there might be mandatory contributions similar to superannuation, or a Medicare-style levy.¹⁷ In a 1996 speech to the National Press Club, then Head of Access Economics Geoff Carmody demonstrated how regressive the Medicare Levy was and is still today. He said:

For most of us, the Medicare Levy is a 1.5% 'flat tax' on all income: but not for all. You see, there are low income exemptions that are means tested and 'clawed back'. The basic 1.5% Medicare Levy applies to all taxable income when you earn more than \$17,191. If you earn less than \$15,903, there's no Levy. What about in between? Here, things turn nasty. Every *extra* dollar of income here means 20c in Medicare Levy. So the 1.5% Levy is really a 20% marginal tax for some poorer people. But there's more. The 20% Levy occurs where income tax is 15%. Here, the *effective* tax rate is really 35%.¹⁸

¹⁶ Crawford, Peter J, *Captive of the System! Why Governments fail to deliver on their promises – and what to do about it*, Richmond Ventures Pty Ltd © 2003, p.7

¹⁷ See *Issues Paper*, pp. 36 - 37

¹⁸ Carmody, Geoff, Tax Cuts or Tax Reform: Which? For Whom?, Address to the National Press Club, 5 April 2006, p. 3

<<http://accesseconomics.com.au/publicationsreports/getreport.php?report=70&id=79>> as at 23 May 2010

In proceeding down such a path of using the tax and transfer system, the Commission will invariably create anomalies and injustices, like the one identified by Mr Carmody. What you should aim to do is lift people, both out of financial poverty and dependence on government (which should be regarded as a form of ‘civil poverty’ where little of your life is free from bureaucratic interference, particularly if you are in receipt of welfare). The first thing that needs to be done is to liberalise the use of special disability trusts. This concept was first introduced by the former Howard Government. However, as I understand from seminars I have attended, and discussion with friends who have considered using such arrangements, the terms are that restrictive as to make the trusts economically and legally unviable for many people. Equally, as with everything else created by government, it was just ‘too complex’.

Again, while the Government may have a legitimate claim to protect its revenue base, the trade-off in complexity of legal arrangements (and compliance costs) should be seriously considered. In much the same way as assessment and eligibility criteria caused stress but little satisfaction for me in the ACP, dealing with the tax and benefits system (sometimes simultaneously) is draining.

This was why I wrote to the Henry Tax Review¹⁹ calling for an end to the churn of benefits and taxes. If long term disability care and support does anything positive, it should reduce (rather than increase) the cost in energy, money and time spent dealing with compliance issues.²⁰

But this does not seem to be the case. In terms of disability care, the Productivity Commission seems wedded to ‘agency models’. By this, I am referring to the fact that you ask a range of questions as to ‘core formal services’.²¹ Their very content demonstrates an impost of regulation and oversight. This is the antithesis of the hopes and expectations I had for the ACP. My ideal would have been:

- A relatively informal arrangement, with the simplest of terms;

¹⁹ See generally Submission to the *Henry Tax Review* <http://taxreview.treasury.gov.au/content/submissions/pre_14_november_2008/Adam_Johnston.pdf> as at 24 May 2010

²⁰ Compliance can prove difficult, even for the Australian Taxation Office (ATO). Of late, we have seen the ATO send letters to taxpayers without refund cheques attached, blaming it on a new computer system. See for example, James Thomson, *Tax Office posts 140,000 tax refund letters – but fails to send the cheques*, Friday, 16 April 2010 11:32, <<http://www.smartcompany.com.au/tax/20100416-tax-office-posts-140-000-tax-refund-letters-but-fails-to-send-the-cheques.html>> as at 29 May 2010. Previously, there have been reported instances of the ATO not being able to initiate action for tax avoidance, due to poor or insufficient records, while agencies such as *Centrelink* have been criticised for misuse of data that they hold. I raised these issues in a submission to the Australian Law Reform Commission (go to <[http://www.healthemergency.gov.au/internet/main/publishing.nsf/Content/eHealth-002/\\$FILE/002_Adam%20Johnston%20pt%202_21-07-09.pdf](http://www.healthemergency.gov.au/internet/main/publishing.nsf/Content/eHealth-002/$FILE/002_Adam%20Johnston%20pt%202_21-07-09.pdf)> and see pp. 5 – 6) where I suggest that it would be ‘far more productive to reduce the incidence of tax and transfers, rather than try to recoup lost revenue’. Why not apply the same principle to people with disabilities and their families? Preparing a report which puts people in a better financial position, by arguing for a reduction in the tax-and-welfare-churn, will do more to ensure the long health and wellbeing of families with disabled relatives, than creating yet another public authority.

²¹ *Issues Paper*, p. 25

- An option, as my needs change, for a carer to live with me. Under this arrangement, I would provide meals, lodgings and contribute to their other personal expenses, in exchange for them being my *Minder*;
- A minimum of official interference, in what is an essential an ‘in kind’ agreement.²² This would have further reduced the need for formal employment ‘time sheets’ and associated paperwork.²³
- An ability for true ‘freedom of contract’ to function, where elements such as OH&S could be traded for security of tenure and/or an increase in the *Minder*’s wage (i.e.: danger money²⁴)

The reality was quite different. Had I not elected to use a Community Care provider (and retained Homecare’s services), I would have been required to find, hire, roster and sign pay sheets for my own care staff. Here again, disabled people and their families end up being required to deal with the unintended consequences of a new government initiative like the ACP.

While some people with disabilities, their families and carers may want a formal structure, many of us will not. It would be beneficial therefore, if as much as is technically possible, people with disabilities²⁵ were taken out of the tax and transfer system. It does not serve us (or many other Australians) that well. A telling example is the case of disability employment.

- *Recommendation 3: Contracts between carers and people with disabilities should be as simple as possible, emphasising more of a ‘semi-personal’ rather than ‘employment’ relationship.*

A rent-seeker’s paradise

Any examination of the disability employment sector will demonstrate that it is highly dependant on government subsidies. The specialist employment agents/brokers are

²² This is a significant change in my thinking, even from when I wrote to the Howard Government’s Working Party on the Needs of Sons and Daughters with Severe Disability (see Appendix 2). My experience with the ACP has so shaken my faith in the ability of government to act in either the individual’s or the community’s ‘best interest’ that any non-government solution is worth considering. Indeed, if what comes out of the Commission’s inquiry is simply the creation of another bureaucracy, I would insist that people (even if potentially eligible) can ‘opt out’ of dealing with the agency and, are also not obliged to make financial contributions, if they choose not to use its services.

²³ The Commission should also take this comment as an answer to another question you ask. In particular, you ask on page 25 of the *Issues Paper* about the impact on current service providers of individualised funding. In many respects, this should not matter; if individuals wish to enter contracts for service with specific carers, then that should be a matter largely for the parties. If this causes some organisations to lose staff and close, then this is simply an example of the free market in operation. In my own case, the free market would have permitted me to retain the carers of my choice, without the resulting bureaucratic argument I described earlier.

²⁴ I do not believe however, that perceived OH&S risks are often risks or dangers. Rather, an army of assessors and regulators have slowed down production and added costs to business, having found a profitable outlet for their personal paranoia and called it OH&S.

²⁵ When using the term ‘disability’ my generally emphasis is on those with life long impairment.

funded by government and, if a worker is placed in a Special Business Enterprise (SBE or sheltered workshop), their “wage” is pegged to the Disability Support Pension. Add to this the fact that many of the businesses themselves will only be viable because of state subsidies, and you realise just how much money is circulating, but how little of it is really “new money” generated by a multiplier affect. Most of it is coming from the taxpayer and supporting a noticeable amount of administration.²⁶

While appreciating that for some people, SBE’s are a significant and necessary form of employment, social interaction and the like, my point in raising them as an issue is to have the Commission ask the question of sustainability. I do not believe taxpayer subsidised employment schemes are economically viable in the long-term. The same is likely to be true of a disability insurance scheme that is publicly funded. Particularly as Australia’s population ages, we will not have the workers to fund such a mammoth transfer of funds to anything up to a quarter of the population; depending on how one defines ‘disability’.²⁷

Some would say you resolve that problem by increasing the number of taxpayers through immigration. However, as entrepreneur Dick Smith has pointed out, Australia’s largely arid climate and limited water supply puts a natural cap (or *should* put such a cap) on the number of people who can live here.²⁸ I concur with Mr. Smith and, do not wish to see radical changes to our city skylines, leading to the same concentrated apartment style living they have to tolerate in places like Singapore.

A re-evaluation of Government’s role

Just how much do we expect governments at all levels to do for us? My short answer is: far too much. Additionally, much of it puts unrealistic burdens on fellow Australians.

²⁶ See my submission to the Fair Pay Commission 2006 Minimum Wage Determination <<http://www.fwa.gov.au/sites/afpc2006wagereview/submissions/JohnstonASubmission2006.pdf>> as at 26 May 2010; note my discussion of the complexities of dealing with the ‘employment bureaucracy’ from page 3. My view, expressed to the Fair Pay Commission was that ‘despite having an (employment) agent, I still seem to do most of the faxing, email and printing of countless applications. While the agent might be able to throw some job notices your way which you might not otherwise know about, their involvement never seems to guarantee an interview or anything even close to that. Therefore, the Government needs to ask, particularly where the agents have access to public funding, whether these agents are actually adding any value to someone’s employment-seeking activities’.

My second submission to the Fair Pay Commission (which was the Appendix to my *Henry Review* submission, beginning at page 4 of the document (http://taxreview.treasury.gov.au/content/submissions/pre_14_november_2008/Adam_Johnston.pdf) outlines my concerns with the current system, focusing on how much of what is produced is real, productive work, while ‘we see that public money subsidises employment agencies placement activities. This is then often followed by the subsidisation of wages, also courtesy of the taxpayer. And this outcome is called “employment”, despite the fact that vast amounts of taxpayers’ money is being poured in at both ends of the system?’ (at page 6 of the document)

²⁷ See *Issues Paper*, p. 7 (Box 1)

²⁸ See for example, *Future Australians could face starvation: Dick Smith*, Posted Mon Jan 25, 2010 6:13am AEDT, Updated Mon Jan 25, 2010 10:30am AEDT, ABC News <<http://www.abc.net.au/news/stories/2010/01/25/2800081.htm>> as at 26 May 2010

They will pay tax, while many of us with disabilities (through no fault of our own) will have far more limited engagement with the workforce and the tax system.

Yet the psychology of much public policy and public debate seems to be: here is a problem; the government must do something about it. An American writer, Gregory Bresiger, put the case against this type of thinking very well, when he reflected on the last US presidential campaign. He wrote:

When was the last time you heard Senator Obama or Senator McCain give a speech on the bloated public sector? Did Senator Clinton, in her recently concluded presidential bid, ever scold voters who constantly want the government to "give" them more and more services?

These are rhetorical questions. Today our ruling parties tacitly agree that no government department can be eliminated, that major spending reductions are forbidden and that the spending spree must continue.

Indeed, Democrats say little or nothing in the federal budget can be cut. The government must expand its responsibilities. It must provide health care and financial security for all. Also, there must be more spending for national security. Still, there is little serious discussion about what all this would cost.²⁹

In my view accumulated administrative and growing care costs will make a disability insurance scheme unsustainable. For example, we have a model to look at when it comes to the Pharmaceutical Benefits Scheme. As a mechanism for making medicines generally accessible and affordable, as well as maintaining the health of those with long term conditions, the program has been successful. However, in 2002 the Commonwealth Government's first *Intergenerational Report* showed that the PBS had more than doubled its impact on revenues, as a percentage of Gross Domestic Product (GDP) in the 1990s.³⁰ Projections contained in the report showed this growth would continue, to the point where it was expected that the PBS was predicted to outstrip all other components of health spending by 2041-42, and do so by a significant margin.³¹

Nothing I know about disability or disability care makes me think that an insurance scheme would do anything other than accrue liabilities at an exponential rate. The cost of care will only grow, as people have come to expect that newly developed treatments and technologies will be applied to their ailments. As highlighted by Bresiger above, we have been brought up to expect such things. However, in my view, we are looking at the issue from the wrong perspective.

²⁹ Bresiger, Gregory, *The Non-Issue That Should be an Issue*, Mises Daily Article, Thursday, July 03, 2008, <<http://mises.org/daily/3020#ixzz0p22Ai9LI>> as at 29 May 2010.

³⁰ Costello, The Hon. Peter, *Intergenerational Report 2002-03: 2002-03 Budget Paper No.5*, Commonwealth of Australia, 14 May 2002, 8 <<http://www.treasury.gov.au/contentitem.asp?NavId=012&ContentID=378>> as at 6 September 2005.

³¹ See *ibid*, 9.

For as long as people look to government for solutions to their problems, we will be bound to the programs and initiatives the state designs. As I said at the beginning of this submission, it was interesting (though not surprising) how the choices I was originally asked to make as part of the ACP, were largely for the administrative convenience of the ACP provider and ADHC. Those who suggest a disability insurance scheme would be any different (or any better than current arrangements) should be pressed as to why?

Again, reform of substance will only come when we are prepared to move away from the current support and welfare structure. This should include removing what might be termed 'structural welfare' for charitable bodies. In my submission to the Senate's 2006 inquiry into the stem cell legislation, I called upon the Government to withdraw tax exemptions for religious organisations,³² repeating this call more generally when commenting on amendments to the Federal Anti-Discrimination Act.³³

In that submission I made clear my desire for disability to become a temporary feature of my life (it has been permanent thus far). A disability insurance scheme potentially locks one concept into public policy; that disability in whatever form, is a permanent part of the human condition. With the advance of science, this need not be the case. As such, while science's timeframe may not benefit me personally, it would be unreasonable to leave future generations with a large financial bill and, an agency which, in order to perpetuate itself and its own interests, drains resources away from efforts to ameliorate infirmity. This is one of my key concerns, which the Commission acknowledges when you state that '(there) may also be risks that characterising people with shorter-term core limitations as disabled might prolong recovery and rehabilitation'.³⁴

- *Recommendation 4: Taxation reform needs to continue post the Henry Review. In particular, the amount of tax and welfare churn needs to be reduced (or eliminated), so that more people with disabilities can be lifted out of poverty/welfare dependence.*

Government: get out of the way

At the beginning of this submission, I expressed relief when my ACP service provider got the hint to 'stay out of my way,' as it were. In many ways, there are some times when

³² See my submission to the Community Affairs Committee 'Somatic Cell Nuclear Transfer (SCNT) and Related Research Amendment Bill 2006' pp. 3 – 4,

<http://www.aph.gov.au/Senate/committee/clac_ctte/completed_inquiries/2004-07/leg_response_lockhart_review/submissions/sub53.pdf> as at 29 May 2010

³³ See my submission to the Senate Standing Committee on Legal and Constitutional Affairs, *Inquiry into the Disability Discrimination and Other Human Rights Legislation Amendment Bill 2008*, pp. 2 -3, <<https://senate.aph.gov.au/submissions/comitees/viewdocument.aspx?id=52150cdb-cecf-4337-bb59-17c1497066c9>> as at 29 May 2010. My submission to the *Henry Tax Review* made similar comments and, to his credit, Dr. Henry realised the 'leakage' from the charitable sector. The Review proposed a rise in the tax deductible threshold from \$2 to \$25 (Recommendation 13; see *Henry Tax Review, Chapter 12: List of recommendations*,

<http://taxreview.treasury.gov.au/content/FinalReport.aspx?doc=html/publications/papers/Final_Report_Part_1/chapter_12.htm> as at 30 May 2010

³⁴ *Issues Paper*, p. 18

it would be appreciated if the whole apparatus of government would fall off a cliff. As stated earlier, in my submission to the *Human Rights Consultation* I referred to the frustration of being closely case managed. I went on to suggest that the nature of government and official scrutiny has changed. In particular, it appears to be significant that:

Section 51 of the Commonwealth Constitution speaks in terms of the provision of ‘peace, order and good government’³⁵ and while there are other sections referring to pensions and benefits, I suggest that many of our Founders would struggle to comprehend many legal developments of the modern day. And I am not making the old States Rights argument about the centralisation of power in Canberra; rather, it is a question of a notable change of focus of regulators and politicians. From peace, order and good government we have moved to protection, obedience and good behaviour.³⁶

People with disabilities and their families already face a high level of administrative and compliance demands. There is a danger, particularly if the Commission recommends the creation of a central, publicly run insurance agency, that compliance will be even more complex. Equally, it is worth considering what might happen to the general insurance market, if a specialist government insurer comes along. A comparator might be the fall in the take up of private health insurance, which caused the Howard Government to introduce the private health insurance rebate. While the impact of a disability insurer will necessarily be smaller (as it involves a specific segment of the population), there will nonetheless be an effect. The Commission should do some modeling on this.

- *Recommendation 5: The Commission should research the potential economic distortions arising from establishing a single disability insurer. The Commission should also consider the potential disadvantages of creating a single agency and, the potential for that organisation to become a ‘big bureaucratic bully’.*

Private actions

Nothing that the Commission recommends should inhibit initiatives people are undertaking in their own right. My submission to your *First Home Ownership Inquiry* highlighted the work of the Singleton Foundation, in providing stable, appropriately modified housing to people with disabilities.³⁷ While government is a partial funder, the focus is on the potential contribution of the person with disabilities and, the services and support they receive in return from the Foundation.

The fact that the government is a bit-player, rather than the central focus, is the element that attracted me to this model. Encouraging the private sector to provide goods, services and support should be an option in the Commission’s deliberations. My personal

³⁵ And the State Constitutions would use similar language

³⁶ *Key Consultation Questions*, p. 2

³⁷ See my submission to the Productivity Commission’s *First Home Ownership Inquiry*, pp. 3 – 4, <<http://www.pc.gov.au/data/assets/file/0008/56654/sub018.rtf>> as at 30 May 2010

experience is that the public sector is significantly overstretched. This was underlined to me, particularly when trying to obtain accessible housing in order to take up a place in the Commonwealth Graduate Employment Scheme in Canberra a few years ago. Ultimately unsuccessful, I related some of my frustrations to the Commission's inquiry into *Mutual Recognition*, as well as a 2009 ACT Government consultation on service improvement.³⁸

- *Recommendation 6: The Productivity Commission should askew any idea of creating a care agency which tries to 'cover the field' in relation to disability care and support. Rather, nothing that the Commission recommends should inhibit initiatives people are undertaking in their own right.*

If government is now overstretched, asking it for new services (or a new agency) is likely to leave many people significantly disappointed.

Yours faithfully,

A handwritten signature in black ink, appearing to read 'A Johnston', written over a horizontal line.

Adam Johnston

May 30, 2010

³⁸ See generally, Appendix 3

Attachment 1

From: Adam Johnston
Sent: Thursday, 2 April 2009 9:58 PM
To: '(NAME SUPPRESSED)'
Cc: '(Name suppressed)'; '(Name suppressed)'; '(Name suppressed)'; '(Name suppressed)'
Subject: FW: My application for Attendant Care

Dear (Name suppressed),

As a result of a conversation with (Name suppressed)I today, I make the following formal election:

Preferred Service Provider: Homecare NSW

Hours requested: Seven

Weekdays - 6am - 7am

Weekends - 1 hour per day, time in morning may vary as parties require

If there is any capacity for any other hours, this can be determined later.

Regards

Adam Johnston
(suppressed)

Libertas inaestimabilis res est - Liberty is a thing beyond all price.
(Corpus Iuris Civilis: Digesta) (Latin-English Phrase)

From: Adam Johnston
Sent: Wednesday, 1 April 2009 9:05 PM
To: '(NAME SUPPRESSED) (Name suppressed)'
Cc: '(Name suppressed)'; '(Name suppressed)'
Subject: RE: My application for Attendant Care

Dear (Name suppressed),

Thank you for your email.

Having read it, I do not know why anyone would go to such lengths to create parallel funding systems in the one agency. Regardless, I know exactly what I aim to get out of this process - if ACP can deliver, I'll sign up - if not, I won't.

1. Homecare

Under any circumstances, I intend to retain my current Homecare Service. This is explainable simply on the basis that it suits me and my current requirements, for a reliable hour service, particularly on weekdays when I work.

2. Other hours not taken by Homecare

Knowing Homecare as I do, I never expected it to take up the balance of hours. This was always going to be the role of "other agencies". As such, when I also found these hours could be banked, I identified the Armidale Conference as the kind of outing I would like to use the balance for.

Please advise of the possibility of such arrangements.

Regards

Adam Johnston
(suppressed)

Libertas inaestimabilis res est - Liberty is a thing beyond all price.
(Corpus Iuris Civilis: Digesta) (Latin-English Phrase)

From: Adam Johnston
Sent: Tuesday, 31 March 2009 9:19 PM
To: HNP/ACP
Subject: My application for Attendant Care
Importance: High

Dear Sir,

I have recently been approved for the Attendant Care Program, but I must say my initial experience does not inspire any confidence.

My discussions have principally been with (Name suppressed) of Community Care Northern Beaches. She has advised that to take up my Attendant Care package I must forgo 20 years of Homecare Service, despite the fact that both programs come from the same department. Being happy to maintain Homecare and the approximate 7 hours a week that gives me in personal care, I will not agree to anything that does not preserve my current service.

Equally, I cannot see any impediment to me banking the balance of hours not used by Homecare for other purposes. For example, I had hoped to attend a conference in

Armidale over several days in July, with attendant care support. The Guidelines available online would appear to make this possible, as they even consider the possibility of overseas travel. Therefore, I aim to bank hours to go to Armidale, but must tell the University I am coming, so that appropriate accommodation can be made available. Conference details are attached.

Can you please advise:

1. Whether the Attendant Care Program could provide me with a care worker for the purposes of going to Armidale in July?
2. Whether my current Homecare service will be preserved? Again, I will not agree to anything which does not guarantee this, in its current form.

Yours truly,

Adam Johnston
(suppressed)

Libertas inaeestimabilis res est - Liberty is a thing beyond all price.
(Corpus Iuris Civilis: Digesta) (Latin-English Phrase)