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Disability Care and Support Inquiry
Productivity Commission,
GPO Box 1428
Canberra City ACT 2601

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Dear Commissioners,

## Introduction

Our family consists of four adults – myself aged 64, a son aged 35, daughter aged 33 and younger son aged 31. My two youngest adult children were born with their disabilities, courtesy of a very rare syndrome– a combination of intellectual and vision impairments with an immune deficiency thrown in for good measure. Their disabilities are lifelong. My first born adult child acquired his disability in his late teens. His disability is chronic with acute, unpredictable episodes and this has had a profound affect on his ability to lead an ordinary independent life.

My two youngest adult children live with me and I provide the majority of care and support that they require and have done so on my own for 20 years as a sole parent carer. The lack of supports available to our family for a greater part of the last 20 years kept me out of the paid workforce and dependent on a Carer Payment, despite the fact that whilst married I had maintained workforce participation. As a result the first to go was the paid professional work, second was our own home.

It has been personally distressing, demeaning and disempowering that, as the only potential breadwinner in our family unit, I was unable to both "bread win" and work in my profession. I became a State Registered Nurse in 1968, hold a Bachelor of Nursing degree and a Masters Degree in of Social Planning and Development. We have lived in four states of Australia - in capital cities, country towns west of the Great Dividing Range, small country towns with populations of less than 1500 people and regional centres. We experienced the problems associated with the lack of portability of supports, having to travel up 800 Kms to access early intervention programmes, unrelenting and unnecessary red tape in accessing appropriate supports and educational opportunities followed by the battle to access post-school options.

Whilst living in rural Victoria my daughter and younger son were assessed for services and support, by DHS, three times in six months. Each assessment consisted of twenty five pages to fill in (twice) and each time there was a change of coordinator thus requiring the next assessment, form filling in(twice) and still no services or support. We moved to Queensland six months after the last assessment (still no supports). To add insult to injury eight years later we received a letter from DHS Wangaratta informing us it was time to update support plans. A further two years later, and despite DHS having been informed that we now lived in Queensland, we received another reminder. After several years, many crises and much battling by degrees, we finally had some services and supports in place and for the first time in years felt a degree of empowerment, that we were indeed citizens of Australia and breathed a sigh of relief that some security for the future was finally an achievable goal. Then "sliding doors and groundhog day" revisited with government changes to policy and funding arrangements which stopped funding to individuals on the basis of individual need and went back to block funding of organizations - leading again to disempowerment, no choice, a take or leave it attitude of service providers and retribution for leaving, or complaining, about a service that is unacceptable, inadequate or unsatisfactory. But worse still is the loss of our National identity and the benefits of citizenship. Nominally people with a disability and their families are Australian citizens but when their lives are dictated around arbitrary service provider boundaries and block funding, we merely become residents of a government defined region in a State and cannot move without loss of supports.

It is very important to note that the disabilities my adult children have were not compensable. This means that over the years they and I have been subjected to the vagaries of Government Policies and the piecemeal, crisis driven disability supports system that has so disgracefully failed to provide support to people with a disability and their families.

## Productivity Inquiry

### Who should be eligible?

The Care and Support scheme needs to be a universal entitlement for all Australian citizens identified with a dependent disability (that is anyone who requires the support and assistance of another person in the activities of daily living). The establishment of a national disability register with compulsory notification of disability at the time of diagnosis of a disability along with an individual assessment of present and projected future needs would facilitate whole of life and long term planning for care and supports for the person with a disability and should include:

- Early intervention including physiotherapy, occupational & speech therapy
- Aids and equipment – including continence aids
- Habilitation
- Intensive rehabilitation
- Housing needs including modifications
- Educational, workforce and post school opportunities appropriate to the capacity of the person with a disability and supports at age appropriate milestones
- Community integration with supports as needed for access to community venues
- Age appropriate accommodation and support
- Support for family in the provision of care/support for person with a disability in order for family to maintain workforce participation
- Regular and meaningful Respite breaks for families providing care and support
- Regular review of needs for supports
- A flexible and responsive system that will respond to increases in need for supports and in emergency situations e.g if the person with a disability or their unpaid family carer becomes ill

It needs to be noted that the assessment of support needs for the person with a disability should be based on their unique needs as an individual. Their needs for support should not be “discounted” on the basis that they live with family or friends from whom they are expected to receive unpaid support. In particular people with a cognitive impairment, as a result of intellectual, psychiatric or acquired brain injury disabilities, must be assessed on their vulnerability to abuse and exploitation.

### Who gets the power?

Australia is a democracy and its citizens expect to make their own decisions and choices throughout their lives therefore it is people with a disability and their families who should have the power over their own lives. The UN Convention on the Rights of People with a Disability, to which Australia is a signatory, explicitly outlines the rights of people with a disability and as such individual funding and self determination should be the overarching principles of the Disability Care & Support Scheme. This Scheme should remain the sole responsibility of the Federal Government in order to facilitate portability and not repeat the problems associated with Commonwealth States/Territories Agreements. Individual funding attached to the individual will empower people with a disability and their families to purchase the supports they require just like other citizen consumers. And just like other consumers in Australia if the services or goods they purchase are not to their liking they will then have the right to take their business elsewhere. People with a disability and their families should, if they desire, manage their own funding. Those who do not wish to do so can vest the money with a service of their choice.

Queensland introduced individual funding in 1998 and this gave people with a disability and their families choices in their lives, they selected their services and if the service was not satisfactory they moved to one that was more appropriate. Between 2007 and 2010 the Queensland Government has moved to only block funding organizations. In supported accommodation block funding provides a bed, use of communal areas in a house (usually rented by the organization), support staff and co-tenants that are not necessarily compatible with each other. The notion of home or your own for people with a disability has been replaced by living in a workplace of the service provider. All the power is vested in the service provider. It is suggested that government's move to block funding is in response to the crisis occurring as unpaid family carers age due to the government's deliberate policy of over reliance on unpaid family carers over decades to provide care and support for their offspring with a disability.

## What services are needed and how should they be delivered?

Services needed will be based on assessment and the needs articulated by the person with a disability and their family.

It is suggested that the Commonwealth fund the individual and the States & Territories assume responsibility for ensuring a sustainable disability service industry. In the past the percentage of individual funding that organizations were able to utilize for the costs of running the service was unrealistic and organizationally unsustainable. No percentage of an individual funding package should be available for an organisation's operational costs.

I have outlined previously what services are required however, accommodation and support will be discussed.

The power imbalance that has in the past, and is presently being rolled out again, resulted in service provider organizations holding the balance of power. This is demonstrated clearly in supported accommodation arrangements as outlined in the appended document " Déjà vu - all over again?" downloaded from the National Carers Coalition site and covers a number of important issues.

Consideration should be given to the introduction of an Adult Foster/Share Care arrangement with payment for a live- in carer (to replace the previously unpaid family carer) under the same tax exempt status as that of Foster carers of children. The difference being that the share carer will live in and share the person with a disability's home. Tax exempt payments to the share carer will not affect the amount of rent that is paid and keep their chosen accommodation option affordable. This is seen to be a suitable solution for people with a disability who live in Public Housing and don't wish to have three shifts of support workers coming into their home on a daily basis. Their home will remain their home.

## Funding

- Individual funding based on individual support needs
- A stand alone, separate Care & Support Levy similar to the Medicare Levy
- Existing employer contributions for WorkCover and the costs of WorkCover Bureaucracies transferred to NDIS pool
- Existing Third Party contributions and Public liability insurances involving long term disability also transferred to NDIS pool.
- Specialist disability funding in Community Health budgets into NDIS pool
- Tax concessions for Company Philanthropy i.e. set percentage of profits contributed to Care and Support Scheme. These may then be offset against income
- Futures fund
- Autonomous and independent of government
- Self Managed funding by the person with a disability themselves (if they want to) or with the assistance of a family member or trusted friend.

## Organising and implementing a new disability policy

No Policies or implementation plans should be constructed without the involvement of people with a disability and their families. They should be the drivers of all initiatives that affect their lives.

There are existing bureaucratic structures in place that can be renamed and staff re trained to accommodate NDIS.

Defined and accountable Commonwealth & State & Territories responsibilities.

An independent Watchdog with BIG TEETH and A SAVAGE BITE to ensure accountability of governments and service providers in delivering the required supports. No excuses, no spin, no diverting of monies, no putting up with shoddy services, no bullying, no retribution, no breaches of the CRPD without a significant penalty which includes naming and shaming, fines and disendorsement of service accreditation.

I would like to thank you for the opportunity to submit to your inquiry and would be available to make an oral submission at your next round of hearings.

Yours sincerely

Felicity D Maddison

# Déjà Vu - all over again ?

## Present Day Disability Services in Queensland

### Step Backwards to the Future?

Whilst other States and Territories in Australia are in the process of introducing individual funding for people with a disability (based on individual need for support) Queensland, over the last 3-4 years, has moved away from individual funding to block funding organisations to provide support to people with a disability. Not only is government block funding organisations but they are actively pursuing a policy of "relinquishment" of individual funding in order to block fund these organisations to, in particular, provide 24 hour supported accommodation.

The method applied by government in obtaining a "relinquishment" of individual funding has been to firstly approach those service providers holding/managing individual funding for people with a disability and offering to block fund their organisation to provide a service if they (the service provider) can persuade the person with a disability and/or their families to agree to relinquishing the individual funding back to government. With offers of 24 hour supports available in a permanent co-tenancy arrangement for the sons and daughters of ageing parent carers concerned with the "what will happen to my adult child when I die?" it is, for many, a timely solution to their dilemma.

The second method employed by government is to provide individual funding designated as emergency non recurrent funding. This funding may be rolled over for a number of funding quarters, raising the expectation for recurrent funding, then government will suddenly announce that the individual funding has run out and offer co-tenancy in a block funded facility. In both cases an assurance is given to the person with a disability and their families for a phased three month co tenancy trial period, to ensure compatibility of co-tenants. Whilst not specified it is implied that if there is an incompatibility amongst co-tenants that an alternative will be available.

The reality is that the phased trial seldom is implemented as stated; co-tenant compatibility is disregarded and the person with a disability and their families are not informed that funding (on an individual basis) will not be available to the person with a disability if that person or their family choose not to take up the co-tenancy, or move out when incompatibility becomes unmanageable. They are also not informed that there is no guarantee that an alternative placement would, or could, be offered. It is a case of "lump it or leave it" with no alternative.

It needs to be noted that it is people with cognitive impairment, whatever the cause, that are the most vulnerable under these arrangements. Increasingly families are reporting that when they raise complaints or decide to cease the co-tenancy arrangements service providers are applying to QCAT for the person with a disability to go under Guardianship and Administration orders (under the guise that “it’s in the Adult’s best interests”). Increasingly the Tribunal is making such orders. The Tribunal’s decisions are based on the conflict with the service provider and the representations made by government Disability Services representatives. The Department’s preference is that people with a disability (living in supported accommodation) go under the Adult Guardian and Public Trustee Queensland.

- Families report that Guardianship orders are then used by the service provider to deny the family any information about the person with a disability on the grounds that they are “not the Guardian” and in some cases control access to the person with a disability by stating that they need to get approval from the appointed guardian first.

- Both the Adult Guardian and Public Trustee Queensland have powers to delegate responsibility to an “appropriate person” and in most cases this appears to be delegated to the service provider. In view of the fact that most delegates of the Adult Guardian have very large case loads the delegates rely on the service provider to make day to day decisions. With regard to contact and access the delegate will base their decisions on any recommendations that the service provider makes. So if a service provider recommends that family members should not be allowed contact with the person with a disability for two months to enable the person with a disability to become accustomed to their new “home” and those they share their “home” with, the delegate of the Adult Guardian will approve that decision.

- It appears that the Public Trustee Queensland also delegates some responsibility for financial matters to the service provider. The service provider, through direct care staff, then manages the day to day finances of the person with a disability.

*In other words service providers (who by definition are paid carers), through such delegations, perform the substitute decision making role that the Guardianship and Powers of Attorney Legislation actually excludes them from performing, either in an informal or formal capacity.*

## But wait – there is more

For some time now there have been rumblings that a third method exists which is reserved for people with a disability and their families who resist relinquishing individual funding. This is to initiate frequent reviews of the funding levels of individual packages and gradually reduce the level of funding.

On 23 March 2010 staff from Queensland Disability Services finally decided to come out of the shadows and be publicly honest about its “future” intentions; this is to implement measures that have been covertly enacted for several years.

QDS have announced that implementation of the following will commence in August 2010:

- Effective 2010 & 2011 there will be no individual Family Support Packages (FSP), individual Adult Lifestyle Support Packages (ALSP) or any funded individual supports for clients of QDS;
- Existing QDS clients with individual FSP & ALSP will have funding decreased/ceased over time;
- Expectation that NGO’s & GO’s will pick up ongoing supports via communities;
- Intake & Assessment processes will change regarding format, style, and eligibility process & access to services;
- QDS facilitators will now be known as Community Linkers;
- Intake team refer to Linkers followed by outsourcing to NGO’s & GO’s for ongoing and sustainable support;
- There will be a limit of $2000 per year/per family for funded services;
- QDS regional offices will commence rolling this out in August 2010;
- All Emergency Respite/Crisis funding will cease;
- There will only be a minimal amount of case management dollars for complex case management. Referral will only be through Linkers;
- The “Goal” is to make it a fairer and more equitable system for disability service clientele.

However, it would appear that the right hand does not know what the left hand is doing in QDS because:

- QDS staff in the Regions are stating that the above **will be** implemented;
- Executives within QDS are stating that QDS will be introducing self directed individual funding initiatives.

Not only is QDS not communicating with each other but prior to now QDS has not been communicating with people with a disability and their unpaid family carers on this matter.

Till now QDS have not seen fit to inform people with a disability and their unpaid family carers of their intentions, much less, consult with them.

Up to this point only Service Providers have been informed and they have a vested and conflicted financial interest in their support of block funding for organisations.

**QDS has not been so forthcoming about the re-opening of the infamous Basil Stafford Centre to permanently house people with disability and challenging behaviours. Has this been accounted for under the new supported accommodation initiatives?**

**Perhaps it is time that the Queensland Government refreshed their memory about their stated commitments to people with a disability and walked the walk instead of just talking the talk.**

Queensland has a *Disability Services Act* with the Act renewed and revamped in 2006. **The Act acknowledges that people with disabilities have the same Human Rights as other Australian Citizens.**

Queensland also has a *Guardianship and Administration Act 2000* that provides a statutory safeguard for people who require support to make decisions in their lives. **This Act also acknowledges that people with a disability have the same Human Rights as other Australian citizens.**

**In July 2008 the Australian Government ratified the United Nations** *Convention on the Rights of Persons with a Disability* **and on 20 September 2009 the Australian Government ratified the** *Optional Protocol for the Convention on the Rights of Persons with a Disability.* **This protocol provides a mechanism for Australians to make complaints to the United Nations Disabilities Committee in the event that all domestic remedies have been exhausted. In ratifying both the Convention and Optional Protocol the Australian Government has enjoined all governments in Australia to a contractual obligation of compliance with the Convention.**

Article 12 and Article 19 of the *Convention on the Rights of Persons with a Disability*

**Article 12**
**Equal recognition before the law**

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

**Article 19**

**Living independently and being included in the community**

States Parties to this Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

(b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.

**To the Queensland Government and your supporting bureaucracy,**

**SHAME! SHAME! SHAME!**