

Walk a Mile in My Shoes DISCUSSION PAPER 1

The Australian Constitution (s 117), the Universal Declaration of Human Rights and The absence of Rights for Australian Family Carers of Citizens with Dependent Disabilities

Preamble

This paper argues that there are compelling Human Rights and Constitutional grounds for the Commonwealth government to take full responsibility for the funding and provision of appropriate and adequate supports to Australian citizens with a dependent disability, and to their unpaid family Carers. The paper maintains that current disability service agreements between the Commonwealth, states and Territories violate citizenship rights and condone age discrimination, particularly for those citizens with disabilities who are aged less than 65 years.

Australians with dependent disabilities are Australian citizens who require assistance and support with the activities of daily living. This need for support in undertaking the activities of daily living may be the result of severe sensory, physical, intellectual or cognitive impairments, or chronic/severe prolonged illness. The impairment may have been present since birth or acquired at a later stage of life. The effect of the impairment may be constant or episodic in nature.

It is accepted that in order for Australian citizens with dependent disabilities to pursue an equality of life as an Australian citizen, one that is on par with citizens with no dependent disability, they require the support of another person.

Over the past three decades there has been a move by Governments away from a “formal system” of collective community response to providing essential supports for Australian citizens with dependent disabilities (through tax revenue) to one of reliance on the “informal” and unpaid support provided by families.

The introduction of Commonwealth State and Territory Disability Agreements (CSTDA) saw primary responsibility for the provision of supports to people with a dependent disability aged less than 65 years and their family carers divided between the Commonwealth and States/Territories with the primary responsibility for the provision of supported accommodation, in-home care, respite and day services resting with each individual State or Territory.

The Commonwealth on the other hand retains primary responsibility for the administration of disability employment services and primary responsibility for the provision of Aged Care services under National Health and Ageing Policy, including facility-based aged care accommodation and facility-based aged respite as well as intensive in-home support packages aimed at keeping frail elderly citizens at home for the maximum period of time.

Similarly, Commonwealth/State/Local Government funding mechanisms through such programs as HACC and CCRC, which provide assistance for home-based domestic care, in-home support and respite etc, are weighted 85% towards aged care and just 15% to disability despite the fact that less than 13% of the total population is aged more than 65 years.

The impacts on Australian citizens who are family Carers

It is widely accepted by government statisticians (ABS) that there are at least 2.6 million unpaid family Carers of people with a disability, handicap or frailty living throughout Australia. Family carers have identified and informed government on many occasions, of a number of compelling issues affecting both themselves and those they support/care for. These issues were clearly articulated in an issues paper generated by the ‘National Family Carers Voice’ and published on the ABC Four Corners Website in March 2005. Issues identified included the barriers and human rights inequities they face as citizens of Australia.

Resources

For younger Australian citizens with a dependent disability and their family Carers, per capita funding and the criteria for receiving funded support varies from State to State to Territory. The averaging of funding levels across the nation shows that some States and Territories appear to be well ahead of others in their funding levels. It can also be clearly demonstrated that some States have lagged below the National average for decades. Furthermore it is suggested that even in States and Territories where per capita funding levels are higher than the national average, funding levels are grossly inadequate to meet even the urgent unmet needs of citizens of Australia with a dependent disability.

Variation in per capita funding levels and the failure of successive governments, both State and Commonwealth, to redress funding inequities has resulted in a severe resource (supports and services) deprivation for citizens with a dependent disability that places extreme undue pressure upon their unpaid family carers.

National Benchmark Inequities

There are no National Benchmark Standards or Policies for funding services and supports for people with a dependent disability under the CSTDA. This is in stark contrast to the Commonwealth Aged Care Benchmark funding formula of: 100 new beds/packages per year per 1000 of the population aged over 70 years. The formula for funding growth in aged care services, clearly demonstrates the gross failure of the CSTDA to deliver fair, just and equitable services to dependently disabled citizens less than 65 years old.

This inequality has led to the current intolerable situation where thousands of Australian citizens with dependent disabilities are languishing on 'urgent' accommodation and support waiting lists in an endless and ever growing queue. Such arbitrary divisions and decisions are clearly 'age discriminatory' for both the disabled person and the family that cares for them.

Resource Allocation and Restrictions

Resource allocation through a variety of programs is nationally inconsistent and varies from State to State to Territory. For instance support may be available through a HACC Program, however each State and Territory distributes through differing outlets – Local Government, not for profit organisations, non government organisations, Health Departments – and all restrict their services to the regions under which they operate.

There is no portability of service, which means that recipients lucky enough to obtain some support in one region cannot move to an adjoining region or they will lose all the support they previously had going to the bottom of the waiting list for support in the new region. Lack of portability of services also applies to individual funding where State/Territory borders form the cut out point.

Effectively Australian citizens with disability and family carers, unlike other Australian citizens, cannot relocate/move throughout their State/Territory or interstate without being 'penalised' and severely disadvantaged by the loss of essential supports. Again these arbitrary state/territory regulations are in vivid contrast to the national aged care system, which does allow families to move interstate and request a bed transfer for an elderly relative in an aged care facility.

The Australian Constitution and Discrimination - SECTION: 117.

"A subject of the Queen, resident in any State, shall not be subject in any other State to any disability or discrimination which would not be equally applicable to him if he were a subject of the Queen resident in such other State."

The Australian Constitution passed as part of a British Act of Parliament in 1900 and took effect on 1st January 1901. This saw the joining together of the States and two Territories (NT & ACT) into a federated government called the Commonwealth Government. Although the States and Territories retain autonomous governments within their own boundaries, the Commonwealth Government is generally regarded as the more powerful partner in the Federation of States and Territories that form the Commonwealth Government. It has been suggested that one of the main reasons for the movement by the Australian people towards federation was the desire to have a single trade area or 'Common Market' throughout Australia through the removal of protectionist burdens on interstate trade.

It should be noted that since the Second World War the Commonwealth Government solely imposes and collects income tax and that the Australian Constitution contains NO Bill of Rights for its citizens.

We believe that Australian citizens who are unpaid family carers and Australian citizens with a dependent disability do not enjoy the same citizenship rights as Australian citizens without a disability. It should be noted that the wording in S117 has not been amended since its acceptance by voting Australians in 1901. It is therefore arguable that the term disability was not a common usage word to describe people with impairment at that time, but was instead used to denote disabling or handicapping actions against Australian citizens. As such we believe there is a case for the Commonwealth Government to take action to remedy both the discrimination and disability that unpaid family carers and Australians with a dependent disability are subjected to as outlined previously.

Human Rights and Australian citizens who are unpaid family carers

On December 10, 1948 the General Assembly of the United Nations adopted and proclaimed the Universal Declaration of Human Rights.

The Universal Declaration of Human Rights

Article 1. *All human beings are born free and equal in dignity and rights*

Whilst Australian citizens may be born free and equal in dignity and rights, where a dependent disability manifests in the individual equality, dignity and rights disappear. There appears to be a lack of understanding, by both governments and the community, that in order to be equal, citizens with a dependent disability require support, usually that of another person. For unpaid family carers there is no dignity in being exploited because of familial ties.

Article 4. *No one shall be held in slavery or servitude*

Unpaid family carers believe that when there are little or no supports available to Australian citizens with a dependent disability, families, out of necessity and under duress, are obliged to undertake the support/care role for members with a dependent disability. Family carers receive no wage for providing a support/care service despite the work that they do being the basis of a human service industry that employs and pays people to perform the same work. Unlike their paid equivalent, unpaid family Carers have no protection and entitlements set down in industrial laws.

Article 13 *Everyone has the right to freedom of movement and residence within the borders of each state (for the purpose of the Declaration state means nation state)* - : see discussion on resource allocation and barriers.

Article 16. *The family is the natural and fundamental group unit of society and is entitled to protection by society and the State* - : unpaid family Carers are neglected by the states and coerced by omission into their role

Article 21. Everyone has *the right to equal access to public service in his country*

Discriminatory practice in resource allocation & availability based on age, denies equal access to public services to people with dependent disabilities aged less than 65 years, impacting harshly on caring families.

Article 23.

(A) Everyone has the right to work, to free choice of employment, to just and favorable conditions of work and to protection against unemployment

(B) Everyone, without any discrimination, has the right to equal pay for equal work

(C) Everyone who works has the right to just and favorable remuneration ensuring for himself and his family an existence worthy of human dignity, and supplemented, if necessary by other means of social protection

Clearly Unpaid family carers do NOT have favorable conditions of work, do NOT receive equal pay for equal work, and do NOT have favorable social protection.

Article 24. Everyone has *the right to rest and leisure, including reasonable limitation of working hours and periodic holidays with pay.*

Unpaid family carers have **no** entitlement to rest and leisure, **no** limitation of their working hours and **no** periodic holidays with pay.

Article 29. In the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society.

There is NO justification for the limiting of the rights of family carers and their family member with a disability to pursue ordinary lives in our democratic and wealthy nation. The 'mutual obligation' rationale of economic rationalization, should mean a just reward for unpaid family Carers' annual contributions of \$30billion to the national economy, but mutual obligation is glaringly absent from government's response.

Lack of Partnership between Government and Family Carers

The reliance on families to provide 'informal support' has resulted in a grossly unequal 'partnership' between governments and family carers. It is estimated that 90% of care and support in the community is provided by the "informal" sector. If every family Carer providing 24 hour care/support to a family member with a dependent disability contributes 90% of the care/support required; this means in every 24 hour period they are providing 21.6 hours of support. However, for many family carers the full 24 hour care/support role is a reality of daily life in an unrelenting 365 day/year unending cycle.

Resource deprivation means that for many family carers there is no time off, no holidays, no sick leave, no paid work, unrelenting pressure to perform in a role for decades under conditions that no paid worker in Australia would be expected to undertake.

Kim Soukieh in ACROD's magazine *DISparity Autumn 2005* has this to say about carers:

"the range (of care roles) is so wide that we can simply dismiss them as people who feed sick people, or wipe their bums, or any other lowly function we would prefer not to do ourselves"

"It is perhaps not entirely accurate to compare carers with sweatshop workers. Caring is arguably closer to voluntary slavery"

With little or no assistance available to Australian families supporting Australian citizens with a dependent disability it is now a point of law that the unpaid work that family carers do in supporting family members with a disability is '**not**' deemed to be "**voluntary**" proving the point that '**necessity**' does not necessarily mean '**voluntary**'.

Below is the substance of a petition, circulated nationally, presented and tabled in Federal Parliament in May 2005

And which now form the basis for our Walk a Mile Campaign. We ask the federal government to:

1. Take immediate action to stop 'age' discrimination in the provision of and choice in cared accommodation, by taking full responsibility for all Australians with dependant disabilities.
2. Act to remove discrimination in access to facility-based respite care and in-home support services throughout the nation by removing age barriers to choice, access and funding of disability services.
3. Implement a Parliamentary Enquiry and Review of Funding Policies and Delivery Systems for Cared Accommodation and Family Support Services for all persons with dependent disabilities.
4. Implement urgent strategies to address years-long disability waiting lists with particular emphasis on frail and aged parent carers.
5. Implement a Parliamentary Enquiry and Review of Funding Policies and Delivery Systems for Mental Health Services so that all Australians with Mental Illness have access to adequate Mental Health Care and Rehabilitation Services, during and following a crisis, with adequate follow through services, throughout the nation.
6. Ensure that People with Mental Illness have access to adequate housing and support before leaving these services.
7. Make an agreement that both of these enquiries will be publicly released and responded to within 3 months of their conclusion.

Walk a Mile in My Shoes DISCUSSION PAPER 2

Unpaid Caring - "Voluntary or involuntary Slavery?"

This discussion paper will explore the concept, raised by Kim Soukieh, of the unpaid carer role as "voluntary slavery". This paper will examine the conditions under which family carers provide assistance/ support to family members with a disability, the external conditions that influence and impact on their care role and recent legal action and laws impacting on family carers. It needs to be stated at the outset that this paper is designed to stimulate and generate debate and is therefore controversial. As such the authors make no claim to be representative of all family carers views, however both authors have lengthy experience in gathering the views of unpaid Carers who have expressed similar sentiments to those of Kim Soukieh. We firmly believe that discussion and raising awareness of the following issues needs to occur.

In order to explore the concept of "voluntary slavery" base line definitions will be used as the reference point for the discussion as follows: **Definitions:**

Voluntary

1. *Law.* a. acting or done without compulsion b. done by intention and not by accident c. made without valuable consideration : a *voluntary conveyance or settlement*
2. done, made, brought about, undertaken etc. of one's own free will or choice.

Volunteer

1. *Law.* a person whose actions are not founded on any legal obligation to so act.
2. one who enters into service of his own free will, or who offers himself for any service or undertaking.
3. *Mil.*, one who enters the armed services voluntarily (rather than through conscription) specifically for special or temporary service (rather than as a member of the regular or permanent army).

Slave/ Slavery

1. one who works under duress and without payment
2. one entirely under the domination of some influence
3. the condition of a slave; bondage
4. a state of subjection like that of a slave

Bondage

1. Slavery or involuntary servitude; serfdom
2. the state of being bound by or subjected to external control (The Macquarie Dictionary)

For the reader who may consider this analogy as extreme or even offensive; unpaid family Carers, make the claim that:

- it is offensive that parent Carers are coerced (by omission) into caring for adult children with dependent disability until the parents die or are so frail that the system is forced to take over....
- It is offensive that parent Carers are the only family caregivers expected to care forever...
- It is offensive that some 20,000 disabled citizens are languishing on urgent state-based supported accommodation waiting lists for years without hope of ever getting a service...
- It is offensive that Federal politicians can mount a widespread public media campaign about tax cuts for PAYE Australians at the same time as the federal government claims there is not enough money to increase disability support services....

Discussion Paper 1

Discussion Paper 1 outlined the role that unpaid family carers undertake in their provision of care/supports for family members with a disability. We have previously argued that necessity does not mean 'voluntary' and the defined "temporary" nature of the role of volunteer certainly does not apply to unpaid family carers. For most family carers it is not by intention that they become carers, a role that is above and beyond the role they would normally experience as a member of a family, it is usually by accident and by free will. However, unpaid family carers have more often than not been perceived to 'choose' to undertake an unpaid role in the provision of supports. The law now says otherwise.

The Law and Unpaid Family Carers

In a recent case in Victoria a caring family, supporting two sons with severe disabilities, was sued by WorkCover (VWA), under section 138 of the Accident Compensation Act which allows for Third Party Liability cost recoveries. VWA sued the family to recover the cost of injury to a paid worker who claimed a work injury whilst working in the family home. The paid worker was employed by a government funded agency that sent the worker into the home to provide personal care and support to the two young boys with a disability. The agency had compulsory WorkCover insurance for their employees and the claim was lodged and paid by VWA to the paid care-worker. Some 15 months after the alleged incident at the family home, VWA sued the caring family to recover their costs under the liable third party Regulations of the Act.

In 2002-2003 the Victorian government introduced and passed an amendment to their WorkCover Legislation specifically to **exempt volunteers** from Third Party Liability under Section 138 of the Act. (both N.S.W. & Qld legislation reflects this change). Based on WorkCover Victoria's action against unpaid family Carers, it is obvious that the unpaid work that the caring family (previously identified) performs for their sons (personal care and support) was not regarded as being **voluntary work**. Therefore they were not regarded as **volunteers** under WorkCover Legislation leaving WorkCover free to sue the caring family.

Persistent public opinion and impassioned requests for the government to exempt unpaid family Carers along with volunteers fell on deaf ears. In August 2005 a Private Members Bill was presented to the Victorian Parliament seeking an amendment to WorkCover Legislation that would offer some protection to family carers from Third Party liability. This Bill was defeated by the government in a tied vote of Parliament. **Therefore it was reaffirmed under law that unpaid family carers are NOT VOLUNTEERS.**

Unpaid Family Carers : Not Volunteers Not Paid Workers

Unpaid family carers are deemed not to be volunteers and not to be workers, despite the fact that **paid support workers perform the same tasks that family carers undertake**, under considerably more favorable conditions than their unpaid counterparts. For instance should a paid worker injure themselves in the course of their paid work they are entitled to Workers Compensation, they are also entitled to sick leave, employer superannuation contribution, paid holidays yearly and have a time limited working week. Paid Carers also have financial reimbursement for time worked over their Legislated hours of work, time limitation and definitive end of working day with minimum hours off before recommencing work. Paid Carers have maternity/paternity leave, bereavement leave, a wage for the work they do and most importantly, unlike unpaid family carers, they do NOT have to find and pay for someone to take their place when they are sick, have time off, or have holidays.

So if family carers are not **volunteers** or **workers** and their family homes are deemed to be **workplaces**, if they perform the same tasks as paid workers, but work 3-4 times as many hours, have no entitlement to time off, no holidays, no sick leave, receive no wage or superannuation, are subject to external control and placed under duress to perform in an unpaid role and their position is not of a temporary nature.

We therefore believe that ***the role that unpaid family carers perform meets the criteria definitions proposed as the basis of this discussion and that the word voluntary needs to be removed from the concept proposed by Kim Soukieh.***

Family Carers – Citizens without Rights

We have previously expressed our belief that family carers' Constitutional and Human Rights are breached by the way in which resources are administered/ delivered by governments. For unpaid family Carers to benefit from the laws and Acts of Parliament of Australia, they first must have a LEGAL STATUS. The ACT and QLD have recently enacted Carer Recognition Policies and WA has enacted a first for Australia – Carer Legislation. These give some recognition of the role played by family members caring for frail and disabled citizens. States such as Victoria, New South Wales and Tasmania lag dismally behind with no agenda for similar Policies to be introduced. Whilst it is clear that Carer Recognition Policy (of itself) will not give family Carers 'rights' without 'entitlement legislation' they do give substance to the absence of unpaid carer rights currently pervading the nation.

Paid workers have Industry Standards, Minimum wages and conditions, unions and industry regulators (IRC) to ensure they are treated fairly and remunerated fairly for their labour. ***Family Carers have nothing to protect their rights or to save them from exploitation by governments and a society that shamelessly uses emotional blackmail to coerce families into caring forever.***

Parents of adult children with dependent disabilities are expected to accommodate and care for them for life. No plan exists to allow such parents to lead ordinary and age appropriate lives, have an empty nest or retire with dignity. The evidence of emotional blackmail for families to continue to care exists in the deliberate creation of years long waiting lists for supported accommodation services. Families are faced with caring - or abandoning loved ones to the scrap heap of crisis care management. **No other families in our society are treated in such a discriminatory fashion.**

Overriding the whole issue of why we are requesting that the Commonwealth take full responsibility for people with disabilities is '**citizenship.**' and the rights that citizenship brings:

- The right to live where you choose, and to move around Australia (exactly like other Australian citizens can and do) without loss of supports!
- The right to receive service/supports from CSTDA, HACC or other funded service that allows disabled persons and the families caring for them to move out of the region and go to another region without having to go the bottom of the waiting list in the new area in which you live!
- The right to be treated equally and without discrimination in choices and levels of funded support options!

Family Carers are asking the Australian people to take a stand in support of obtaining Human Rights for unpaid Carers and formal recognition through legislation, together with an end to age discrimination in the funding and provision and choices for disability support services.

Family Carers are asking all of our elected representatives at the Commonwealth, State and Local Government level to act immediately to ensure the implementation of a National Enquiry which will address the issues as outlined here.